Caregivers' Experiences of Informal Support in the Context Of HIV/AIDS

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Social support is an important buffer for family caregivers of people living with HIV/AIDS (PLWHIV/AIDS). With limited formal support options, these caregivers have to rely increasingly on informal networks. Yet, accessing this avenue is also fraught with difficulty due to the stigmatising nature of HIV infection. Research in this area is not just not sparse, but focusses largely on sources of support and the circumscribing effects of stigma. To further our understanding, a qualitative study was conducted using various concepts from social support theory. Twelve family caregivers in Mumbai, India, were interviewed, using the in-depth interview method. An iterative, thematic analysis was done through which themes and major themes were identified. Major themes included sources of support, types of support received, spontaneous support, soliciting support, caregivers' perceptions of support experiences and reciprocity. The findings raised several issues for intervention.

Keywords

Family caregiving, social support, HIV/AIDS

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Social support is an important buffer for family caregivers of people living with HIV/AIDS (PLWHIV/AIDS). With limited formal support options, these caregivers have to rely increasingly on informal networks. Yet, accessing this avenue is also fraught with difficulty due to the stigmatising nature of HIV infection. Research in this area is not just not sparse, but focusses largely on sources of support and the circumscribing effects of stigma. To further our understanding, a qualitative study was conducted using various concepts from social support theory. Twelve family caregivers in Mumbai, India, were interviewed, using the in-depth interview method. An iterative, thematic analysis was done through which themes and major themes were identified. Major themes included sources of support, types of support received, spontaneous support, soliciting support, caregivers' perceptions of support experiences and reciprocity. The findings raised several issues for intervention.

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Introduction

An extensive body of literature underscores that providing care to an ill family member is a stressful experience for the entire family (See, for example, Baider, Cooper, & De-Nour, 1996; Chesler & Parry, 2001; Chilman, Nunally, & Cox, 1988; D'Cruz, 2002; Hilbert, Walker & Rinehart, 2000; Kuyper & Wester, 1998; Mailick, Golden, & Walther, 1994; Northouse, Dorris, & Charron-Moore, 1995; Radina & Armer, 2001). Within the family, caregivers, who have a greater degree of involvement in the caregiving process, are subject to more adverse outcomes. These include experiences of objective and subjective burden, and detrimental effects on physical and mental health (Berg-Weger, McGartland Rubio, & Tebb, 2000). While caregiving research has disproportionately focussed on negative caregiver outcomes (D'Cruz, forthcoming), it has devoted limited attention to the role of social support in buffering them (Jankowski, Videka-Sherman, & Laquidara-Dickinson, 1996). Studying this aspect is of significance because social support has been shown to be positively related to good health. It is associated with better health outcomes, better coping and less negative effects of stress (Cohen & Syme, 1985).

Explorations of this aspect of caregiver experiences are particularly relevant in the context of HIV/AIDS. The progressive, long-drawn and terminal nature of the infection compound the stress engendered by the caregiving role but the stigmatising nature of the virus circumscribes caregivers from seeking and receiving much needed support. Indeed, the limited research

available in the West provides evidence of this. For example, Jankowski et al. (1996), in a study of male and female confidants of PLWHIV/AIDS, reported confidants' networks to be constricted in contact and size. Confidants had diminished "weak social ties", namely, those with acquaintances, co-workers and neighbours, and relied primarily on "strong social ties" with family members and close friends. While limiting contacts resulted in fewer questions and lower likelihood of having to divulge the diagnosis, using misrepresentations of the diagnosis such as maintaining a veil of pretense or a diagnostic charade, though an important means of coping, made interaction more stressful and reduced the support available. Confidants reported that having at least one person with whom they could share the truth served as a safety valve for their emotional burdens. Yet, disclosure of diagnosis resulted in outright rejection in several cases. Moreover, where confidants provided care to PLWHIV/AIDS, the ensuing time constraints resulted in less social interaction and hence, less support. In these various circumstances, professionals played an especially important role in providing support.

