

## **THE FAMILY CONTEXT OF CARE IN HIV/AIDS: A STUDY FROM MUMBAI, INDIA**

**PREMILLA D'CRUZ**

**Indian Institute of Management Kozhikode, Calicut, Kerala, India**

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*Though the continuum of care model has been adopted in HIV/AIDS intervention, there is little empirical work documenting the experiences of caregiving families. Addressing this gap, a study on family caregiving and care receiving was undertaken in Mumbai, India. In-depth interviews were conducted with seven seropositive caregivers, seven seropositive care receivers and five seronegative caregivers. Thematic analysis of the data was conducted, yielding a number of key themes. This paper discusses the key theme of the family context of care which includes the caregiving system, family values, perceived mode of infection, gender of the seropositive person, and class. Implications of the findings for policy and program planning are discussed. Key words: Family, Care, and Organization of Care*

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### **Introduction**

HIV/AIDS has grown from an infection that at first was seen as affecting gay men in a few American cities into a pandemic. Nelkin, Willis and Parris (1990) maintain that AIDS:

is no ordinary epidemic. More than a devastating disease, it is freighted with profound social and cultural meaning. More than a passing tragedy, it will have long-term, broad-ranging effects on personal relationships, social institutions and cultural configurations...the effects of the epidemic extend far beyond their medical and economic costs to shape the very ways we organize our individual and collective lives. (p. 1)

Psychosocially, HIV/AIDS is a chronic illness with a long-term, incapacitating, terminal, and stigmatizing character. As is the case with other chronic illnesses, HIV/AIDS unleashes a devastating effect on affected families. Changes in family roles and relationships, drain on the family economy and deprivation, emotional distress, and caregiver burden are frequently observed outcomes, particularly contemporaneously when policies of community care and reduced social expenditure are forcing families to undertake the responsibility for their ill members. These effects are influenced by various family related factors such as structure, life cycle, processes, support systems, and belief systems as well as extra-familial influences, such as socio-cultural beliefs and health care services (D'Cruz, 1998).

But apart from these similarities, there are other unique effects, specific to the distinguishing features of the infection. Given the nature of the disease, it is not unlikely that the caregiver as well as the care recipient and perhaps other family members, are unwell too (Lesar & Maldonado, 1997; McCann & Wadsworth, 1994; Millon, Mantero-Atienza, & Szapocznik, 1992; Reidy, Taggart, & Asselin, 1994; Seeley, Kajura, Bachengana, Okongo, Wagner, & Mulder, 1994). Not only do caregivers have a dual role, being clients with psychosocial needs and service providers in need of advice and information to manage ongoing care (Sosnowitz & Kovacs, 1992), but they also experience extra demands, with limits on the care they can provide, alternating between periods of providing care and needing it. Further, since the pandemic has struck mainly young adults, caregiving engenders role reversals that represent major upheavals for families. Elderly parents and dependent, young children often end up performing the caregiving role, sometimes unsuited for their age (Lesar & Maldonado, 1997; McCann & Wadsworth, 1994; Reidy et al., 1994).

The caregiving experience for HIV/AIDS is therefore a complex one, singularly different from that of other chronic conditions (Lesar & Maldonado, 1997; McCann & Wadsworth, 1994; Reidy et al., 1994). The role of the family in the provision of care in HIV/AIDS is considered to be much more stressful than it is in other diseases. With the virus targeting mainly young adults in the sexually active and economically productive age group, with its stigmatizing and terminal nature and with the prolonged "living-dying interval" (Pattison as cited in Stephenson, 1985, p. 80), the challenges of caregiving in HIV/AIDS have become a much discussed issue. Yet in terms of empirical investigations, caregiving remains one of the least studied areas. The existing literature is based on earlier data and does not always mention any methodological and conceptual details, with empirical studies being few and far between. Many of these studies have a focus on the family in general, and caregiving is touched upon as a part of the family experience. An exclusive focus is therefore lacking, and hence many complexities are lost. To address this gap, a study exploring family caregiving and care receiving was undertaken in Mumbai, India. This paper presents one major theme which emerged from the study, namely, the family context of care which highlights how care is organized in the family. Other major themes included the influences on the process of caregiving, the experience of being a care receiver and the caregiver-care receiver relationship.

## **The Context**

The HIV/AIDS epidemic in India has reached alarming proportions and it is believed that if current transmission rates continue, India will soon have the largest concentration of AIDS affected individuals in the world (Verma & Roy, 2002). India's National AIDS Control Organization (NACO) estimated the range of HIV infections in 2002 to be between 3.82 to 4.58 million (NACO, n.d.). Data further point out that Maharashtra, Tamil Nadu, Andhra Pradesh, Karnataka and Manipur have the highest rates, whereas Arunachal Pradesh, Assam, Meghalaya, Sikkim and Rajasthan report little or no seropositivity. Similarly, urban areas have higher rates than rural areas, while the number of male cases outweighs that of females (NACO, 2001). Micro-level studies add to these data by pointing out the growing incidence of seropositivity among rural populations; married, monogamous women; housewives; voluntary blood donors; women attending antenatal clinics; and pediatric HIV/AIDS cases (see, for example,

Gangakhedkar, Bentley, Divekar, Gadkari, Mehendale, Shepherd, Bollinger, & Quinn, 1997; Verma & Roy, 2002). The spread of HIV infection in India is mostly driven by the heterosexual transmission (Panda, 2002). A majority of women have no risk factors other than being married to their husbands. Increased HIV infections in young women from the reproductive age group are accompanied by an increase in vertical transmission and pediatric AIDS (Verma & Roy, 2002).

The numerous predisposing and precipitating risk factors that either directly or indirectly facilitate HIV transmission in India are intricately linked with social and cultural aspects of life including migratory patterns, increasing urbanization, poverty, illiteracy, subordinate status of women, double standards of morality and gender norms, 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 (see Verma & Roy, 2002 for a detailed discussion).

