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Perceptions of Women Living with AIDS in Rural India Related to the Engagement of HIV-Trained Accredited Social Health Activists for Care and Support

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Abstract

A community-based participatory research study was conducted using focus groups with 39 women living with AIDS (WLA) in the rural setting of Andhra Pradesh, India. In addition, three

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nurses, two physicians, and five reproductive health accredited social health activists (ASHAs) took part in focus groups. The WLA offered insight into the benefits of HIV-trained ASHAs including emotional support, assistance with travel to health care providers and antiretroviral therapy medication adherence. Health care providers also identified benefits of using HIV-trained ASHAs and suggested modalities for how to train these individuals. These findings will contribute to the design of a future program of care involving HIV-trained ASHAs.

Keywords

accredited social health activists (ASHAs); HIV/AIDS; rural India; women

Approximately 2.3 million adults are living with HIV/AIDS in India, of whom 38% are women (Joint United Nations Programme on HIV=AIDS [UNAIDS], 2008). The state of Andhra Pradesh has the second highest HIV adult prevalence rate in all of India (0.97% total; 0.75% for women and 1.22% for men), according to the National Family Health Survey (NFHS, 2008). Data from antenatal clinics indicate that almost half of 23 districts in Andhra Pradesh have HIV prevalence rates for women above 2% to 2.5% (National AIDS Control Organization [NACO], 2007), indicating a feminization of the epidemic in this area. Indeed, 85% of HIV transmission in India is sexual, and 75% of women living with HIV/AIDS (WLA) become positive within the first few years of marriage (Solomon, Chakraborty, & Yepthomi, 2004).

In India there exist gender-specific disparities in HIV prevention and treatment. One of the main factors influencing India's HIV epidemic is a high rate of gender stratification, in which women experience extreme social disadvantage (Bloom & Griffiths, 2007). Indian women suffer disproportionate vulnerability to HIV/AIDS (Kambou, Magur, Hora, & Mukherjee, 2007), often because they often lack HIV awareness, live in conditions of poverty, and experience gender inequity (Van Rompay et al., 2008). WLA have been found to have low levels of psychosocial well-being (Solomon et al., 2008), which is confounded by the fact that many women live in rural areas and are socially and physically distant from help and government resources (NFHS, 2008).

The purpose of this study is to assess the benefits and challenges related to engaging HIV-trained accredited social health activists (ASHAs) in the care of WLA in the rural district of Nellore, Andhra Pradesh. Our goal is to determine the utility and acceptance of a new HIV-trained ASHA who can promote the health and well-being of rural WLA in partnership with rural health care professionals. It is hoped that these findings will promote the development of culturally sensitive strategies targeted for WLA in rural India.

IMPACT OF HIV/AIDS AMONG WOMEN

The rising rate of HIV infection among women in India is even more concerning due to the fact that HIV-infected women are significantly more likely to experience adverse pregnancy outcomes such as breech presentations, anemia, or stillborn births (Lionel et al., 2008). According to a 2006 Joint Technical Mission report, there are 189,000 HIV-positive pregnant women living in India (Surjushe & Maniar, 2008). It is estimated that each year, about 56,700 infants are infected with HIV in India as a result of vertical transmission, despite the availability of a government-sponsored prevention program (NACO, 2006).

In India's male-dominated culture, women are finding they must choose between the stigma of becoming infected with HIV from their husbands or the less desirable option of remaining childless (Solomon et al., 2004). WLA are also less likely than men to seek care for sexually transmitted illness (STI) and HIV as a result of gender discrimination (Burogohain, 2008).

Women receiving antiretroviral therapy (ART) have reported significantly lower mean psychosocial well-being scores than men ($p < .01$), indicating a need for programmatic emphasis on the quality of life of WLA (Solomon et al., 2008). Mental illness is common in Indian women, with the prevalence of mixed anxiety-depressive disorder as high as 64.8% in some reports (Sarkar, 2008). WLA have also reported financial difficulties, problems with childcare, compromised help-seeking behaviors related to stigma, role strain, and gender discrimination (Joseph & Bhatti, 2004). Joseph and Bhatti concluded that escape avoidance was the most preferred coping strategy among WLA who had seropositive husbands, indicating a need for emotional support in the community.