Poindexter and Linsk's (1998) study of older, female, African-American caregivers pointed out that while respondents experienced reciprocal support from their care receivers as well as support from spiritual sources, external support came largely from relatives. Friends were rarely resorted to, partially due to the experience of discrimination and ostracism following disclosure of the HIV diagnosis, and partially because respondents did not wish to disclose their HIV caregiving to persons outside the family. Though they manifested the need for additional social interaction and support, respondents felt that they could not trust anyone to receive the truth and power of their stories. With their choices for accessing the external support limited, they could not enjoy the stress buffering effects of social support and were losing their community at the most trying and painful times of their lives.

Poindexter and Linsk's other (1999) study of a similar population found that because of the anticipation of HIV related stigma, caregivers of HIV positive individuals did not widely disclose the HIV diagnosis, if at all. Consequently, they neither experienced overt HIV related stigma nor received support that acknowledged their struggles as HIV affected caregivers. The study reported that although church participation and spirituality were important sources of social support for the respondents, they varied in their disclosure patterns to churches. While eleven of those who attended church had disclosed to no one in their churches, two had told only the pastor, and another two had told the pastor and a few church members. There were two others who had gone public in their churches, but their disclosures were received with different responses - one noticed no ramifications, and one was disappointed that none of the church members provided support.

While the aforementioned studies provide valuable insights into caregiver experiences of social support in the context of HIV/AIDS, a closer look at them from the point of view of social support theory highlights their limited foci. That is, these studies examined sources of support, and the circumscribing effects of stigma on support seeking and the consequent loneliness. But social support is a multidimensional concept and its study must necessarily touch upon aspects such as solicited versus spontaneous support, types of support solicited versus those received, positive versus negative support, actual versus perceived support, and reciprocity (See, for example, Boyce, Kay, & Uitti, 1988; Cohen & Syme, 1985; Cooke, Rossmann, McCubbin, & Patterson, 1988; Erickson, 1989; House & Kahn, 1985; Revenson, Schiaffino, Majerovitz, &

Gibofsky, [1991](#); Sherbourne & Stewart, [1991](#); Unden & Orth-Gomer, [1989](#); Williams, [1993](#)). Moreover, in the case of HIV/AIDS, an exploration of the process of accessing support and its relationship with disclosure is also relevant. With these objectives in mind, a study of caregiver experiences with the informal support system in the context of HIV/AIDS, was undertaken in Mumbai, India.

Method

Design

The study adopted the qualitative approach. A phenomenological orientation was incorporated since the objectives were to explore subjective meanings and experiences from the respondents' points of view. In-depth interviews were employed as the method of data collection, and in order to facilitate this process, an interview guide was developed (See appendix). Observations made during the course of the interview were recorded.

Sample

Public, private and voluntary health sector organisations working in the field of HIV/AIDS in the city of Mumbai, India, were contacted for the study. The researcher knew about these organisations either because of her personal contacts with the organisations themselves or with people who knew them; or because she had heard about their work from other professionals or the media. Agreement of these organisations to assist the researcher was on a voluntary basis. Respondents from these organisations were chosen through purposive sampling (Morse, 1991). Caregivers with past or present experience of caring for male and/or female positive people, infected through the sexual and/or parenteral modes, who had moved beyond the asymptomatic stage and who had shared their serostatus with the caregiver were included in the study, regardless of whether the caregiver-care receiver relationship was based on blood or marital ties or whether the familial form was traditional or not (See Macklin, 1987, for a discussion on forms of family). Co-residence of the caregiver and care receiver was not a necessary criterion for participation.

Of the 12 caregivers who participated in the study, 7 (6 women and 1 man) were seropositive caregivers and 5 (2 men and 3 women) were negative. Their ages ranged from 27 to 60 years, and all but 1 caregiver resided with their care receivers. Six positive caregivers and 4 negative caregivers cared for one positive person. Of these, 6 looked after a spouse who had passed away before the study; 2, their sons; 1, a brother; and 1 was an adopted daughter who was deceased at the time of data collection. One male positive caregiver had cared for his positive mother-in-law and positive wife (both of whom had died prior to the interviews) and was currently caring for his positive son, while one negative male caregiver was looking after his positive father and positive brother. Six caregivers belonged to the lower income group (< Rupees/Rs. 2000 per household per month); 3 to the lower middle income group (Rs. 2000 per household per month to Rs. 6000 per household per month); 1 to the middle income group (Rs. 6000 per household per month to Rs.12000 per household per month); and 2 to the upper income group (above Rs. 12000 per household per month) (See table 1 for details).