Intervention initiatives are in keeping with the dictates of India's on-going economic reform process, commonly referred to as the "structural adjustment program" (SAP). Consequently, community care is the preferred alternative for managing the demands of the infection. Families are thus responsible for the care and support of their seropositive members. While this development finds consistency with India's collectivist social fabric (Dalal, 1995), cutbacks in health care outlays reduce the extent of support that may be expected from the health care system, particularly the public sector (Qadeer, 2000). Further, the espousal of patriarchal values ensures that division of labor within the family resembles what Chow and Bertheide (1988) term as the "separate spheres model", such that within the household it is women who shoulder the caregiving role.

## **Method**

### **Design**

The study adopted the qualitative approach. A phenomenological orientation was incorporated since the aim was to explore subjective meanings, experiences, and interpretations. This strategy was considered appropriate since it facilitates the understanding of the essence of experience (Creswell, 1998). In-depth interviews were employed as the method of data collection and in order to facilitate this process, an interview guide was developed. Questions such as the following were asked: "What does it mean for you to be a caregiver?", "How did you come to assume this role of caregiving?" and "How has this experience (caregiving or care receiving as the case may have been) influenced your life?" Observations made during the course of the interview were recorded. Where interviews were conducted in the homes of participants, observations about the setting facilitated an understanding of the situational context. Apart from this, observations of participants' behavior during the course of interaction contributed in highlighting their mood at the particular time and in underscoring their affective reactions to their predicament.

## Sample

Purposive sampling was relied on, and hence an attempt was made to ensure that gender, class, and a range of family forms were included. In addition, the positive person included in the sample had to have at least one opportunistic infection.<sup>i</sup> At such a stage of the infection, there is a greater likelihood of them to be in need of, and in receipt of, care. Secondly, only those seropositive individuals who have shared their serostatus with a family member were to be included in the study.

Given the complexities associated with inquiries on stigmatizing illnesses, difficulty in identifying and retaining respondents was anticipated. The researcher therefore, simultaneously contacted a number of organizations involved in HIV/AIDS related work in the city of Mumbai. In keeping with ethical guidelines in HIV/AIDS research, the researcher did not approach potential respondents directly. The staff of the organization introduced the idea of, and explained the purpose of, the research to people (either seropositive individuals or their caregivers/family members) accessing services from them, and only after they agreed and were comfortable enough, was the researcher introduced to them.

Following rapport building and soliciting their co-operation, respondents signed a consent form, informing them of the details of the study and their rights as participants. The location of the interview was decided by them, as was the possibility of tape-recording the interviews. At least two interview sessions per respondent were desired. This preference was conveyed to the respondents during the rapport building process, in order to ensure that they made an informed decision regarding their participation.

The process of getting participants for the study was an arduous one largely because of the stigmatizing nature of the HIV pandemic, which makes positive people afraid of getting involved. Fears related to confidentiality, use of data and consequent discrimination. Time constraints due to roles and illness severity and fluctuations were two other important considerations.

Nineteen people (seven seropositive caregivers, seven seropositive care receivers and five seronegative caregivers) participated as units of inquiry in the study. Of these, there were seven male care receivers, two male and three female seronegative caregivers, and one male and six female seropositive caregivers. The age range for male respondents was 26 to 37 years, while for female respondents it was 27 to 60 years. Four respondents belong to the upper income group, two to the middle, three to the lower middle, and eight to the lower income group. Four respondents belonged to quasi-families. That is, the family context in these instances represented non-traditional forms and hence was termed quasi-families. The traditional family context was defined by the presence of blood/marital ties, whereas the quasi-family situation comprised of a network of relationships that respondents considered to be their families, within which care was provided. It was respondents' definitions of the caregiving context as being similar to the familial one that prompted the researcher to include them in the study. Seropositive individuals in these cases had no family of their own, had no contact with their families, or opted not to accept care from their families due to the latter's negative attitude, and had grown emotionally attached to friends or employers, with whom their interactions resembled family relations.

Sixteen respondents were interviewed in the organization premises while three were interviewed in their homes. Fourteen respondents consented to tape recording the interviews while for the remaining five, the researcher maintained detailed notes. While interviews were conducted in Hindi, the national language (11 respondents), Marathi, the regional language (three respondents) and English (five respondents), all notes were kept in English. Thus, interviews recorded on audio cassettes were translated into English during transcription and those which were kept as field notes were also written in English. Though the preference for at least two interview sessions was discussed with the respondents in the beginning, time constraints precluded this possibility with seven of them, who had only a single interview session.

### **Data Analysis**

During the period of data collection, the researcher read the transcripts and field notes carefully and repeatedly “immersing” herself in the data (Crabtree & Miller, 1992). Immersion allowed the researcher to identify themes and categories emerging from the data (Marshall & Rossman, 1999). For example, through a reading of the data the researcher observed the presence of more than one caregiver for many seropositive respondents. Labeling this observation as the theme of the caregiving system, categories such as primary caregiver, multiple caregivers, partnerships and sole caregivers were developed to capture the several emerging types. Themes and categories were developed into patterns that linked overarching themes and categories, a process facilitated by Miles and Huberman’s (1984) tools such as charts, matrices, event lists, causal networks, and memos. For instance, to establish the dynamics of multiple caregiver arrangements, event lists, time-ordered matrices and causal networks provided insight into how members of the caregiving system came to share responsibilities and what influenced this process. The use of such tools was interspersed with memoing, which allowed for the data to be developed to conceptual levels that integrated events, processes, and outcomes (Miles & Huberman, 1984), leading to the use of a nomothetic rather than ideographic language and to emergence of interpretations (Patton, 1990). Proceeding in this manner allowed for various understandings of the phenomenon under study to be developed. 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 the data were collected, the researcher immersed herself further in the transcripts and the preliminary findings. She not only identified more themes and categories, but also through the use of Miles and Huberman’s (1984) tools and memoing, she developed more patterns, thereby working towards more interpretations. Further, she subsumed under major themes, those patterns, themes and categories and their linkages within and across respondents that held together in a meaningful yet distinct way (Guba, 1978). That is, immersion into and contemplation (an incubation stage) about the emergent constructs and patterns resulted in creative insights (Patton, 1990) as to how particular groupings collectively yet singularly contributed to a holistic understanding of various aspects of the phenomenon under study. Thus, constructs and patterns that together completed the description and explanation of a particular facet of the caregiving-

