

Impact of HIV/AIDS on Mothers in Southern India: A Qualitative Study

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Published online: 22 October 2008
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Abstract The purpose of this study is to explore the perceptions and needs of mothers living with HIV to gain greater insights into the challenges they face in relation to their health seeking behavior, fears around disclosure, and issues related to stigma and discrimination. This qualitative study utilized focus groups consisting of a sample of 60 HIV-infected mothers recruited from a large maternity hospital and STD clinic in Chennai, India. Discrimination by physicians and other health care workers has been a major impediment expressed by mothers living with HIV in accessing quality health care. Mothers living with HIV are increasingly concerned about how and when to disclose their HIV status to their children and the repercussions which could result from disclosure. The findings of this study call for urgent intervention strategies taking into consideration these various concerns and needs of mothers living with HIV and their children.

Keywords HIV · Mothers · India · Qualitative research

Introduction

Infection rates are rising rapidly among young women in many parts of the world and especially in developing countries; women, in particular, suffer more from the

adverse impact of HIV (Human Immunodeficiency Syndrome)/AIDS (Acquired Immunodeficiency Syndrome) than their male counterparts (Fleischman 2003; National AIDS Control Organization (NACO) 2006). With the prevalence of 0.38%, in India, the number of infected women has steadily risen to about 39% of the reported cases (NACO 2006). Studies from India have documented an increase in HIV among monogamous married women (Chatterjee and Hosain 2006; Gangakhedkar et al. 1997; Newmann et al. 2000; Pallikadavath and Stones 2003). Furthermore the percentage of HIV cases attributed to mother to child transmission (MTCT) has increased several fold in recent years (Gupta et al. 2007).

When a woman is diagnosed with HIV, she is looked upon with suspicion and her morality questioned, especially when a woman has been tested earlier than her spouse for HIV, as is commonly done in several antenatal clinics (Mawar et al. 2002). These challenges make it extremely difficult for them to take care of their health needs. Studies have also suggested that this maybe due to gender differences with delay in diagnosis in women, inferior access to health care services, internalized stigma and poor utilization of health services (Kremer and Sonnenberg-Schwan 2003; NIAID 2006; Rosenfield and Yanda 2002; Thomas et al. 2005). Women are also afraid of disclosing their HIV positive status which they fear may result in physical violence, expulsion from home, feelings of shame, and or social ostracism or property being seized after the death of their partner (Black and Miles 2002; Human Rights Watch 2003; Maman et al. 2002; UNICEF 2005). Mothers living with HIV/AIDS (MLH) therefore carry a triple burden of being HIV-infected, mothers of children who may or may not be positive themselves, and care givers to their infected spouses. The challenges they face are innumerable which is hardly explored.

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The purpose of this study is to examine and understand the various factors that impact MLH to understand their various health care needs, barriers to receiving health care, and their perceptions with regard to stigma and disclosure issues. The findings from this study could help plan effective intervention strategies aimed at empowering MLH by supporting them in promoting a better quality of life.

Method

Design

A qualitative approach utilizing focus groups was conducted with MLH with the help of a semi-structured interview guide (SSIG). The SSIG was developed based upon the Comprehensive Health Seeking and Coping Paradigm (CHSCP) which presents constructs which cover sociodemographic, situational, and social factors, cognitive appraisal, coping responses and health outcomes as they relate to the challenges MLH face seeking and obtaining care, caring for their children, and maintaining emotional health. The SSIG was piloted with individual interviews with 2 MLH, two focus group discussions with MLH, composed of 4 and 5 women, respectively. These MLH did not participate in the final focus groups conducted. In addition, extensive discussions were conducted with a community advisory board (CAB). The CAB composed of 15 members representing various disciplines which included medical officers, counselors and superintendents of the maternity hospital and government hospitals as well as representatives of non-government organizations that worked with HIV infected women, and MLH themselves. The CAB helped guide the study from its initiation and provided helpful insights. As a group, the CAB was also consulted after the data was collected and analyzed in order to assist the researchers in reviewing the findings and providing interpretation.

A total of nine focus groups were conducted, lasting 60–75 min, with groups ranging from 3 to 7 women. The study was approved by the Ministry of Health, Government of India and the University's Human Subject Protection Committee.