Table 1: Socio-demographic profile of respondents

	Gender	Age	Serostatus	Class	Number of care receivers	Co-residence with care receiver(s)	Relationship with care receiver(s)
1	Female	27	Positive	Lower middle	1	Yes	Wife
2	Female	36	Positive	Lower middle	1	Yes	Wife
3	Female	40	Positive	Lower	1	Yes	Wife
4	Female	30	Positive	Lower	1	Yes	Wife
5	Female	38	Positive	Lower	1	Yes	Wife
6	Female	33	Positive	Lower	1	Yes	Wife
7	Male	37	Positive	Lower	3	Yes	Husband Son-in-law Father
8	Female	40	Negative	Middle	1	Yes	Mother
9	Female	60	Negative	Upper	1	Yes	Mother
10	Female	55	Negative	Lower	1	Yes	Adopted mother
11	Male	36	Negative	Upper	2	Yes	Father Brother
12	Male	33	Negative	Lower middle	1	No	Brother

Procedure

In keeping with ethical considerations in HIV research, the researcher did not approach potential participants directly. Instead, the staff of the organisations from where the sample was being drawn identified respondents who matched the specified criteria and introduced the idea, and explained the purpose of, the research to them. Only after they agreed and were comfortable enough, the researcher was introduced to them. Following rapport building and soliciting their co-operation, respondents signed a consent form, informing them of details of the study and their

rights as participants. These included voluntary and informed participation, freedom to withdraw at any point of time without giving any explanation, and confidentiality. They decided the location of the interview, as also the possibility of tape-recording the interviews. Nine respondents were interviewed in the organisation premises while 3 were interviewed in their homes. Seven 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 (7 respondents), Marathi, the regional language (3 respondents) and English (2 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. There were 3 interview sessions with 1 caregiver, 2 sessions with 6 caregivers and 1 session with 5 caregivers.

Interviews were informant directed in that they started at points which respondents wished to discuss. Nonetheless, they covered the various areas of the interview guide as well as explored issues emerging from the data. Probes and prompts were used judiciously thereby allowing an open-ended interview structure to be maintained.

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, 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). Linkages, if any, with social support theory were made at this juncture. Miles and Huberman's (1994) tools were then used to examine the linkages between themes, patterns and categories and thereby initiate interpretation (Patton, 1990). Proceeding in this manner, she 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 the data were collected, the researcher immersed herself further in the transcripts and the preliminary findings. Through the use of Miles and Huberman's tools and memoing, she not only identified more patterns, themes and categories in the data and look 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 (Guba, 1978). Interpretations based on this level of analysis were made.

Methodological rigour was maintained through prolonged engagement (Lincoln & Guba, 1985), and consensual validation (Eisner, 1991) / peer debriefing (Lincoln & Guba, 1999). Prolonged engagement led the researcher to spend a lot of time in the organisations 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 respondents' narratives. Immersion in the data during the process of analysis helped the researcher gain insight into respondent experiences and ensure the rigour 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 is important to note that social support theory partially guided the formulation of the interview guide so that the researcher could holistically explore all aspects of social support, as subjectively experienced by the respondents. But data collection was in no way limited by theory and the in-depth nature of the interview ensured that the understanding of social support was furthered through respondent narratives. In keeping with the phenomenological tradition, the experiences of the researcher were not allowed to interfere with the inquiry - the researcher suspended her own points of view (Creswell, 1998) allowing respondent perspectives to prevail. During the analysis, respondents' narratives were examined for themes, patterns and categories, and if these related to existing social support theory/concepts, they were used to deepen knowledge of the same. Other findings emerging from the data were used to expand the understanding of social support.