care receiving experience were synthesized into a key theme. To illustrate, themes and patterns relating to the caregiving system, caregiving values and the role of gender, class, and perceived mode of infection were seen as jointly highlighting the dynamic complexity involved in how care was organized in the family and were hence constituted into the key theme of the family context of care, discussed in the present paper.

Methodological rigor was maintained through prolonged engagement (Lincoln & Guba, 1985) and peer debriefing (Lincoln & Guba, 1999). Prolonged engagement led the researcher to spend a lot of time in the organizations where the data were collected. This gave her a chance to observe patients accessing services from there and to discuss her observations with the staff. Particular importance was given to rapport building with the respondents. It was opined that making the respondents feel comfortable and establishing their trust would play a critical role in helping them to share their stories. During the course of the interview, the researcher used probes and cross-checks to better her understanding of the respondents' narratives. Immersion in the data during the process of analysis helped the researcher gain insight into respondent experiences and to ensure the rigor of the findings. For peer debriefing and consensual validation, the researcher shared her analysis procedures and outcomes with academicians and practitioners. Academicians working in the areas of HIV/AIDS, family care and qualitative research methods as well as practitioners working in the field of HIV/AIDS care and support reviewed the researcher's methods, interpretations, and findings, providing critical evaluations, suggestions, and feedback. The incorporation of their inputs strengthened the analysis. This process continued till most, if not all, the academicians and practitioners agreed on the analysis and its outcomes.

It may be relevant to mention at this juncture that the author herself conducted the study. She designed the inquiry, collected the data, and completed the analysis. Primarily, the author's interest in the experience of caregiving, her having been a family caregiver for a length of time, served as the underlying motivation that sparked off the study. In the paper, the author has referred to herself as the researcher.

## **Findings**

The family context of care subsumes themes relating to the organization of care in the family. It brings out the dynamics involved in assigning caregiving responsibility, including the composition of the caregiving system, values underlying care, and the influence of the perceived mode of infection and of the class and gender of the seropositive individual on the provision of care.

### **The Caregiving System**

Within themselves, households (HHs) and/or families were found to form various caregiving systems. Though caregiver and care receiver responses to direct questions on who the caregiver was portrayed a simplistic picture, with most responses indicating a single caregiver, who was either the person who actually provided the positive person with care or whom the seropositive respondent felt closest to, conversation during the course of the interview brought forth the complex organization of care. It highlighted that invariably, a single seropositive person has more than one person involved in providing him or her with care, (i.e., multiple members of the HH and/or the family participated in

the provision of care). However, the presence of multiple caregivers did not imply equal distribution of caregiving tasks. In some cases with multiple caregivers, the concept of primary caregiver was brought into play. The primary caregiver is the person who bears the bulk of the responsibility for the caregiving role, both in terms of actual execution and decision making.

Six seropositive caregiving wives formed an important group, as caregivers for their HIV infected husbands. Not only did these women have to care for their seropositive husbands, while simultaneously being HIV positive themselves, but also the in-law family provided them with little or no support in their caregiving role, even when they were living in joint households with their in-laws. In order to cope with their experiences and with the caregiving role, wives turned to, and received support from, their natal families, though the bulk of responsibility for task performance and decision making remained vested in them.

In other cases with multiple caregivers, actual performance of caregiving tasks and decision making about care generally rested in two different persons. Thus, persons who actually provided care were not necessarily the ones who made important decisions about caregiving. Age, position in the family and command over family resources were significant deciding factors in this matter. For instance, in the case of a concordant couple with matrilocal residence, where besides the spouses, their child and the wife's mother were also seropositive and concomitantly symptomatic, both husband and wife provided care to each other and to the other ill members, while simultaneously making care related decisions as well. The wife's seronegative younger brother, who lived in the same HH, assisted in caregiving (in spite of knowing the serodiagnosis of his HH members), till he inherited the family property. Once he took command over family resources, he withdrew his support to his sister's family and forced them to vacate the house. This case shows that decisions regarding care provision depend to a large extent on the one who owns family resources.

In the case of an unmarried seropositive male, initially living with his family of origin and later shifting a residential facility, his sister-in-law who commanded the family resources took charge of his care, though the actual performance of caregiving tasks was relegated to his mother, a non-earning member of the HH. In such cases, caregivers who were financially dependent on others for resources to provide care found that they had no autonomy to provide care as they wished.

I want to do so much for him (my son) but I have to depend on \_\_\_\_ (my other son and his wife) for money. And she (the other son's wife) is so angry with him for creating problems for us that she does not want to spend on him, just give him the bare minimum, so she restricts the cash that she gives me. That leaves me with hardly any chance to do what I want...it is so upsetting... (elderly seronegative caregiving mother)

Where power relations come into play, one finds that the task of executing the more burdensome caregiving tasks can fall on the shoulders of dependent family members, regardless of age. When this involves elderly members of the family who have other roles and responsibilities and when caregiving is intensive, the performance of caregiving tasks can lead to adverse health consequences for the caregiver.