Participants and Setting

The participants were recruited from two maternity hospitals, a large sexually transmitted disease (STD) clinic and antiretroviral therapy (ART) clinic in the government hospital in Chennai, India. The study inclusion criteria were: documented HIV-positive mothers living with one or more children aged 0–10 years; age 18 or older; ability to speak in Tamil, the spoken language of the women; willingness to provide written consent in participating in the

study and no evidence of cognitive dysfunction as assessed by the investigator using the Short Blessed Screener (Katzman et al. 1983). A sample of 60 women was recruited. The women ranged in age from 23 to 42, mean age 30 years. Approximately half had 1 child, with two women having 3 or more children. Over 40% of the children were age 10 or older. Approximately one-third of the women were housewives, while the remaining women worked in assorted jobs including as tailors, teachers, or as staff in offices or national government organizations.

Procedure

The MLH were recruited from the sites with the help of outreach workers from the positive women network, counselors, and MLH themselves. Those interested in being a part of the study notified the research staff members who were available at a designated and private room at the site. After information was provided about the study, written consent of the women was obtained. All women who met eligibility criteria were provided a date and time to join the group.

At the time of the focus group, a number of eligible MLH were greeted by the focus group facilitator and a research assistant; both were well trained in methods of qualitative focus group design. The topic guide was used for each focus group. All discussions were tape recorded with permission of the MLH. One of the nine focus group discussions was not taped due to audio recorder malfunction. However, the content was written verbatim by the research assistant during the focus group and reviewed by the research facilitator for accuracy. During the focus group sessions, the research assistant also captured observations such as nonverbal interactions, gestures and emotional content of the women by means of field notes.

Data Analysis

Transcripts from the groups were analyzed using computer methods and manually. NVIVO, a qualitative software program was used to store and organize the focus group interview data. Data were summarized to determine the factors that prevent MLH from seeking, obtaining and maintaining care; and the challenges they face living with HIV/AIDS. Content analysis was carried out once the transcripts were summarized. This was performed by selecting several units of analysis and then quantifying participant response around each category.

Results

Transcripts from original data transcribed from the nine focus groups were divided into five general themes related

to health care issues surrounding stigma experienced by MLH. These included: Health Care Needs of MLH, Sites MLHs Seek Care, Disclosure Issues Related to Family and Friends; Stigmatization issues, Impact of Stigma on Health Seeking Behavior, and Strategies for Improving Access to Health Care. We used content analysis of the groups to evaluate the number of separate examples elicited from focus group participants' responses. (Table 1).

Health Care Needs of MLH

Most of the women said that they sought care when they had symptoms which were perceived as unbearable and for which they could not relieve with a home remedy or with symptomatic drugs like paracetamol or a pain killer which they would access over the counter at a pharmacy close to their residence. The symptoms they sought care for were usually upper respiratory and included severe cough with a fever or gastrointestinal symptoms. Several women reported they became concerned when they had skin lesions or pigmentation of the skin; which would be noticeable to others; this made seeking care more urgent. Few stated that they sought care when they had gynecological symptoms such as bleeding or a white discharge. While MLH delayed care for themselves, all of them said they would seek care if their children were ill.

The MLH who were on ART reported that they realized the importance of ART and would go to the health facility to access ART regularly. Some of the women said that they had problems when they went to different facilities for their ART for their child as ART centers for children were few.

Sites MLHs Seek Care

The MLH interviewed sought remedies for their health care needs by accessing health care institutions. About 60% of the women said they had received care in governmental hospitals, and half had received care in private clinics. Those who reported that they had received care in the governmental hospitals did so because care in government hospitals is provided free-of-charge. As one woman stated, "...if I do not have money, I go to a government hospital. Otherwise [I go] to a private clinic." However, a second woman added, "In government hospitals, they ask us to go and get a card and delay us so much that we get more sick."

Among those receiving private clinic care, the perception was that physicians were superior and the time spent waiting for treatment was less, compared with public facilities. Another reason for going to private care facilities was that the clinics functioned in the evenings which was convenient unlike government hospital which were accessible only in the mornings when the women were most busy with household chores and child care activities. Yet, for one woman, the physician at one private clinic was not able to fulfill his promises. This woman commented:

I did not know about treatment for HIV being available free in government hospitals. I went to a private hospital for my husband as the doctor promised drugs to cure him. I spent Rs. 7,000 and was then told that in spite of treatment, he could not cure my husband and told us to go to the government hospital

Table 1 Sample focus group questions

Please tell us what health services you have sought in the last few years?
If you ever had a time when you had a health-related problem but did not seek care for it, what stopped you, or got in your way?
Where do you, or your family, typically go to seek this care?
What kinds of HIV/AIDS programs would you like to access or feel you need?
What do you think might be reasons you, or your family, might not get treatment for HIV/AIDS?
Do you think you, or people like yourself, would be willing to receive HIV/AIDS assistance at your maternity clinic?
What might be some strategies you might suggest to clinic directors who might like to integrate your approaches within this clinic?
How can the clinic directors encourage their clients who have HIV/AIDS to seek such services within their clinic sites?
Did you have any problems with regard to disclosure of your HIV status?
Do you have any concerns about disclosing your status/spouse's status to your children?
Do you plan to disclose and if so, when?
Do you have any concerns about disclosing your child's HIV positive status?
Do you need help in disclosing your HIV status or your child's HIV status to your child or to others in the family? What help might you need in this regard?
Have you experienced any discrimination on account of the illness?
Are you a member of a self help group? Do you think self help groups can be involved in any intervention program?

in Tambaram for further care. That is how we went to a government hospital.