CHALLENGES EXPERIENCED BY WOMEN AFFECTED BY HIV/AIDS

Focus groups have revealed that stigmatization (Tarakeshwar et al., 2007; Thomas et al., 2005; van Hollen, 2007), poverty (Kambou et al., 2007), lack of HIV-related transmission awareness (Pallikadavath, Garda, Apte, Freedman, & Stones, 2005), and lack of access to resources (Ghosh, Wadhwa, & Kalipeni, 2009) are key challenges faced by many Indian women with HIV. A qualitative study of HIV-positive individuals in Chennai found the major theme of stigma, or living a life of fear, was related to isolation and discrimination experienced by WLA (Tarakeshwar et al., 2006). Women in this study expressed a fatalistic view of HIV infection, feeling powerless to protect themselves. The impact of stigma was related to guilt and shame, issues surrounding disclosure, and worries about the future. Findings from these studies can guide the design of interventions focused on increasing access to care for WLA and bolstering their social support and emotional health, particularly as they relate to stigma (Gupta et al., 2008).

HIV-related stigma is pervasive in Indian society, with those living with HIV perceived as being “perverted” and “sinful” (UNAIDS, 2001, p. 7). These beliefs extend to those working in the health care sector, further alienating WLA from receiving needed care. HIV stigma in India extends to the family members of WLA, as evidenced by the fact that children of HIV-infected parents are denied the right to go to school in some cases (Kodandapani & Alpert, 2007).

THE UNIQUE CASE OF RURAL WOMEN LIVING WITH AIDS

Women who live in rural villages in India face unique challenges to receiving HIV care. Two-thirds of households in the state of Andhra Pradesh reside in rural areas (NFHS, 2008), which generally have village populations of 500 to 3000 persons each. Less than half (45%) of rural women have ever attended school, and their comprehensive knowledge of HIV is particularly low (15%; NFHS). High levels of HIV stigma and extreme marital power differentials have been found to exist in rural areas of Andhra Pradesh (NFHS).

Rural villagers have difficulties traveling to government hospitals to obtain free ART, related to travel expenses (equal to a week's salary for one round-trip), length of travel (up to 6 hours each way), and stigma and discrimination from hospital employees (van Rompay et al., 2008). About half (49%) of households in Andhra Pradesh cited distance as the reason for not seeking care from government facilities (NFHS, 2008). This is crucial since despite the fact that NACO has 32 ART sites in Andhra Pradesh, there is only one site in the district of Nellore, which is hours away from many rural villages. In addition, one study found that 32% of HIV-infected individuals reported nonadherence to ART as a result of either financial constraints or unwanted side effects (Tarakeshwar et al., 2006).

INTERVENTIONS TO MANAGE HIV/AIDS

For these reasons, community-based interventions are needed to reach rural WLA, targeting the issues of health care access, ART adherence, emotional support, and stigma. One of the most effective strategies to control the HIV/AIDS epidemic is improvement in community health education (Solomon et al., 2004). Interventions have been developed, based on feedback provided by people living with HIV and health care providers, to meet the HIV educational needs of persons living with HIV/AIDS. For example, the Sonagachi Project is an effective community-wide HIV intervention program that has been found to be both effective and sustainable for over 12 years (Jana, Basu, Rotheram-Borus, & Newman, 2004).

Community-based organizations that address women's health care needs should be used to develop HIV peer education programs (van Rompay et al., 2008). Currently, female village health workers known as reproductive health accredited social health activists (ASHAs) are being trained in India to promote the health and well-being of pregnant women, as well as provide care and support for the newborn. These government-trained ASHAs assist village women with pregnancy testing, registering antenatal cases, providing vaccinations, and improving infant and maternal morbidity and mortality by registering and referring pregnant women for antenatal and postnatal care and to hospitals for birth. However, training material for these paraprofessionals outlines very limited roles and responsibilities toward women who are HIV infected (Ministry of Health and Family Welfare, 2005). These reproductive health ASHAs focus predominantly on the health of pregnant women and the infant and mother during the first 6 months post delivery. They are paraprofessionals by training and generally educated at the fifth- to eighth-grade level.