I have all kinds of problems - heart, blood pressure/BP, arthritis. Seeing to all these things - the house, cooking, washing clothes, cleaning vessels, and then on top of it, seeing his (my son's) condition and looking after him, makes me more sick. When he is in hospital, it is even worse because then I have to run around alot. Even coming here (to the residential facility, which is located on the outskirts of the city) is really exhausting for me, after completing all the housework. (elderly seronegative caregiving mother)

Partnership in caregiving, where the performance of caregiving tasks was shared almost equally between two caregivers, was observed in three cases. A thalassaemic,<sup>ii</sup> HIV positive male adolescent was cared for by both the parents who divided the responsibility and the performance of caregiving tasks. In another case of a separated HIV positive intra-venous drug user (IVDU) living with his family of origin, his mother and sister took turns to look after him.

Both his father and I look after him (the son). For example, on a day when he has a transfusion, his father takes him to \_\_\_ (a public hospital in Mumbai) in the morning and stays with him over there, while I prepare breakfast and lunch. Then I take the breakfast and lunch, and go to the hospital, and while his father proceeds to work, I remain with him and bring him home in the evening. His father sees to the supply of all the thalassaemia related medicines, while I go to \_\_\_ (another public hospital in Mumbai) and bring the homeopathic medicines for HIV. So like this, we divide and manage. (seronegative caregiving mother of seropositive thalassaemic adolescent)

Two respondents had a single caregiver, termed as the sole caregiver, where the entire responsibility for caregiving rested with just one person. The sole caregiver, thus, not only provided care but made all decisions pertaining to the process. A seropositive child was looked after by his widowed seropositive father, while a male HIV positive respondent received care from his employer, in a quasi-family context of caregiving.

Seth (my employer) looked after me all by himself without taking anyone's help. (widowed seropositive man)

Children were performing caregiving tasks for their seropositive parent in two HHs. The absence of adults other than the seropositive parent in the HH and no/limited support from informal sources put the onus of caregiving on the offspring. In these cases, the child's role was confined to the performance of caregiving tasks while decision making remained with the care receiving parent and/or, if present, the support system. In one HH, the child caregiver (aged eight years) looking after his widowed seropositive father, not only had to provide care single-handedly, following the withdrawal of the support system after a point of time, but was himself in the symptomatic stage of HIV infection. He therefore alternated between periods of providing care and receiving it from his seropositive father. In another HH, a widowed seropositive woman had two sons (aged 12 and 16 years) who shared the caregiving responsibility. In this case, caregiving

was undertaken by the children with support from the mother's natal family, though geographic distance impinged on the extent of support that they could provide.

When I am ill, my sons look after me. After all, there is no one else. My (natal) family is concerned, but they are not in Mumbai, so there is limited support from their end. My sons cook, wash vessels and clothes, clean the house, come with me to the doctor, get my medicines, see that I rest and take my medicines. They know what illness I have - the \_\_\_ (a public hospital in Mumbai) doctor told them both 2 years ago. So the younger child reads the paper for information about the illness. They have been looking after me like this for a period of two to three years. (seropositive caregiving wife/widow)

### **Caregiving Values**

Familial values were found to underlie caregiving behavior. As a result of these values, respondents were unable to point out one single predominant motive for caregiving, resulting in a blurring of innumerable reasons such as a sense of duty, love, lack of choice, humanitarian concern and social reasons.

You could say both love and duty. They (my brother and father) matter to me, so I want to do it...and yet at the same time, as a part of the family, I have to do it - there is no question of a choice. So it is difficult to say which one is more important. Basically, it is all linked to family ties. (seronegative caregiving doctor son and brother)

In families with blood/marital ties, it was this deep-rooted sense of familism that was also instrumental in providing caregivers with the tenacity and grit to go on with their role in the face of acute burden.

It was troublesome for me - single-handedly managing him (my husband), my child, the house...it was really tough. But I love my family, and it is for me to see to them, no matter what the cost. So I would just keep at it somehow. (seropositive caregiving wife/widow)

While this familial orientation as described above was evidenced in quasi-family situations also, reaffirming the collectivist nature of the social context of developing countries, it was the emotional bonding between the caregiver and the care receiver which made a critical difference to the continuity of the caregiving process in these cases. High degrees of emotional bonding resulted in caregivers doing their best, providing care throughout the course of the infection notwithstanding the strain involved, whereas in instances where there were lower degrees of emotional bonding, caregivers ceased the caregiving process when they felt that the provision of care was getting burdensome.

### **Perception of the Mode of Infection**

The seropositive diagnosis was not received as a neutral event by HH or family members. In the case of male HIV infected respondents whose lifestyles of drinking,

gambling and visiting sex workers were seen as responsible for acquiring the HIV infection, HH/family members generally felt anger towards them for inviting problems into the family. They saw the positive person as responsible for creating hardships for the family and blamed him for their predicament.

He (my HIV positive son) has just wanted to enjoy himself - all the time going out with friends and drinking, coming home drunk. From what he told the doctor, he has gone for sex outside too. He never has once contributed to the house, forget about money, even in terms of doing things for us. Instead, he has only brought problems for us. And now he has brought this terrible illness - we have to look after him, and face the world. Naturally, we are upset. My other son and his wife are terribly angry - they wonder how much they are supposed to keep doing for him. (elderly seronegative caregiving mother)

The provision of care in such cases was accompanied by negative feelings.

In three instances, two of which involved sisters-in-law as caregivers, anger was overtly expressed and affected the process of caregiving. Caregiving was thus regarded as an undesirable but unavoidable responsibility. Caregivers' resentment here was manifested by the grudging provision of the minimal care required.

My other son's wife is so annoyed with him (my seropositive son) that she gives just the bare minimum support. That too, because she has no choice but to look into his needs. (elderly seronegative caregiving mother)

When such feelings influenced the caregiving process, even though families had the resources to provide the best possible care, they would restrict it to looking after the most pressing needs, namely, medical and physical needs of the positive person with the minimal emotional investment, such that the care receiver was not neglected.