Disclosure Issues: Family and Friends

The majority (95%) of participants agreed that disclosure was a very sensitive issue. Fears surfaced, such as reactions of in-laws, and the impact of disclosure on their children. For example, women feared children might discriminate against them, the information would affect their studies, or they may tell others about their mother's HIV status. They were also concerned about admission to schools being affected if the status of the mothers becomes known. As one woman stated, "What happens to the education of the children if they need admission and their status is known?" Yet, 10% of the participants felt that HIV status should be disclosed to children; as she later explained, it was important "so that they will support us and care for us".

Thirty-eight percent of the women stated that it was best not to disclose HIV status to their children until they were older and able to understand the impact that HIV/AIDS brought to the household and to the family unit. Some women were of the opinion that it would be best to wait until the child was at least 15 years of age before disclosing the mother's HIV status. While most of the women were of the opinion that disclosure needs to be done, there were few who felt that it was better not to disclose. As one woman stated, "There are children of different natures, some withdrawn and quiet. It is better not to tell them." Who should disclose HIV status to the children was another area of concern that surfaced. Women requested help from health care providers in disclosing their HIV status to the family. MLH needed help with whom to tell, when to tell, how to inform, and what might be the implications.

One woman thought that a counselor, not the mother, should make the disclosure. Others suggested that doctors may be able to assist mothers with respect to disclosing HIV status to the children. As one woman stated, "Some children are aggressive. It is better a counselor deals with disclosure issues". Another woman revealed, "My son is 6 years old. He comes asking me why I go to hospital so often—I just shut him up!! Who should tell? It is better to disclose status through mother" or via the grandmother". Some women had already disclosed their status to their parents, but far fewer to their in-laws. As one woman disclosed:

My husband and in-laws know [about my HIV status]. They [in-laws] treat us badly by keeping separate plates for us. Even the water we drink is separate.

Women diagnosed during the antenatal period, did inform their husbands. However, disclosure was not easy and some women requested help from a counselor in

disclosing. Moreover, fears surfaced as to unwarranted disclosures to others. As one woman reported "the nutrition packet we are given has a label saying it is for HIV. We are scared that others will see it and know." Other women voiced concern about the impact of disclosure on other aspects of household life ranging from the impact of the children to legal and property issues. As one woman revealed "I fear that other children may not play with my children if they know their HIV status". We will face problems with respect to property matters. One MLH said:

My husband died of HIV leaving me and my son with the disease. His family knew about our illness. Once my husband died, my brothers in law refused to give us any share of the property. They told me that anyway I and my son would also die due to HIV and there was therefore no need for the property to be shared among us.

Another issue brought out among the women was the frustration they felt in responding to questions from neighbors and friends on their frequent visits to the hospital. "When people see us going to hospital often they ask us where we are going." Other housing issues surfaced such as need for place to sleep, and greater awareness of the plight of mothers affected with HIV/AIDS in the community as one woman knew of an HIV positive family who was asked to vacate the house on knowing the HIV status.

Stigmatization Experiences

Stigmatization by physicians and other health care workers was experienced by the majority of MLH (97%) in accessing care. As one woman stated:

When they [physicians] see our case record and see the reactive status, they treat us differently. Once they find a reactive status, they probe further and ask sensitive questions.

Another woman lamented:

...the doctors... they do not even touch us if they know our HIV status.

When my child was born, the doctors refused to touch the child. They did not even take me to the delivery room. The nurses did not touch me - my mother is the one who cleaned the child. The doctor said that she was married recently and was scared to be infected.

(When this woman narrated this incident, she choked with emotion and there were tears in the eyes of the others too who were reminded of similar experiences...)

