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Challenges Experienced by Rural Women in India Living with AIDS and Implications for the Delivery of HIV/AIDS Care

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Abstract

Researchers explored the barriers to AIDS care for rural women living with AIDS, and investigated alternative delivery models to increase the women's adherence to anti-retroviral therapy. Community-based participatory research focus groups were conducted by the researchers with a convenience sample of 39 women living with AIDS from a Primary Health Center near Chennai, India and with nurses, physicians and Accredited Social Health Activists (Ashas), lay health care workers. The most prevalent barriers expressed by the women were sickness-related, psychological, financial issues with childcare, and distance and/or transportation to the site. Women living with AIDS reviewed Ashas favorably.

Keywords

HIV/AIDS; women; India; lay healthcare worker

Approximately 2.5 million women in India are living with HIV/AIDS according to recent estimates from the National AIDS Control Organization (Ghosh, Wadhwa, & Kalipeni, 2009). Women comprise 39% of all HIV/AIDS cases in India (Ghosh et al., 2009) and the infection rates continue to rise among women (Kodandapani & Alpert, 2007; Majumdar, 2004) and, in particular, among young women (Thomas, Nyamathi, & Swaminathan, 2008).

Growing evidence from researchers suggest that HIV/AIDS is spreading from urban to rural India (Pallikadavath, Garda, Apte, Freedman & Stones, 2005); with about 60% of cases occurring among rural residents (Sinha et al., 2008). Those most affected by the spread of AIDS into the rural areas of India are women who are illiterate, and among the lower socioeconomic strata (O'Neil et al., 2004). Other researchers have implicated low levels of HIV awareness, conditions of poverty, and gender inequity as contributors in the growing HIV/AIDS epidemic among women living in rural India (van Rompay et al., 2008).

Researchers have conducted studies to better understand how a lack of knowledge, poverty and gender inequality impact women living with HIV/AIDS in rural and urban India. Women living in rural India are particularly vulnerable to HIV/AIDS infection due to lack of awareness of AIDS transmission risks and unequal access to health care information (Gupta et al., 2008). Rural Indian women are also vulnerable to HIV because they may be trapped in sociocultural conditions of subordination, where women are not expected to speak openly about sex and sexuality (Solomon et al., 2008). They may also be denied access to

information or medical treatment due to geographical isolation, or they may not be able to protect themselves against potentially unsafe sex with their spouse (van Rompay et al., 2008).

In terms of adherence to antiretroviral therapy, the women reported a number of factors that have led to decreased compliance. One major constraint reported by the women is lack of finances (Tarakeshwar et al., 2006). The cost of antiretroviral therapy, and the perceived lack of benefits of this treatment also have been identified by researchers as barriers to medication adherence (Kumarasamy et al., 2005). Tarakeshwar et al. (2007) found that fear of taking antiretroviral therapy is another reason women become noncompliant with medical therapy. The women's fear of disclosure may also result in a lack of social support. Further, researchers have indicated lack of social support and lower levels of HIV-related knowledge are associated with lower antiretroviral therapy adherence (Sarna et al., 2008).

HIV-related stigma is a key challenge faced by many women living with AIDS in India (Steward et al., 2008; Tarakeshwar et al., 2006; Tarakeshwar et al., 2007). Women who have reported high levels of HIV-related stigma are also less likely to disclose their HIV status due to fears of discrimination (Steward et al., 2008). When accessing health care, women living with AIDS are further impacted by the challenge of stigma (Thomas et al., 2005; Tarakeshwar et al., 2006); additional challenges exist as a result of a lack of transportation, lack of finances, and inability to secure care giving for either a sick spouse or a child (ren) (Thomas et al., 2008). In addition, many Indian women living with HIV, report depression as a challenge, as significantly higher levels of depression have been reported among HIV positive women, compared with their HIV-negative counterparts (Gupta et al., 2008).

The provision of health education by trained health care professionals is one of the most effective strategies to control the HIV/AIDS epidemic (Solomon, Chakraborty & Yephthomi, 2004). Programs offering community-centered reproductive health and HIV prevention education have been advocated by researchers (Kambou, Magar, Hora, & Mukherjee, 2007). Researchers have also recommended that health care providers address stigmatization when caring for HIV-infected individuals. Indian women with HIV have reported that education (Ghosh et al., 2009) and HIV counseling (Pallikadavath et al., 2005) have been inadequate. The authors of this paper describe the findings of a series of focus groups, conducted to further refine our understanding of the challenges faced by HIV-positive women, living in rural India.