My other son's wife ensures that just the most essential things are done for him (my seropositive son), beyond that she is just not willing to spend at all. So even though we can afford to give him better care, she refuses to do so. (elderly seronegative caregiving mother)

However, most mothers, siblings and wives did not let their anger interfere with the provision of care.

Yes, he (my husband) created a lot of problems for us. Because of his behavior only he got AIDS, and my daughter and I have had to suffer. But I never once let my anger affect my caregiving. I cared for him with a clean and willing heart - I did my best, leaving no stone unturned. (seropositive caregiving wife/widow)

In the case of wives, the sense of spousal duty came out vividly, stemming not just from love and duty but from their belief that they should not be found wanting in their caregiving by others.

Love and duty as a wife, yes, but more than that, I didn't want the whole world to say that her husband is ill but she is not bothered. Because my parents got me married so it is necessary that I look after him (my husband), that I do my best, so that no one can turn around and say she abandoned her husband, that he did this and so she did that. Now people can say that no matter what he did, she looked after him and that too, well. (seropositive caregiving wife/widow)

Secondly, wives perceived the death of their husbands as being a threat to the well-being and future of their families. Realization of the significance of their husbands' survival for the future of their children and for their own social status as married women in a patriarchal society pushed them to do their best to provide care, in spite of their negative feelings and the accompanying burden.

I never, ever felt that I was undergoing a lot of trouble. I only felt that if he (my husband) got well it would be good for all of us, we would be a complete family, the children would have their father, no one would call me a widow, both of us would be able to earn and we would all be happy. But if he died, then the children and I would both suffer a lot. So I did my best. I never thought of it as trouble or anything. I just thought of the future and did it. (seropositive caregiving wife/widow)

Within this group of mothers, siblings and wives who did not allow their negative feelings to affect the caregiving process, the terminal nature of the infection created a sense of helplessness. "I can't help you" was a commonly reiterated statement. But while they acknowledged that there was nothing they could do to reverse the HIV diagnosis, it did not deter them from doing their best for their seropositive care receiver.

I knew that nothing I did would change things, finally he (my brother) would die of AIDS. But still, I wanted to do all that I could for him. (seronegative caregiving brother)

Among these caregivers, those looking after seropositive family members in advanced stages of the infection sought to "make their last days as comfortable as possible." This was described in terms of the provision of physically comfortable surroundings, the reduction of physical pain and discomfort, optimal satisfaction of as many needs as possible, and emotional solace and reassurance of being loved and valued.

In the case of six seropositive caregiving wives, though all these women had been infected by their husbands, the perceptions of their in-law and natal families in this matter differed. In-law families tended to blame the woman for bringing home the HIV infection and passing it on to their son. They thus left these women to look after their husbands single-handedly, and the women's health and support needs were neglected by the in-law family, even when they were living together as one unit.

Natal families, on the other hand, recognized the women as "innocent victims" of their husbands' lifestyles and responded with an attitude of protectiveness.

My (natal) family knows that I am innocent in all this. They know what I am like and that I have done nothing to get this disease. They know that my husband is responsible. They know how much I have suffered and how my in-laws have treated me. That is why when I came back to my mother's house after his death, she welcomed me with open arms. And the moment I have the slightest sickness, my mother at once sends me to the doctor – she gives me money. My younger sister also at once insists that I see a doctor. They are just after me. My mother tries to make me understand because sometimes I get so tense. So they care a lot. (seropositive caregiving wife/widow)

In the case of the thalassemic adolescent who had been infected through blood transfusions, his parents' perception of the source of HIV infection went far beyond the "innocent victim" orientation. Here, they considered themselves to be responsible for his health situation and their intense guilt and remorse propelled them towards doing their maximum for him.

Similarly, though the source of infection for the infected child respondent could not be ascertained, his caregiver father perceived him as an "innocent victim", and experienced acute distress to see him suffer. Doing the optimum possible in the caregiving process was the father's means of coping with his feelings.

I have no idea how \_\_\_\_ (my son) has got this disease. But one thing I know, he is innocent. And it is the unfairness of the situation that upsets me. Seeing a small child suffer like this is beyond me. The only way I can control my feelings is by doing what ever I can for him. (widowed seropositive caregiving father)

### **Gender of the Seropositive Person**

Gender of the HIV infected respondent was found to be a critical factor when analyzing the response of most families. Married HIV positive women were found to be at a disadvantage. Not only did they have to care for their seropositive husbands, while simultaneously being positive themselves and in need of care, but also the in-law family provided them with no support at all, neither for their caregiving role, nor for their own health status, even when they were living in joint households with their in-laws.

When he (my husband) was ill, I used to look after him by myself. Even when I was my in-laws' place, I used to look after him, they never helped me, even though it was their own son. They knew that I also had AIDS and had to take care of myself, but that did not make any difference - they did not show any concern for my health. (seropositive caregiving wife/widow)

The families of married HIV seropositive males thus were unsupportive, considering the care of their son to be the duty of his wife. Poor relations between the daughter-in-law and parents-in-law, negative perceptions of the infection and the belief that the daughter-in-law was somehow responsible for the son's seropositivity were some of the reasons why families abandoned their daughters-in-law, even though in some cases they could afford to support them.

My mother-in-law had been nasty with me from the beginning. And once his illness was known, though she knew very well what her son's lifestyle had been, she insisted that I had done something at my mother's place and come, she never considered her son to be at fault. So obviously, she would not want to help me out. (seropositive caregiving wife/widow)

Moreover, the fear that they would have to look after the son's family after his death and share the property with them made them withdraw from the relationship.