The government of India believes that ASHAs can have a very powerful impact on the health and welfare of people living in India, by way of providing an interface between the community and the Public Health System (National Rural Health Mission [NRHM], 2009). Specifically, some of the objectives of the ASHA are to create health awareness, promote good health practices, and increase utilization of existing health services (NRHM). Indian health policy under the NRHM is currently supporting the state of Maharashtra in carrying out an ASHA training program that is based on four content areas: basic health and hygiene, maternal and child health, HIV/AIDS, communicable diseases, and advocacy (Seattle Aid India Organization, 2009). In addition, the future for an expanded role of ASHAs is already under way, with the launch of a nationwide ASHA training program with full implementation targeted for 2012 (Chiranjeevi, 2009). However, to date there are no published studies on how ASHAs can be integrated into the care and support of rural WLA living in India.

IMPACT OF LAY PROVIDERS ON HIV/AIDS OUTCOMES

Only two studies have assessed the impact of peer lay health providers in enhancing knowledge about HIV and improving care delivery to populations affected by HIV/AIDS in India. One revealed that peer educators can effectively disseminate information to less-educated communities (van Rompay et al., 2008). This study used peer educators to empower individuals in rural areas with HIV prevention messages and concluded that peer education is an effective way to “break the silence” of HIV-related stigma and is sustainable because of the use of community workers (p. 8). In the second study, Sivaram and Celentano (2003) revealed that training peer educators can be effective for AIDS prevention in rural India.

Although few studies exist examining the use of peer education and support related to HIV in India, these ASHAs are comparable to other lay health providers who have been studied in the literature. For example, lay health advisor (LHA) programs began in the United States

in the 1970s to train natural helpers in the community to inform, educate, and provide social support regarding health issues within their social circles (McQuiston, Choi-Hevel, & Clawson, 2001). They have been identified as trusted leaders in their social networks (Israel, 1982). Studies have been conducted on the use of LHAs in the community regarding issues including (but not limited to) HIV in migrant workers in the United States (McQuiston et al., 2001; Somerville, Diaz, Davis, Coleman, & Taveras, 2006) and the Netherlands (Martijn et al., 2004); cervical cancer in Native Americans (Christopher, Gidley, Letiecq, Smith, & McCormick, 2008); breast cancer in African Americans (Yu et al., 2007); and cardiovascular health in immigrant Latinas (Kim, Koniak-Griffin, Flaskerud, & Guarnero, 2004). These studies confirm a promising impact of peer educators on improved health indicators in multiple areas around the world.

However, the goal of the ASHA is to be an activist in the community, as well as a lay health provider (Lahariya, Khandekar, Prasuna, & Meenakshi, 2007). This indicates an expansion of the role previously studied in the above-cited literature. Related to what is known about the use of lay health providers in other settings, it is possible that HIV-trained ASHAs could be used to fill the gap that exists for HIV care of rural women in India. Because reproductive health ASHAs are already trained with respect to reproductive and maternal-child health, the integration of HIV care and support could be a natural extension of their current roles. However, no information currently exists about the perspectives of WLA regarding this new type of lay health provider. In addition, the perspectives of other health providers, including nurses, physicians, and existing reproductive health ASHAs, regarding the implementation of an HIV-trained ASHA are unknown.