Findings

Sources of support

Caregivers defined the informal support system as close relationships from which they derived social support. As a group, caregivers' informal support network comprised the extended family/relatives and friends, though the composition of individual caregiver support systems varied. A support system comprising only extended family/relatives was described by 5 caregivers, whereas 6 caregivers spoke of extended family/relatives and friends constituting their supporters. Among these, 2 specified that their friends included religious people, and 1 included religious leaders and professional colleagues. One caregiver had only friends as her support network.

Types of support received

Caregiver descriptions of the kind of support received pointed out to seven broad categories. These included emotional support (11), material support (9), financial support (8), medical support (1), informational support (2), network support (3), and physical support in the execution of caregiving tasks (4).

Spontaneous support

Eight respondents reported that all or some of the members of their informal support systems responded to their observable needs.

"I have not told my (natal) family about his (my son's) HIV, nor have I asked them for help. But they know how hard things are for us. They know that he has thalassemia, that he is not keeping well of late. They know that we are not well off, and that now we have lots of tension and problems because of money, his health, and so on. So on their own, they help us."

This was even though in some cases, the support system did not know the care receivers' serostatus. There were a few instances where spontaneous support was given only for a limited period of time, either because the support system was unable to help out for a longer duration or because knowledge of care receivers' serostatus made the support system withdraw.

Respondents perceived the spontaneous support as reassuring, but at the same time, mentioned that since it was based on observation alone, it could not fulfil all their needs.

Soliciting support

Soliciting support involved behavioural and affective dimensions. Behaviourally, caregivers described a process involving a series of complex decisions that they made, contingent on their circumstances, while affectively, numerous competing feelings were reported.

The behavioural dimension Accessing support from the informal support system was an easy, taken for granted process prior to the knowledge of the care receiver's seropositive diagnosis. Caregivers would frequently approach their relatives and/or friends for assistance as and when required, being inhibited only by a desire not to trouble others and a feeling of shame to be dependent. Knowledge of the infected family member's HIV diagnosis, however, because of its stigmatising nature, changed their approach.

When support was required after the HIV infected person's serostatus was diagnosed and the support system was not aware of the diagnosis, the decision to solicit support did not come easily. Deep deliberation and careful thinking preceded the decision. Caregivers meticulously weighed the pros and cons of whether they should seek out help. Firstly, they evaluated their need to see if it demanded immediate attention or could be postponed. In other words, they were willing to put off attending to their needs until they became absolutely unavoidable. Once this was resolved, then based on what they actually needed, they considered possible sources of support. Of these, they shortlisted those who were in the best position to help them out and from whom they were comfortable receiving support. The next thing to decide upon was whether support seeking should involve disclosure of the seropositive diagnosis or not. Depending on the need and/or who they were accessing support from, caregivers decided what exactly they should tell and whether they should disclose their care receiver's seropositive status during the process of accessing. More than anything else, the need they were seeking to satisfy dictated the necessity for disclosure. Some needs necessitated the disclosure of the care receiver's HIV status and caregivers had no choice but to comply.

"We (my wife and I) were looking for a place where we could keep him (the positive care receiving brother) till his TB (tuberculosis) subsided. We felt that though HIV does not spread, TB does and since our children are small and the house is tiny, if he lives with us, they may get it. But we knew of no such place, so we decided to contact Father. ___ (a priest known to the family) and Sister ____ (a nun known to the family), as they were the only ones who could help us. And since we were looking for something specific, we had to tell them that he had HIV. Even to tell them we felt bad. But what to do? That way they are such great people, we knew that they would never turn against us and they did not. Of course not. That is why we did not mind approaching them, but still we felt bad."

Where the need was not so specific and could be fulfilled by a number of persons, a different process operated. If families could trust the person from whom they were seeking support with the secrecy of the diagnosis and be sure that he/she would help them without being judgmental, soliciting support was accompanied by disclosure, even if it was not needed or asked for and could have been avoided. If, on the other hand, they were not sure how the person would react, they would cover up their need for support with a plausible excuse, refusing to take the risk of being truthful. A process of discerning was thus apparent.