Basically, their (my in-laws') main concern was that they would have to look after me and my daughter, and I was also infected, so I would be soon be as sick as my husband and then, after my death, they would have to do everything for my daughter. They also wanted to cut off their ties with me because they did not want to give me my share of the property - what if I remarried? (seropositive caregiving wife/widow)

These seropositive caregiving wives, hurt and bewildered by the behavior of their in-laws and in need of support to cope with their experiences, looked towards their natal families during the lifetime of their spouses and/or after their deaths. It was the familial orientation and love and bonding of the natal family which ensured that these women and their families were not abandoned, regardless of the natal family's economic position. Their support assisted women in their caregiving role, while also seeing to their health needs and to the well-being of their children.

All the women spoke of their concomitant gratitude to, and awkwardness with, their natal families. Having experienced rejection from the in-law family and indifference from their husbands, and given the cultural attitude towards the position of married daughters in the natal home, and in some cases the economic position of the family of origin, these women realized the value of the natal family's support. They knew that if their natal families had not come to their rescue, they would have no one to care for them.

When my in-laws threw me and my daughter out of the house, I had nowhere to go. I didn't want to come back to mother's place because among us, we have a custom that we stay with the in-laws only. Once a girl is married, she is dead for the natal family. And my family is also not so well off that they could afford to keep me and my child. So I thought I should go with my child and live in an orphanage. But the \_\_\_ (NGO/non-governmental organization) people made me understand that since I had a (natal) family, I should go to them, being my own people, they would not abandon me. So I decided to go back and when I asked them, my mother said, 'As long as I am alive, I will look after you.' If it were not for them, I do not know where I would be today. (seropositive caregiving wife/widow)

At the same time, they felt hesitant to trouble them, and hence tended to defer seeking support till they could no longer manage on their own. This was done even though such postponement involved neglecting their needs and precipitating feelings of

emotional isolation. This discomfort stemmed from cultural beliefs that once a woman is married, she no longer belongs to the natal home. In some cases, the poor economic position of the natal family made women feel awkward to access support from them. Women were therefore found to defer seeking support till they could no longer manage on their own.

In the case of male seropositive respondents, the marital status of HIV positive men seemed to alter the equation of caregiving within their families. For married positive men, their wives were expected to provide them with care virtually single-handedly, regardless of HH composition and the latter's serostatus. In contrast, in cases of single/unmarried/widowed/separated males, members of their family of origin undertook caregiving, even though in a few cases, this care was limited.

### **Class of the Positive Person**

The present research brought to light an interesting dynamic in relation to the class of the seropositive respondent, pointing out that it cannot be taken for granted that positive people from middle and upper classes will receive better care than positive people from lower classes merely by virtue of the presence of family resources. Caregiver and family perceptions of the source of HIV infection and its implications as well as gender impinged on the caregiver's/family's decisions regarding the use of family resources for the treatment and care of the positive member.

In the case of male family members, where caregivers and families believed them to be innocently infected, or where they believed that in spite of their anger they should do their maximum to provide care, then even if they belonged to the lower income group, caregivers and family members were not deterred by the paucity of resources and would often go out of their way, even to the extent of incurring loans and debts, to provide the best possible care to their care receivers.

I never even thought of the expense involved in caring for him (my husband). I never even stinted, or cut down, or thought that too much was being spent on him. How I managed to get money from here and there, God only knows. I never once felt that so much money was going. I just wanted him to get well. He used to feel that lots of money had gone in his treatment. He used to ask me also, "All this money where do you get from?" Because we had nothing. (seropositive caregiving wife/widow)

Where caregivers and families believed that the male seropositive member was guilty for bringing home the infection and their anger over this colored the caregiving process, respondents received limited care from their families of origin, though the families had the resources and could afford to provide them with better care.

They (my brother and sister-in-law) don't have a financial problem in caring for me, they have enough money. But inclination is not there because she (my sister-in-law) is angry with me for my past behavior which is responsible for this AIDS. So lack of care is not because of lack of money. (unmarried seropositive man)

In one such case, the entire family agreed with this course of action. In the other two cases, the mothers of the seropositive men wished to do their best for their sons, in spite of their anger, whereas the sisters-in-law, influenced by their anger, believed that only limited care was appropriate. In both cases, mothers being aged and dependent had to adhere to the dictates of the sisters-in-law who controlled the family resources, though they tried to do their best within the constraints of their situation.

In the case of women, in-law families, going by the “guilty orientation,” chose to reject their seropositive daughters-in-law, even though in most cases they could afford to provide some support. Natal families, operating on the “innocent orientation,” provided assistance, notwithstanding that they could ill-afford it in some instances.

Thus, while it is logical to assume that due to differences in resources, upper and middle income group families would provide better care to their seropositive members as compared to poorer families; this was not found to be true in all cases.

### **Discussion**

India’s adoption of the structural adjustment program (SAP) has resulted in cutbacks in health sector expenditure and promotion of policies for community care. This transfers the responsibility of care for ill people to their families, adversely affecting the micro-environment of the household (Qadeer, 2000) and unleashing severe financial strain, especially for poor families (Prabhu, 2000). This paper has elaborated upon the family context of care, paralleling what Kahana, Kahana, Johnson, Hammond and Kercher (1994) term the spatial axis, (i.e., who provides care and how this person came to be the caregiver).

Among the study findings, the identification of caregiving systems beyond the sole caregiver model supports the criticism that the sole caregiver model is idealistic since multiple family members help out significantly in the provision of care though one of these may play a prominent role (Keith, 1995). The identification of the primary caregivers, partnerships and sole caregivers moves along the same lines as Keith’s (1995) research on the division of labor between offspring caring for an elderly parent where three caregiving systems, primary, partnership and team, were identified. The primary caregiver system was where one person carries all or most of the caregiving responsibilities. In a partnership, two people contribute equitably to the caregiving work and are equal in authority and responsibility. In a team, tasks are shared by a group of family members in an organized, planned, and integrated manner.