Methods

Design

A focus group approach was conducted by the research team with Indian women living with AIDS, and they were prescribed antiretroviral therapy for their worsening AIDS condition. Qualitative methodology was selected by the researcher team to better understand the life experiences of the women living with AIDS and their hopes for better access to and improved treatment and care. Community Based Participatory Research was also selected by the research team in order that the voices of the women living with AIDS and other community members be represented in the design, implementation and evaluation of research designed for the populations of interest. The women living with AIDS and members of a community advisory board further strengthened the Community Based Participatory Research by guiding the questions that the research staff utilized in focus groups with other women living with AIDS, nurses, physicians, and lay village women, and deliberating over the responses of the focus group participants in designing a future intervention that would be most desired. The community advisory board also utilized by the

research team ensured knowledge of the social and cultural perspectives and experiences of the target population.

The community advisory board we constructed was composed of 10 members made up of nurses, physicians, women living with AIDS and Ashas (Accredited Social Health Activists); who were government-trained lay village women focused on the reproductive health of women in India. The inclusion of these lay village women was critical as they served as a model for the future training of HIV-focused Asha that would be the key player in a future intervention trial.

The research team met with the community advisory board before and after the focus groups and provided helpful insights into possible ways to access women living with AIDS and the challenges women living with AIDS experience in receiving treatment in the rural setting. The community advisory board members also provided refinements in the semi-structured interview guide which guided the focus group discussions. Finally, the members of the community advisory board helped shape the intervention program which was being designed. These community advisory board members were not included as focus group discussants.

Four focus groups were conducted by a trained researcher and her trained staff assistant, with a total of 39 women living with AIDS. Each woman was involved in one focus group and the numbers per focus group ranged from 9–10. Each focus group lasted 60 – 90 minute duration (in length). One additional focus group was conducted by the team with nurses (n = 3) and physicians (n = 2) serving the targeted area, and a final focus group was held with the Ashas (n = 5).

The Ministry of Health, Government of India, the Indian Council for Medical Research, the All India Institute of Medical Sciences, and the University of California, Los Angeles Human Subject Protection Committee approved this study.

Participants and Setting

The research team recruited a convenience sample of 39 women living with AIDS from a large Primary Health Center which are basically small rural clinics staffed usually by 1–2 physicians and a few nurses and ancillary staff. The Primary Health Center is the site where women living with AIDS receive only symptomatic care. Surrounding each Primary Health Center are the villages; each health center is surrounded by up to 30 villages.

Women were eligible to participate in the study if they had verified evidence of being on ART, were 18 or older, were able to speak Telegu (the spoken language of the women), or English and signed consent in the presence of another family member or an attendant to participate in the study.

The women living with AIDS ranged in age from 20 to 45, and a mean age 30. Over 40% of the women were married; however, three women had not heard from their spouses for over six months and considered them missing. A little more than half of the women had received any formal education. Almost all the women (87%) reported working part time or full time. Approximately 20% of the women had no children while 15% had three or more children.

The Ashas, non-HIV trained (n = 5) formed a fifth focus group. Ashas function as a liaison between the village women who are pregnant or recently delivered and the hospital setting and assist the women in traveling to the hospital for the delivery and support maternal and child health. These Ashas were invited as we were interested in their perspectives as it

related to the extension of their care and support specifically for women living with AIDS. For the most part, they were educated between 6–11 years.

Physicians (n = 2) and nurses (n = 3) who worked in the PHC were also invited to gain their perspective of caring for village women living with AIDS. They formed the (last) separate focus group. Nurses and physicians; all were employed and educated between 6–11 years or had professional training.

Procedure/Implementation—The research team announced the study by approved flyers posted at the Primary Health Centers. Women living with AIDS who were interested in participating and who contacted the research team were provided further information about the study details. If interest continued, women living with AIDS would then be read the informed consent by a researcher staff member, provided time to ask questions, and if interest continued, asked to sign the informed consent. Subsequently, the women were assessed by the research team for eligibility including antiretroviral therapy status. Women who met eligibility criteria were then provided by the research team with a date and time to join the group.

At the initiation of the focus group session, participants were greeted by a facilitator and a research assistant that were well trained in focus group methodology. The semi structured interview was utilized by the facilitator to guide the discussions which were recorded with participant permission. At the end of the focus group sessions, the research team collected data about the participants' date of birth, employment status, marital status, number of children and age of children. Upon completion of the focus groups, the participants were thanked for their time and paid a nominal incentive. See Table 1 for sample questions on semi structured interview guide.