A second woman reported that the doctor sits far away from her when providing counseling and instruction. Another woman concurred, "Some of the doctors and even

counselors wear masks when they talk to a HIV-positive person. They also turn their faces from us. If doctors treat us with so much indifference, how do we expect others to be considerate?” Another MLH noted, “I was asked very embarrassing questions when my little daughter was HIV positive. The doctors accused my husband saying he must have been drunk and sexually abused my child”. Confidentiality was also an issue a number of women reported. As one woman revealed, “If the status is known, it spreads like wild fire and everybody comes to know.” For another woman, the ward caregivers were also rude as one woman recounted:

In the maternity hospital, when I went for delivery, the ward boy sent me last to the theater. I was put in a corner, in the last bed where [there were] no facilities; not even a fan was there. The doctors and nurses were aware of what had happened to me but did not bother. I never went back to that hospital.

Impact of Stigma on Health Seeking Behavior

Approximately 50% of the women did not want to receive HIV care at the maternity hospitals because of the bad memories of how they were treated during the birthing process. One woman narrated her experiences at the maternity hospital when she went for their delivery.

In the hospital, there are different wards given to women infected with HIV. When I had my labor pains, I screamed and shouted with no assistance from anybody. Finally, the baby came out and my mother pleaded for help. Then finally a doctor came to my side. The ayah told my mother to clean up the blood and refused to touch it for fear of being infected.

Other women did not want to receive care at the maternity hospital for fear of being recognized by others seeking maternity services. One woman reported “There are many other women including our relatives who will be there at the maternity hospital and we are scared of being recognized”. For another woman, “We are not interested because the nurses from the maternity hospital come to our homes to vaccinate the child. Once they know I am positive, others will come to know. It is better that HIV drugs are available in general hospitals.”

However, other women thought integration of care under one roof was quite important. One woman stated, “soon after delivery, mother and child can access health care without delay if care was provided in the maternity hospital.”

Another woman remarked that drugs to prevent HIV transmission could also be available at the maternity hospital:

Usually the drug is given to the mother before delivery and then to the child when the child is born and then we are sent to another ART clinic to access ART care. It would be better for ART to be given for both mother and child in the maternity hospital.

Strategies for Improving Access to Health Care

For some women, suggestions were offered on how to improve access to health care despite the stigmatization experienced. One woman stated, “It is better to have treatment given in a different place like a general hospital with all the other specialties and the HIV unit is not identified separately”. This sentiment takes stigma away from a setting such as a maternity hospital where child-bearing neighbors may come to know the HIV status of a mother in the community who would not normally be receiving care for a maternity hospital.

Additional comments included the inclusion of second line drugs, more financial help, and free ART support to be lifelong. Emotional support was another strategy that women perceived as being very helpful in accessing care and was actively requested by the women. For many women, having the diagnosis of HIV or AIDS is often a solitary crisis and having the support of counselors, or other women like themselves, is uplifting. Also important was ways to engage the public with information about HIV/AIDS. TV serials were considered very important by several women as they felt that they attract the community. Best times for these programs were on the weekends when there would not be any competition with weekday serials. Considering popular actors to send out positive messages about persons affected by AIDS was raised by one woman. Finally, use of self help groups for family impacted by HIV/AIDS was thought to be helpful by several women.

Discussion

HIV/AIDS is still a feared and stigmatizing disease and disclosure of HIV status is a complex phenomenon embedded in various types of social relationships (Bairan et al. 2007). Our findings reveal that MLH often deal with the unenviable task of balancing the stigma and physical needs of illness with the needs of their families and, in particular, their children. Negative themes emanating from the MLH, and similarly from the literature, include fear, uncertainty, forced secrecy for fear of being ostracized, behavioral changes in the children, and shifting responsibilities between the mother and the child (DeMarco et al. 2001). As a result of the fears MLH experience, decision to seek care for themselves is left for the most serious of

problems. This information is critical for health providers and policy makers to plan effective interventions to enable MLH to have a better quality of life.

Overall financial implications seem to determine the choice of health providers in seeking health care, with most MLH opting for government health facilities. However this decision has its own share of problems with women expressing discrimination in government hospital facilities. Such discrimination extends from being delayed procedures purposefully at the hospitals, to being meted out with differential treatment by health providers at all levels. The differential treatment has been expressed in being refused care during labor, angry reactions from health care workers, being confined to different wards and doctors maintaining a distance while attending to them. The embarrassing and sensitive questions MLH reported being subjected to by health care providers have left a scar on the MLH who have gone through these bitter experiences.

In contrast, MLH who sought private care have been lured by the false promises of cure which have incurred huge expenses. This has also resulted from their lack of awareness of HIV care, especially with regard to free ART available in government hospitals. Similar findings have been reported in a study from Bangalore, India on a smaller sample of HIV positive women, reflecting financial difficulties faced by women, as well as discrimination and inadequate care (Joseph and Bhatti 2004). In yet another study, HIV positive women revealed specific concerns experienced when accessing prenatal care; these fears included disclosure and fear of anger from health providers (Lancioni et al. 1999). Obstacles to accessing HIV-related care and antiretroviral drugs were prevalent in the literature (MacQueen et al. 2007).