The dynamics determining the assumption of the primary caregiver model in instances of multiple caregivers and the operational complexities involved reflects not just the well-known patriarchal structure of Indian families but also the role of economic power and dependency in family processes. This adds on to works such as Keith’s (1995) which points out the role of family size, gender of caregiver and family values as well as Piercy and Chapman’s (2001) which highlights the influence of expectations, family rules, religious training, role modeling and role making, in deciding the caregiving system.

Familism and collectivism stand out as overarching factors influencing the assumption of the caregiving role and the process of caregiving. Pyke and Bengston (1996) believe collectivism and individualism form the organizing principles behind families’ responses to elder care needs. According to Pyke and Bengston, collectivist and

individualist orientations to family relations undergird different strategies of family care. In their study of elder care, they found that individualists minimize caregiving and rely on formal support in the care of frail elderly parents. They do not abandon their parents, but serve as managers of their parents' finances and care arrangements, and generally maintain regular social contact with them. Collectivists assume care for frail parents even when care demands are high and associate nursing homes with family abandonment and Dickensian conditions. Commitment and attachment are typical of adult children of collectivist families. Though caregiving constrains their lives, they do not express resentment of the burdens but derive a positive identity from their caregiving role.

Besides individualism and collectivism, research on HIV/AIDS has also demonstrated the central role played by the perception of mode of infection and gender of the seropositive person (Bharat, 1995, 1996), as this study does. Bharat's inquiry (1996) highlights the extent to which gender of the positive people influences the process of caregiving. According to her, men qualified for care by virtue of their gender. Wives, even those who were infected, would neglect their own needs and exert themselves in order to provide care to their husbands. Mothers did likewise for their sons. For women, care was largely a self managed activity. Though some women were cared for by their parents (but being conscious that they were a burden on their already poor parents, they made no demands for care), others had no one to show any special concern. In-laws were not bothered about daughters-in-law but only about their sons, often blaming the former for their sons' condition. Thus, women provided care, but were not assured of care to the same extent. In fact, some women because of their caregiving role, were allowed to stay in their in-laws' home while the husband was alive and following his demise, were made to leave. One woman was made to leave even during the husband's lifetime in order not to tax HH resources when the husband was going to die. Women who were allowed to stay on as widows were on terms dictated by the husband's HH, making them vulnerable. Only in one in-law HH was the wife seen as the HH's responsibility and given all care and support (Bharat, 1996; Bharat & Aggleton, 1999). HH involvement in care was greater for men than for women. While this differential treatment can be explained by the more advanced state of ill-health of the husband and by the socioeconomic background of the wife's parents, this is only a partial explanation. The fact remains that men do not ask for care, it is provided naturally because of their gender, whereas women have to look for it (Bharat, 1996; Bharat & Aggleton, 1999).

Since the Indian woman's identity in adulthood is tied to marriage and motherhood (Kakar, 1988), women express apprehension over possible widowhood, since it makes them vulnerable on several fronts. D'Cruz and Bharat's (2001a) review indicates that besides financial difficulties and problems in child-rearing, widows faced lower social status, lacked companionship, feared sexual advances, felt scared at night, felt unwelcome at auspicious functions, were exploited by the in-laws and so on. Seropositive wives in the present study were only too well aware of this and hence, in spite of anger towards their husbands' lifestyles and its consequences, they wished, for their own well-being and that of their children, that their husbands survive and hence, they provided optimal care. Moreover, since being a good wife means being a good woman (Chitnis, 1988), wives were concerned that their care provision should not be found wanting and should not be a source of blemish to their reputations. Women are also considered to be guests or visitors in their natal homes from the time of their birth till the

time of their marriage, and spend their childhood being groomed for culturally designated roles of their future life with their husbands and in-laws (Chitnis, 1988). Once they are married, they belong to the in-law household. This indoctrination partially explains women's reluctance to return to their natal families and to seek support from there.

The perception of the source of the infection is another critical variable impinging on the family context of care. Bharat's (1995) review underscores that because HIV/AIDS is associated with lifestyles that are characterized by sexual overactivity, promiscuity and permissiveness in society, the person with HIV is attributed with such a lifestyle and blamed for bringing shame upon the family. The family therefore may not consider it to be its moral duty to extend care. The family, while sheltering a seropositive individual under its roof, may psychologically isolate the individual, leaving him/her alone for the most part of the day and/or avoiding physical care for fear of contagion. Caregivers in these families tend to perceive the disease as a deviance and the HIV positive member as psychologically weak for giving in to sexual urges. Support and care may also be determined by the family's perception of the HIV positive person as "innocent" or "guilty." The "guilty" are those who have brought upon the problem due to their "uncontrolled sexual conduct", such as people with multiple partners and/or those with the power to corrupt men such as commercial sex workers (CSWs). Guilty are also those who reject the rules of society like IVDUs and those who deny the dominant sexual order, that is, homosexuals. Family care for such people may be less forthcoming or provided unwillingly out of a lack of choice. The "innocent," on the other hand, may be cared for with love. These include those who have suffered infection during actions considered normal or nurturing like those infected during blood transfusions or childbirth, or those who have been infected for no fault/action of their own. Not only the family, but also the community, may come forward to help in such cases. At the same time, the perception of the wife as an "innocent victim" of her husband's sexual conduct may not be accepted by all sections of people in developing societies, where the husband's family blames her for acquiring the infection and sees her as a burden and denies her care (Bharat, 1995, 1999).

The present study brings out an interesting dynamic: the interaction between perceived source of the infection, gender of the infected person, and class which affects the way economic factors operate in the provision of care.