Data Analysis

Content analysis was conducted by a trained research staff under the supervision of the investigator. Transcripts of the taped focus groups were analyzed manually by trained research assistants. The transcribed notes were analyzed line by line until themes emerged and saturation was achieved and coding failed to reveal any further unique categories (Corbin & Strauss, 1990). The content analyses reflected the physical, psychological, and social challenges women living with AIDS face in receiving care and antiretroviral therapy; the current health care delivery model in terms of HIV/AIDS, and the factors which may enhance adoption of a revised health care delivery model for persons affected by HIV/AIDS. The credibility of the data to accurately represent the perceptions of the participants (Sandelowski, 1986) was supported by rigorous field notes, meticulous transcribed focus groups and discussions of the findings with the community advisory board who also included women living with AIDS in order to seek their feedback (Sandelowski, 1993). In addition, themes identified by content analysis were reviewed by a more experienced researcher. Dependability of the data was assured by the research team's use of the semi structured interview guide, which was designed by researchers and community advisory board members alike.

Results

The major themes revealed by the women living with AIDS related to their barriers to adherence of antiretroviral therapy, their challenges in accessing care due to the current care delivery model and their perspectives on desired intervention. The numerous barriers to antiretroviral therapy adherence revealed by the women included: a) the physical barriers relating to symptoms of worsening AIDS and the side effects of the medications they were taking; b) the psychological sequelae of having AIDS; c) the stigma they experienced related

to having Ashas visit their village homes; and d) their social barriers such as difficulty paying for transportation to receive antiretroviral therapy, lack of childcare, and lack of accompaniment to the clinic. The current health delivery model, which resulted in the need for women living with AIDS to travel long distances to receive care for HIV/AIDS and receive their next monthly supply of antiretroviral therapy, presented additional challenges to women living with AIDS. These findings resulted in future perspectives for the research team to use in designing intervention models to improve their care.

Barriers to Adherence to ART

Physical illness—One of the most pervasive barriers to adherence for women living with AIDS was being symptomatic and unable to travel to seek care or to receive their monthly supply of antiretroviral therapy at the District Hospital. In India, antiretroviral therapy is only supplied at the District Hospital level as National AIDS Control Organization-trained physicians are assigned to these sites. As one woman expressed, “Most of the time we miss taking the medicines because we are sick”. A number of other women revealed problems with bloating of abdomen, itching, body pain, and leg and arm pains. For another women, it was worsening asthma and for others, fever and diarrhea.

A number of the women living with AIDS revealed that side effects of taking the antiretroviral therapy created yet another barrier. One woman shared her experiences, “Two months I used [antiretroviral therapy] regularly; after that I missed taking it because of too many side effects.”

Poor psychological health—Poor emotional health was likewise encountered, and based upon the experiences of a number of women, was just as powerful a deterrent to adherence as physical illness. As one woman revealed, “If I am mentally sick, then I am also physically sick. I have to keep myself positive for life; then I do not miss my medicines”. For another woman, the psychological strain from the visible side effects of antiretroviral therapy was disheartening.

From last 2 years, I am availing antiretroviral therapy medicines free of cost every month from District Hospital and from last January I became very thin and my skin became dark. Then I consulted HIV specialist at the District Hospital. The Doctor said it is the side effect of medicines, so he changed my medicines. Even then I found no change in my body. ..I am a cook in a hostel. I nearly lost 10 kgs since last January. More than the weight, my face became thin and ugly day by day. From the time I lost weight and people started asking me about my HIV status; it is making me more depressed.

Stigma experienced by women living with AIDS. The women living with AIDS were asked if there were any concerns they might experience if HIV-trained Ashas would visit them in their village homes. The findings were very clear in that while stigma was experienced, due to the seriousness of their illness, Ashas would still be welcome.

For one women living with AIDS, concern over loss of health far outweighed concern over stigma that might be experienced,

“If I fear stigma, then I lose my health. If I lose my health, my children and husband, and family will suffer. Why should I fear receiving support and change my life towards a healthier side. I am saying this from my heart and on behalf of all women living with AIDS.”

Other women verbalized similarly,

“We have no problem as long as Ashas support us emotionally and also help us to be healthy”

Concerns originally raised by researchers in the literature were that women living with AIDS prefer to receive care in distant locations due to fear of stigma. However the women living with AIDS for the most part stressed that this was not the case. They revealed that they did not fear receiving care at the Primary Health Center. As one woman stated,

No stigma, no fear to visit village Primary Health Center if all the care is provided at the Primary Health Center. It reduces all our difficulties of financial stress, travel stress, child care. Why should we feel stigma when our problems are reduced to greater level.

Another woman reported that if PHC were able to provide refills of her antiretroviral therapy, then adherence would be much better. Further, “if the medicines are available at the local PHCs, then we do not miss the dose”.