"See, I will approach those who I will benefit from. And I will ask them for help. Now whether I tell them the diagnosis or not, depends. My family will help in looking after, but I will not tell them the diagnosis because they will collapse, they may refuse to care. But I'll tell them such that they will take precautions. With my professional friends, I can rely on them for medical and emotional support, and they will keep it confidential. So I can tell them the diagnosis. With my religious friends, I go for emotional support and I'll tell them it is a deadly illness. That would suffice."

Reluctance to solicit support and fear to disclose the care receiving family member's HIV seropositivity were very clearly seen even in instances where the care receiver was said to be "innocently" infected and was not seen as personally responsible for acquiring the HIV infection. One caregiver, looking after a thalassemic seropositive adolescent who had been parenterally infected through blood transfusions, was hesitant to access support from the support network and did not see disclosure as an option.

"We (my husband and I) have not told anyone, except household members, about his HIV infection. Even our extended family members do not know. People may or may not understand, you never know. And if we tell and by chance, it slips from their mouths to others, then our entire community will come to know, and not everyone will be good and understanding. Even though he has been infected due to a blood transfusion, and everyone knows he is a thalassemic, once they are told he has this AIDS, one never knows how people's minds will work - they may just insist that he has done something wrong and then reject us. So instead of having that tension, it is better to keep it to ourselves and manage on our own. Of course, I feel it - the loneliness and pain are so acute, it would be a relief to share them. But the risk always remains, so we feel it is better to stay silent. What I tell you so easily and in the process, experience so much relief, I cannot tell anyone."

Another caregiver, a doctor whose HIV positive father had been infected through infected intravenous (IV) equipment, decided that soliciting support and disclosure of his father's serostatus would be only with his medical friends whom he was sure would understand and could be counted upon to support and maintain confidentiality.

The affective dimension Caregivers reported that soliciting support was accompanied by a plethora of feelings. Besides feeling bad that they were in a position of dependency where they needed support and could not manage on their own, they approached their support system with both the hope of things improving and with the fear of being rejected, and if there was disclosure of the care receiver's HIV status, then the fear of the information being spread, and of inviting stigma and isolation. There was also a feeling of helplessness and lack of choice that led one to seek out the support in the first place. Shame, humility and hope thus coexisted.

The emotional turmoil that accompanied the decision to, and the process of, accessing support got exacerbated when these requests were met with refusal. Caregivers received these negative responses with great disappointment and a sense of rejection, compounding their feeling of isolation.

"I went to the village with such hope. I felt that his (my husband's) brothers (who were there) would do something for us. Here (in the city), there was no one to help and I had to see to him, the children and the house. So we felt it was better to go there to them. But they did not help. They said, 'We have no money, we have our own families, so we cannot help you.' But I did not need money. Basically, it was because of AIDS that they did not wish to come near. So they did not help. My brothers saw to us. I felt very, very bad, but if they did not wish to help, but what can be done?"

Such feelings were true even in cases where the refusal came from only a part of the support network, while the rest continued to support. Moreover, the intensity of the feelings multiplied when soliciting support involved disclosure of the care receiving family member's HIV positive status, and the support system, in addition to refusing to help, spread the serostatus within the social network. The caregiver not only had to cope with less support than desired, but also with the negative reactions of the social network.

"His (my husband's) brothers refused to help. But as if that was not bad enough, they told everyone. So people would not come near. They told the doctors, so they refused to treat. They would not touch or examine him. I felt totally alone and helpless. At least my brothers stood by me."

Yet, the decision not to access support and/or to maintain the secrecy of the care receiver's serostatus from the informal support system precipitated acute loneliness in caregivers. This feeling of loneliness coexisted with the receipt of spontaneous support, because such support could address only their observable needs, leaving the rest unfulfilled.

Overall, all caregivers reported receiving some support, either spontaneous and/or solicited, from at least a part of their support system, for at least some period of time.

" I told my (natal) family that we had AIDS. They understood what it meant but still, they behaved with us as before and they helped us out as before. If they saw that we needed help, they would at once respond. Or if I asked them, they never refused."