METHOD

Design

Using a community-based participatory research (CBPR) approach, a qualitative study was designed utilizing focus groups to understand the perspectives of rural WLA receiving ART regarding the integration of a new lay health provider in the community. Select health care providers, both professionals (nurses and physicians) and paraprofessionals (existing reproductive health ASHAs), were also included in focus groups to offer additional insight. The CBPR approach enables the community to guide the design of this and subsequent phases of research regarding the use of ASHAs in rural India. This strategy incorporated the guidance of a community advisory board as well as in-depth insight into the life experiences of affected individuals and care-givers (Sandelowski, 2000).

Three focus groups were conducted with a total of 39 WLA. Two additional focus groups were conducted with health care providers; one focus group included nurses ($n = 3$) and physicians ($n = 2$) and a second focus group included reproductive health ASHAs ($n = 5$). These health care providers (of whom all were female except the two physicians), were selected as key informants based on their experience working with WLA in rural village areas with high HIV prevalence in one selected *mandal* (subdistrict) of the district Nellore in Andhra Pradesh.

Comprehensive Health Seeking and Coping Paradigm

Focus groups were guided by a Semi-Structured Interview Guide, a listing of predetermined open-ended questions that incorporated the theoretical constructs of the Comprehensive Health Seeking and Coping Paradigm (Nyamathi, 1989). Based upon the original theoretical foundations proposed by Lazarus and Folkman (1984) and Schlotfeldt (1981), these constructs, which have guided previous work with women living with HIV in India (Nyamathi, Thomas, Greengold & Swaminathan, 2009; Thomas, Nyamathi, &

Swaminathan, 2009), include factors that relate to the challenges facing WLA. The focus for this study includes sociodemographic factors (women experiencing challenges of being impoverished), situational factors (living in the rural villages far from district hospitals), personal and social factors (needing inner strength and social support), and coping responses (strategies WLA use to seek information and request health care). All of these factors relate to health outcomes.

Community Advisory Board

Prior to the initiation of this study, a community advisory board was formed, composed of 10 persons including physicians, nurses, reproductive health ASHAs, and WLA. The health care providers were key informants from the rural primary care clinic where the study was to take place. Despite the fact that the reproductive health ASHAs are not HIV-trained, they have experience caring for childbearing WLA and therefore can offer insight into the perceptions and feelings of this population. These board members were not part of the focus group discussions and met as a group prior to the start of focus group sessions and upon completion of all focus group sessions. Each board meeting or focus group session lasted between 60 to 90 minutes.

The community advisory board served as the voice of the community to assist researchers in understanding the nature of delivering HIV/AIDS care in rural areas, as well as the barriers and facilitators of offering support to WLA. Board members also reviewed the outcomes of the focus group discussions and engaged in lively discussions about how to actualize support for the needs of WLA within the constraints of existing AIDS care guidelines. The board members assisted in the refinement of the interview guide used in the focus groups, helping to ensure that it was culturally sensitive and linguistically appropriate for WLA.

Participants and Setting

A total of 39 WLA were recruited from a large primary health center in the Nellore district of Andhra Pradesh, which was surrounded by approximately 30 villages where the WLA resided. Women were eligible for the study if they were currently taking ART and had their drug cards as validation, were 18 or older, spoke English or Telugu (the official language of Andhra Pradesh), and consented to participate in the study. The women ranged in age from 20 to 45, with a mean age of 30. Approximately 20% had no children while 15% had three or more children. Almost all the women (87%) were employed, with more than half working in agricultural jobs. Over half the women (51%) reported no formal education, and 44% were married.

In addition, health care providers including nurses ($n = 3$) and physicians ($n = 2$) and reproductive health ASHAs ($n = 5$) participated in the focus groups. The health care workers reported a mean age of 34 and two thirds were married. All nurses reported 6 to 11 years of education, while the physicians reported professional schooling. All were employed. The majority (80%) of the reproductive health ASHAs reported 6 to 11 years of education while one reported less than 6 years.

Procedure

The study was approved by the Ministry of Health, Government of India, the ethical committees of the Indian Council for Medical Research (ICMR), the All India Institute of Medical Sciences (AIIMS), and the University of California, Los Angeles (UCLA) Human Subjects Protection Committee. Approved flyers were posted in the primary health center, which provided general details about the study along with contact information for the research staff. Once contact was made by an interested woman, the research staff offered

further details about the study in a private area. If she agreed to participate, informed consent was provided, along with a date to return for a focus group.