Social Barriers to Adherence

Difficulty paying for transportation or Antiretroviral Therapy—A common barrier women experienced was the lack of finances in traveling to the District Hospital to seek care or pick up their medications. As one woman revealed,

Traveling from Allur to Nellore District Hospital for which I spent Rs.50 to 100... Nearly 7 to 8 hours time it takes for my travel, visiting a doctor, collecting my antiretroviral therapy medicines.

Particularly for women who are unable to work to any extent or only work part time, financial challenges were apparent. This was disheartening for women who were able to work but who lost wages in order to make the full day journey to seek care. “Because I miss my daily wage... and depending on it very much ...this problem...stops me at times to go pick up my medicines”

Lack of Accompaniment—Due to the long journey, for some, not having someone accompany the women was problematic. For one woman,

I go alone to collect my medicines. By the time I come home, it is very late in the evening. I come back and cook my food; I face lot of difficulties whenever I collect my medicines....

For another women,

On many occasions, when I am very sick no one accompanies me to the District Hospital, even if I call someone to help me. No one helps. I wish someone helps me to go and visit the District Hospital or local Primary Health Center.

Lack of Childcare—For other women, lack of childcare prevented several in keeping up with their medication in a timely manner. Women revealed leaving children with family and neighbors when possible, or if no caretakers were available, they were forced to take them along. As one woman reported, “Whenever we have to visit the District Hospital, it becomes difficult to leave our children alone or we request the neighbors. Sometimes they oblige, sometimes they do not.” Being able to collect their antiretroviral therapy at their local Primary Health Center was mentioned as a way to minimize problems of traveling, childcare, and costs.

Current HIV/AIDS Delivery Model

As stated earlier, a number of women lamented about the need to seek care or receive their next dose of antiretroviral therapy at the District Hospital rather than the local Primary Health Center. Generally, physicians at the Primary Health Centers would treat only symptomatic ailments such as fever and diarrhea; they often would refer HIV positive persons to the District Hospital for evaluation of worsening HIV/AIDS or side effects of antiretroviral therapy. One woman reported “Whenever I visit the District Hospital for collecting my antiretroviral therapy medicines, I also visit HIV/TB specialists for my other problems. For fever and cold, I get care from the Primary Health Center itself”

Healthcare providers believe care should be available at Primary Health Center instead of District Hospital

A number of nurses agreed that by receiving care at the Primary Health Center, women living with AIDS would reduce many of the barriers they face in adhering to antiretroviral therapy. In addition, it would reduce the number of home visits the nurses would need to make as the women could easily access the Primary Health Centers. One of the nurses also added that “Even people will opt for testing also, [if] the treatment and antiretroviral therapy is available at the Primary Health Center level”. Among the lay women ASHA, there was also agreement that ART must be made available at Primary Health Center level. In fact, it would be welcomed by all ASHAs.

The two physicians also agreed that once the first dose was administered at the District Hospital with treatment care and advice provided, follow up with medicines can be made available from village Primary Health Center. As one physician remarked,

Yes, if the Director of Health should issue the Government Order to supply antiretroviral therapy from Primary Health Center, I am ready to treat HIV patients here. If antiretroviral therapy medicines are provided at the Primary Health Center, then it is easy.

Feasibility of Providing Care at PHCs

Despite the enthusiasm of the care providers, a number of caveats were raised. As stated earlier, government support would be critical for this change of health care delivery to occur. As one physician noted, “If the District Authority takes a decision on the antiretroviral therapy and expert services [are] made available at the Primary Health Center level, then it will work”. However, it was clearly noted by another physician that additional physician providers would be needed at the Primary Health Centers for this change to occur. “If there is a proposal to increase or recruit more medical doctors, then it may be possible”

Nevertheless, the physicians remarked that currently major treatment for HIV/AIDS is provided only at the District Hospital. However, in the case of TB for HIV positive persons, World Health Organization-sponsored TB eradication - DOTS (Directly Observation Short Course Therapy), both treatment and medicines are provided in the Primary Health Centers. “In the same way if HIV/AIDS also treated, people will definitely accept the intervention”

Discussion

Our focus group analysis from the perceptions of rural women living with AIDS reveal that there are several barriers to antiretroviral therapy adherence including illness-related factors, financial constraints, problems with traveling long distances to receive therapy, childcare issues, stigma, and psychological problems. Our findings are consistent with those reported by other investigators revealing that feeling sick or ill and traveling away from home to receive treatment were correlated with decreased adherence among participating Indians

(Shah et al., 2007). Sharma et al. (2007) found that financial constraints such as those imposed by the costs of antiretroviral therapy were associated with decreased adherence among AIDS-affected persons in India. Among other things, providers should be sensitive to the needs of HIV-infected people and have a greater awareness that health care may be compromised and women may miss their scheduled appointments because of childcare burdens (Bharat & Mahendra, 2007). HIV-related stigma was also associated with decreased adherence with ART, among men and women receiving antiretroviral therapy in Chennai India (Safren et al., 2006). In a review article by Nischal and colleagues (2005), additional factors were associated with inadequate adherence with antiretroviral therapy including psychological problems, lack of trust between clinician and patient, and drug toxicity profile.