Caregiver perceptions of support experiences

Caregiver perceptions of their experiences with their informal support networks varied along a continuum of satisfaction-dissatisfaction, and were based on three factors, namely, the content of support, the extent to which their needs were met and their perceptions of the availability of support.

The content of support referred to the presence of positive and negative components. Fulfillment of needs moved through various degrees, from complete fulfillment to no fulfillment at all. The perception of the availability of support was linked to the willingness and ability (in terms of time, resources, geographical proximity/distance, and so on) of the support system to support.

At one extreme were 2 highly satisfied caregivers receiving positive support that fulfilled many of their needs and was perceived as easily available.

"With her (my sister) by my side, I needed no one else. She went out of her way to help, and never once a mean or hurtful word...no reproach or taunts...Her behaviour was such that I knew that she was there, I only had to ask for what I wanted, and she would never hesitate or hold back. It was like...guaranteed."

At the other end of the continuum were 2 caregivers who were deeply dissatisfied. Though their support networks were geographically proximate and capable of helping, their reluctance to do so led caregivers to feel that support was only somewhat available. Support system reluctance arose from their anger towards the HIV infected individuals for their lifestyles and for inviting problems into the family, and from their negative perceptions of HIV infection and not from a lack of resources. Moreover, since support often was inadequate and inappropriate, it failed to meet the needs of caregivers and left a feeling of dissatisfaction. One elderly mother looking after a seropositive son in a joint household where her other son and his wife controlled family resources stated:

"She (my other son's wife) is so angry with him (my seropositive son) for getting this AIDS that, though they (my other son and his wife) have enough money, she just refuses to give me anything much to spend for him. Instead, when I ask, she keeps grumbling that they have to do...and gives me the bare minimum. It becomes really difficult for me to look after him with this kind of an attitude but what to do?"

Between these two extremes lay two sets of caregivers. In one group were caregivers in receipt of only positive support that fulfilled many of their needs and was seen as somewhat available. A satisfied feeling was apparent.

"Sister ___ (a nun) and Father ___ (a priest) have done alot for us (my family and my positive brother) - whenever we need something, whatever they can do, they do. And they never make us

feel bad about it, they never point out that they are doing so much for us. But finally, how much can one expect - they have to help others too, so we ask only when there is no other alternative."

In the other group, four caregivers expressed mixed feelings where both satisfaction and dissatisfaction coexisted. In one case, the caregiver was receiving positive support from one part of her support system, which was perceived as somewhat available and as meeting some of her needs. She was happy with this. But the other part of the support system refused to support her and evoked dissatisfaction in her.

In another instance, a female seropositive caregiver who had looked after her seropositive husband had received high levels of positive support from her natal family. She knew that despite their limited resources, if ever she needed anything, she only had to ask them and they would do their best for her. The support that she received helped her satisfy many of her needs. Yet she felt that her natal family should have done more for her. Thus, though she praised all that they had done for her and acknowledged their constraints, dissatisfaction was also concomitant.

" My people (natal family) supported us a lot when he (seropositive husband) was alive - they used to come, inquire if I needed anything, or I would phone and tell them...money, food, coming to the hospital, looking after ___ (child), everything...so much they have done...even when he died, my people saw to everything. They have their own families, their own homes and jobs, and we are not well off people, but still, they always accommodated my needs. Yet, I feel that they should have been with me more - I used to be by myself in the hospital, they would come for a few hours only. When he was admitted near by, I had to go to their place to pick up the food and all, for every meal. I feel that they should have come with it. But how I can tell them - they should understand on their own, right? After all, they could see that I was all by myself...I am ill too - so they should come over here more often. If people are really around one, one feels much better...And how can I keep asking them? I feel that they know my condition, so they should do on their own. If I ask, they will surely do. But why should I ask?...naturally I feel so alone."

This woman also reported anger over the indifference of her in-laws.

"And those people (in-laws) even after knowing that he (husband) was so ill, didn't ask a single word. Once they knew he had this illness, they hardly came and never, ever bothered. Their own son...but they did not care at all. Everything was left to me. Don't even speak to me about them - they fill me with such fury."