Type of health care institution the MLH preferred to receive care also varied. While some women preferred to seek care at the government hospital in order to diffuse the HIV/AIDS stigma of seeking care in a maternity hospital where childbearing neighbors might come to know their status, other women liked the maternity hospital provision of all care under one roof. Aside from these fears, MLH agreed that providing education about HIV/AIDS to the community is critical to reduce HIV-related stigmatization (Mawar et al. 2005).

Disclosure, and all it entails, remains a vital issue for mothers who are HIV-positive (Vallerand et al. 2005). The current study has highlighted the impact of HIV disease on MLH as they face the burden of deciding whether to disclose their HIV status to their children. Women feared children might discriminate against them, the information would affect their studies, or they may tell others about their mother's HIV status. There was also concern about admission to schools being affected if the status of the mothers becomes known.

While most mothers felt that it was important to disclose their HIV status to their children when they were 15 years or older, there were concerns on how and who needs to disclose their HIV status to their children. Findings from studies have reported that more than a quarter of parents reported not knowing how to tell their children (Corona et al. 2006) and confirmation that parents were more likely to disclose to older than to younger children (Armistead et al. 2001; Lee and Rotheram-Borus 2002).

Fears that also surfaced from this study were related to the unwarranted disclosure of their HIV status to others; which again could have an adverse impact. This was with special reference to the nutrition packet that was initially given by the government to patients receiving ART, which carried the red ribbon label. This reflected the status of the person who received it. Frequent visits to the hospital also led to many questions and women expressed problems in dealing with this curiosity and fear that others would come to know of their status. Such fears by the community have resulted in being asked to vacate the house as well as legal and property disputes and loss of entitlement to the MLH and their children.

Other studies have suggested that fewer women have disclosed their HIV status to others (e.g., family, friends) than to their partners (34% vs. 84%; $P < 0.001$), largely because of fear of disclosure (Manopaiboon et al. 1998). Participant reports documented extensive verbal and physical abuse and neglect experienced by persons living with AIDS and identified negative consequences experienced by such persons whose HIV-positive status was disclosed to family, friends or community members (Dlamini et al. 2007).

Aside from community-wide education via TV serials and other broadly-focused media, MLH desire education about HIV/AIDS so that they are become better informed. In addition, the desire for social support and compassionate care was critical.

Recommendations for Future Intervention

These findings call for urgent intervention strategies for MLH and health care providers, taking into considerations their needs. Based on the findings of the study, future research is needed in the conduct of a controlled intervention trial with MLH to test an enhanced intervention program. Areas of need include physical health, compliance and parenting behaviors, mental well-being, family support and social networking. In addition, the children of the MLH should be assessed in terms of health, adaptive functioning and behavioral adjustment outcomes. To maximize the intervention effects, research staff should promote and optimize skill-building in the coping,

caregiving, and problem-solving domains for MLH. Moreover, intervention programs need to be made culturally sensitive and adaptable.

Furthermore, the findings reflect the need to review the existing advocacy and awareness programs in the community on HIV/AIDS. The urgency is to include more positive messages on the availability of medical care free of cost at government hospitals and the need to treat people living with HIV/AIDS without discrimination. Policy recommendations relate to the need for intensive training for health care providers and technical staff who interact with patients as it relates to issues of stigma and discrimination perceived and experienced by persons with HIV/AIDS. This training is critical in order that care be delivered in a sensitive and compassionate manner. Health care providers at all levels need to be equipped with intensive training to sensitize them on the need to treat MLH without discrimination and provide them quality of care. Effective counseling services are also needed by MLH and their children to address disclosure issues, while the inclusion of supportive and compassionate care is a mainstay for continuous and non-interrupted care.

Conclusion

This study has provided a multidimensional portrayal of the impact of HIV/AIDS on MLH in Southern India. In spite of the advancements in the health care system with the introduction of ART and integrated counseling and testing services provided free of charge at government health facilities, it is of concern that awareness of, and access to facilities available for MLH is still lacking. This lack of awareness has resulted in frustration of incurring huge unaffordable expenses among MLH and false promises of cure. The paradox is for those who access health care facilities as discrimination and issues of stigma continue to pose an impediment to MLH's quality of care. Another burning issue that MLH face in their role as caregivers is that of disclosure, especially with regard to their children.

Acknowledgement Funding was received from the National Institute on Child Health and Human Development, R03HD052145.

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