In addition, women living with AIDS also commented that the provision of social support, such as being accompanied to the District Hospital for antiretroviral therapy or having neighbors help with childcare, would be very beneficial. This is consistent with findings from studies showing that the provision of social support can improve outcomes among HIV-infected persons (Kumarasamy et al., 2005; Majumdar, 2004). Tarakeshwar et al. (2007) have discussed importance of providing emotional support to people undergoing antiretroviral therapy, and have recommended that the clinical care of people undergoing antiretroviral therapy include counseling in order to maximize treatment adherence. Our focus group participants need for financial support is consistent with reports documenting the high costs associated with HIV infection (Krishna, Bhatti, Chandra & Juvva, 2005; Kumarasamy et al., 2005; Tarakeshwar et al, 2006).

Our participants were also asked to provide input with respect to the type of delivery model they would favor regarding the future provision of HIV treatment. Currently, most of the HIV-related care received by our participants occurs at the District Hospital. In India, there are private clinics which may provide more personalized, convenient HIV-related care, but the financial burdens of the illness limit this option to those who are able to pay (Kumarasamy, Venkatesh, Mayer & Freedberg, 2007). For one participant, the more expensive, private clinic was reserved for emergency care only.

We found that the women living with AIDS would like to receive care at the PHCs, as opposed to the District Hospital because the Primary Health Centers are closer to the villages. In India, where primary health care is provided through a network of facilities (including Primary Health Centers and District Hospitals), the closer the facility is located to the user's home, the more likely it is used (Bajpai & Goyal, 2004). Our findings are consistent with findings from a report by the International Planned Parenthood Federation (2004), which showed that Indian women believe that government hospitals are located far from the community and that community-based clinics should be used to provide HIV-related care.

We also solicited the perspectives of Asha, nurses and doctors regarding health care delivery models and suggested changes. Our healthcare participants agreed that care should be available at the Primary Health Center, not at the District Hospital except for initial dosing. More specifically, our participants said that ART should be made available at the Primary Health Centers because the latter are located right in the women living with AIDS's immediate community and, consequently, are more convenient. Our findings are consistent with a review by Nischal et al (2005) who believe that adherence to antiretroviral therapy is essential for successful treatment, but that restricted access to primary medical care or medications can compromise adherence. Our healthcare participants agreed that care should be carried out in an environment which is free from stigma. This is supported in a review by Bharat & Mahendra (2007) who observed that health care providers often experience

negative attitudes towards people living with HIV, and concluded that quality care can be delivered if stigma and negative attitudes towards these people are eliminated.

Conclusions

The research team explored the perceptions of the challenges faced by rural women in India living with HIV. Our women living with AIDS participants were able to offer a wide variety of suggestions as to what elements to include in a future HIV-related intervention. Chief among the suggestions was that HIV-related care be offered locally, at Primary Health Centers as opposed to the present system where most of the care is provided at the District Hospital. Our healthcare participants believe that Primary Health Center care is feasible and practical. Moreover, they believe that there is a special advantage to providing HIV-related care, closer to where the women living with AIDS actually reside and where it can lead to greater antiretroviral therapy adherence in the long run. Based on these findings, we plan to design an intervention to meet the challenges of these women based on their responses, in conjunction with input provided by formal (physicians and nurses) and informal (lay health volunteers) healthcare workers. Our ultimate goal is to create an educational program, built from input provided by focus group analysis, to help women deal with the challenges of living with HIV in rural India.

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Table 1**Sample Questions Used in the Semi Structured Interview Guide**

What are your thoughts about the health care provided to you as a patient with AIDS?

How have you been able to access the medications regularly?

What has been helpful to you in getting your medications regularly?

Probes:

Support from family and friends?

Assistance from clinic staff?

What are the challenges you have faced in taking your medications regularly?

What factors cause you to miss obtaining your medications from the District Hospital?

Has transportation to the Hospital ever been a problem for you? If yes, please explain.

What other factors have caused difficulties in getting your medication?

Probes:

Physical illness

Mental health issues

Childcaring

Cost

Stigma

What would be your thoughts about having specially HIV-trained Ashas visit you at your home?