Reciprocity

Negative feelings associated with being in a position of dependency led caregivers' need, and ability, to reciprocate taking on greater significance, in an attempt to compensate for their predicament. Yet given their meagre economic resources and role overload, most caregivers (8) could reciprocate only emotionally.

"I want to give her (my sister) back something in return, for all that she has done for me. After all, how much can one keep taking from others - it is not a nice feeling - one should give also. But I have nothing so all I can do is show her my concern and affection."

Reciprocating in tangible terms, either through role performance or provision of economic resources, was possible only for four caregivers.

"My (natal) family has helped me out alot, given us so much. When he (my husband) was ill, and before that also. But we were never able to repay them, because we had absolutely nothing. Now at least (after his death), with his provident fund/PF and my earnings, I have paid off the debts and I can think of giving them something. In fact, I definitely will, because they have done so much, and I feel so ashamed that we used to keep taking, taking, asking, asking, without giving back."

Nonetheless, being able to give back even a little bit, in whatever form, restored some sense of dignity in caregivers.

"Even though I can give her (my sister) only my concern and affection, it makes a difference. At least, I am giving something back, and not only taking. So I feel good about it. By showing her my concern and appreciation, I ease her strain. She also feels that I am thinking of her, and not just selfishly taking from her all the time."

Implications

In this age of structural adjustment, decreased social welfare and reductions in health sector allocations, community care has become the watchword for secondary and tertiary health care interventions (Duggal, 1998). But 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 recognised and recommended ideal form of intervention to deal with the infection (See Global Programme on AIDS/GPA, 1995). The result is that family caregivers have to bear the bulk of the responsibility for the care and support needs of their sick members, experiencing considerable burden and adverse health effects in the process (See D'Cruz, 1998, 2000). That caregivers need support to cope with the demands and outcomes of their role requires no reiteration. But contemporary policies have left very limited options from formal sources and have augmented the roles and responsibilities of the informal support system. Unfortunately, the study of caregiver support in relation to informal networks has remained a largely unexplored area. To this end, the present study has extended our understanding in the context of HIV/AIDS.

The findings have implications for intervention. Firstly, they underscore the necessity for the development of various caregiver services. These include counselling services, the provision of material and financial assistance, support groups and respite care services. In the case of an infection like HIV/AIDS, such services assume significance because the stigmatising nature of the infection limits support seeking from informal sources and consequently, caregivers are left to fend for themselves. At the same time, the extent to which these needs would be taken cognisance of and responded to remains questionable in the light of structural adjustment

policies, cutbacks in health sector expenditure and reduced social welfare. Nonetheless, their relevance should not be overlooked.

Secondly, the findings of this study suggest the importance for members of the informal support system to be educated about and sensitised to HIV/AIDS. Such endeavours could incorporate a two-pronged strategy. They could provide knowledge about the infection, thereby dispelling myths and misconceptions; and also descriptions of its demands and impact, thereby bringing home the predicament of the caregiver. With this information, members of support systems would be less likely to withdraw from the caregiver and to provide negative support, but instead would be more likely to rally around him or her.

Finally, the study points out to the urgency with which public awareness about HIV/AIDS should be created. Building up awareness would have two advantages. Firstly, the community would be sensitised to the experiences of caregivers and instead of discriminating against them, they would reach out to them. Inappropriate support would also be eliminated. Secondly, caregivers, being reassured of an understanding response, would come forward and seek support.

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Appendix

Interview Guide

Sociodemographic profile of respondent:

Gender
Age
Household income per month
Serostatus
Number of care receivers
Relationship with care receivers
Co-residence with care receivers

1. Composition of the caregiver's informal social support system.
2. Caregiver perception of the availability of social support.
3. Types of social support received by caregiver.
4. Caregiver opinion on manner in which social support is given.
5. Caregiver evaluation of social support received. Impact of social support on caregiver's life.
6. Process by which caregiver seeks social support and its relationship with disclosure of care receiver's serostatus.
7. Caregiver's reciprocity to the informal social support system.

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