Participants gathered at the assigned community site and were greeted by a well-trained focus group facilitator and a research assistant who conducted most of the focus groups in Telegu. Both staff were trained by the lead author. The questions were guided by the Semistructured Interview Guide, which was formulated based on an extensive review of the literature on issues of relevance to WLA and refined by the community advisory board. Topics of interest included challenges WLA experience with ART adherence and how HIV-trained ASHAs might best be engaged to enhance care and support. The focus groups with nurses and physicians identified similar issues, as well as the necessary characteristics of future ASHAs, responsibilities of this new paraprofessional, the type of training needed, and other care-related issues. All discussions were tape recorded and later transcribed by the research assistant.

Data Analysis

The recorded and transcribed sessions were analyzed to determine the participants' perspectives regarding benefits and challenges WLA face and their perception of the use of HIV-trained ASHAs as care partners in the community. Themes raised by the participants were identified and coded by a trained research assistant and verified by the research leader. After coding was completed, a catalogue of each theme, particular type of respondent and number of responses were recorded. Findings of the focus group discussions were related back to the community advisory board for further discussion and verification.

RESULTS

Content analysis revealed the unique needs of WLA for care and support as well as their perceptions of the major benefits and a few challenges they might expect with the provision of an HIV-trained ASHA as a partner in their care. Women shared significant challenges related to living with AIDS. They projected the types of assistance they would need from ASHAs in the areas of emotional support, travel for health-related visits, and ART adherence. The theme of stigma also emerged, as related to the prospect of care provided by an HIV-trained ASHA. Additional themes surrounded the implementation of an HIV-trained ASHA program: responsibilities of the ASHA, characteristics of an ASHA who would be most desirable for the position, compensation for ASHAs, and the type of training ASHAs should receive.

Challenges Experienced by WLA

Need for emotional support—The need for emotional and spiritual support was raised by one-fourth of WLA. In particular, one participant mentioned that while nurses do visit them occasionally, emotional support is not commonly provided. As one woman revealed:

We need more of emotional or spiritual support. Because sometimes we are down and sick emotional[ly] ... We welcome ASHAs to talk to us. Support will be a great help.

We like ASHA's to accompany us to District Hospital or the primary health center or private clinic when we are sick. We welcome ASHAs [to] visit our homes ..., talk to us, [and] support us emotionally.

Need for health-related travel support—Assistance with travel for health-related visits was verified by all the women who participated. For one-third of WLA, being accompanied by an ASHA to hospitals, primary health centers and other health care facilities was very

important, particularly when the distance was very far or if the WLA was not feeling well. Illness was also mentioned as a challenge five WLA faced, which required visiting the district hospital. As one women reported:

From the time I started using ART, I have problems like bloating of abdomen, itching, body pain, legs and arms pains. Whenever I visit District Hospital for collecting my ART medicines, I also visit HIV/TB specialists for my other problems. For my minor fever, diarrhea, when I visited PHC (primary health center), the doctor asked me to consult specialist at District Hospital...

In the rural setting in particular, all persons affected by AIDS must receive all ART and AIDS-related medical care at the district hospital, rather than a closer primary health center located within an hour or two from their village home. Travel time to the district hospital took at least 7 hours. This was a major issue that negatively impacted adherence to ART medication.

Need for support with art adherence—Support for adherence to the ART regimen was raised by the women. All verbalized the importance of taking their medication, but when asked how many had never missed a dose, only two hands were raised. A major challenge the women experienced was not only transportation to distant hospitals but also better instructions on how to take the medications. The difficult journey was captured clearly by one WLA:

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 a lot of difficulties whenever I collect my medicines, but I do it because I know the importance of the medicines.