There is an obvious need to work with families on a variety of fronts. Education and counseling for attitude change and healthy family dynamics are relevant to assist families in overcoming their negative thoughts and feelings towards HIV/AIDS and towards the seropositive member, and to enable them to provide care in a willing manner. As a part of this, elucidating to families the relevance of support in stalling the progress of the infection would be useful. Families also need help to develop into systems which support caregivers in positive and appropriate ways. Special programs of support including self-help groups, support groups, material and financial assistance, and respite care need to be created for seropositive caregiving wives and for elder caregivers who face extraordinary problems that compound the strain of their caregiving roles. A relevant first step in this direction is the incorporation of a family focus in health sector interventions, which by and large, is lacking (D'Cruz, 2003). An emphasis on comprehensive primary health care rather than on vertical programs must be given priority in health policy (D'Cruz & Bharat, 2001b).

In addition, seropositive wives need to be made aware of their rights in the matrimonial home. Both natal and in-law families must be sensitized to the predicament of their caregiving daughters/daughters-in-law, especially those who are seropositive. Long standing cultural beliefs that reinforce patriarchy need to be challenged and a different world view promoting gender equality, presented. To this end, efforts towards the empowerment of women should move beyond mere economic and political empowerment and encompass social empowerment (Deshmukh-Ranadive, 2003).

There is growing belief that children as caregivers are developing into a significant group, though the exact number is not known (Joint United Nations Program on HIV/AIDS, 2000). As we have seen, children assume this role when one parent dies in a nuclear family and there is usually no one to look after the other parent and siblings, some of whom may be infected (D'Cruz, 2001; UNAIDS, 2000; UNAIDS, 2001; Joint United Nations Program on HIV/AIDS/United Nation's Children's Fund/United States Agency for International Development, 2002). This is a version of skip-generation parenting, which involves parentification of youth (Campbell, 1999). The role of child caregivers conflicts with the state of childhood, challenging dominant conceptualizations of children as dependent, passive and non-productive, and prompting policy makers to state unequivocally that child caregivers should be treated as children first and as caregivers second (Chinouya-Mudari & O'Brien, 1999). In their study of African migrant children, living in London looking after seropositive parents, Chinouya-Mudari and O'Brien (1999) have shown that children who care perform a wide range of duties such as household tasks, child care, and personal care for ill relatives, while also being a pillar of support to parents and other siblings who are going through emotional and physical turmoil, as a result of HIV/AIDS. Children experience burden on account of their role but this is augmented by the psychological stress and trauma of watching parents and siblings deteriorate and die. Caregiving poses a threat to children in terms of their psychosocial development as a result of exclusion, isolation, and interference with education. While this could be because of time constraints, it is often attributed to parental concerns about confidentiality, which makes them limit the number of associations children have. Children themselves may set limits on their social worlds, trying to keep the 'family secret' even if they are not fully aware of the reasons why. The overall strain can lead children to mental ill-health. Undoubtedly, child caregivers need emotional, physical, financial, and material support. The initiation of programs where volunteers from the community or professionals/para-professionals from health care agencies share some of these children's tasks, providing respite care, is of relevance and could help children to attend school, socialize and experience at least a part of their childhood.

Though institutionalization as a means of care runs contrary to contemporary policies of community care, it is an alternative for those who have no blood/marital families to look after them/who have been rejected by their families. Given these circumstances, can we eliminate institutionalization altogether? What alternatives can we develop to provide sustained, positive support? Addressing these issues is an important priority for policy makers and service providers working in the field of HIV/AIDS intervention.

Overall, despite the stigmatizing nature of HIV/AIDS, no positive person included in this study was completely denied care. This proved to be an encouraging finding. Families transcended themselves and undertook the responsibility to fulfill the needs of

their seropositive members. Even though it was sometimes difficult for families in terms of their economic resources, roles and responsibilities, family dynamics, and perceptions of gender and of the HIV infection, support in some form (even when it was limited) was forthcoming, at least for some period of time as in some quasi-family contexts. Even seropositive caregiving wives who were rejected by the in-law family, had their natal families to fall back on. At the same time, the supportive role played by the family cannot be taken for granted. It is well known that families experience severe adverse effects as a result of HIV/AIDS, and as McGrath, Ankrah, Schumann, Nkumbi and Lubega (1994) warn, in the absence of adequate support, families will be unable to cope. Policies and programs to support families and facilitate their adaptation are of utmost significance in order to ensure that families do not disintegrate under the burden of HIV/AIDS related demands.

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### Author Note

Premilla D'Cruz completed her Ph.D. from the Tata Institute of Social Sciences, Mumbai. She is currently an Assistant Professor in Organizational Behavior, at the Indian

Institute of Management Kozhikode. Her research interests include gender, creativity, emotion, health studies, information and communication technologies, family psychology and qualitative research methods.

Premilla D'Cruz, Indian Institute of Management Kozhikode, Kunnamangalam, Calicut 673 571, India; Phone: + 91 495 2803001 extn 115; Fax: + 91 495 2803010; Email: pdcruz@iimk.ac.in, premillaruth@yahoo.com

### Notes

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<sup>i</sup> Opportunistic infections are infections caused by organisms that rarely cause disease in persons with normally functioning immune systems. These organisms have been acquired from the environment. They are carried in the body as part of the normal organisms kept in balance by the immune system. This has several implications: 1) Opportunistic infections are unlikely to be transmitted to others, since other people are already carrying the organisms; 2) These infections are rarely curable; however they are often controlled. In most cases, long term therapy is required to suppress the organisms once the acute illness has been treated; and 3) More than one infection can be present at a time, each requiring different medications. Treatment may be lengthy, but most of the infections can be controlled with medication. Because it is so important to use the correct medication for a specific organism, infections must be identified using a variety of tests. Giving antibiotics without a diagnosis can subject a person to side effects of an unneeded drug, and delay starting the correct treatment (Davis, 2000)

<sup>ii</sup> Thalassemia refers to a diverse group of genetic blood diseases characterized by absence or decreased production of normal hemoglobin, resulting in microcytic anemia of varying degrees (Thalassemia, n.d.).

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