Providing clear instructions on how the medication is to be taken was also clearly verbalized by one woman, “Help to direct us on how to take medicines.” In addition, two women mentioned that childcare was a challenge. As one women reported, “I go alone to get my ART medicines and I go before night and stay in Nellore to ensure early in the day I get back to home. I leave my daughter at my neighbor's home.”

Three-quarters of the women reiterated that the challenges they face with needing emotional support, assistance with travel, and instruction related to how to take their medicines and keep healthy were overwhelming to them. These women revealed that no one helped them with any type of support.

Perspectives Regarding Stigma

Stigma experienced by WLA

When asked about any concerns WLA might have if HIV-trained ASHAs were to visit them in their village homes, findings revealed that three WLA identified that this could accentuate HIV-related stigma in the community. However, due to the seriousness of their illness, 11 WLA explained that ASHAs would still be welcome to visit them in their homes. For one participant, the relationship of stigma to loss of health was poignant:

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 WLA.

Another WLA explained that the need for basic care and support was more important than any stigma that could result from possible sharing of information:

We really do not have any problem with ASHAs ... visit[ing] us. Even if information is shared, we do not mind as long as we get some kind of emotional

and other support from them. Presently, we are suffering because no one visits us and we lack emotional and other kind help from anyone. If someone is offering care, why should we feel stigma?

Other women verbalized similarly:

We have no problem as long as ASHAs support us emotionally and also help us to be healthy ... We do not feel the stigma. We welcome ASHAs to visit our homes and help in every possible way ... We also heartfully accept and we do not worry about stigma. We welcome ASHA, nurse or even doctor's visit to our home or even visiting village PHC's (primary health centers)...

Three reproductive health ASHAs in the group revealed that WLA accept the existing reproductive health ASHAs and nurses freely for any help and that stigma is not a major barrier to the receipt of care. However, as ASHAs normally live in the village of the population they serve, a number of ASHAs and the nurses discussed whether the residence of the ASHA could affect stigma. As one nurse indicated:

I think when the ASHA of the same village visits WLA any number of times ... [if] the ASHA belongs to the same village, people will not object or suspect the woman to be living with AIDS. The ASHA and the WLA will be comfortable visiting and talking to each other. But if an outside ASHA visits the WLA a number of times, people of the village may suspect the woman to be living with AIDS.

Another nurse also sensed that issues related to stigma were improving in rural areas as evidenced by an example of one very sick WLA:

Recently, there was a case study of a WLA who was very sick and [bedridden]. She was a widow and also on ART. She has two small kids, and no relatives are living in the village. When she was bedridden, all the villagers including the village head got together and helped her to go to the hospital and supported her financially. After 3 months, she is better and taking care of her children. In this case it is clear that people are ready to help WLA without any stigma.

Stigma experienced by ASHAs—Interestingly, the reproductive health ASHAs recognized that caring for WLA could result in self-experienced stigma as well. However, all ASHAs responded with a clear understanding of how HIV was transmitted and a denial that caring for WLA would impact their personal life. As one ASHA revealed, “When our own family members question us why we help WLA, [we reply], we like to work with WLA.”

Moreover, the ASHAs were well educated with facts about HIV transmission. As one ASHA reported, “It [AIDS] is not a communicable disease; but it is acquired by having a sexual relationship with a person living with HIV or by using unsafe needles or blades or unscreened blood.” When asked about challenges for unmarried women, one ASHA replied, “No, we are comfortable working with WLA whether we are married or unmarried.”

Implementation of HIV-Trained ASHAs

Responsibilities of the AHSA—The reproductive health ASHAs present at the focus group sessions provided unique perspectives on the responsibilities of an HIV-trained ASHA in caring for WLA. Two responsibilities include making the woman comfortable, and ensuring confidentiality. As captured by one ASHA,

We must talk to her whenever possible about her health problems [and] we must be friendly towards her; then she will share all her problems..., and also we must ensure her about the confidentiality of her information. We will not share any

information outside. We must make her comfortable [for us] to visit her home or she to visit us

I tell her that you are like my sister or daughter. ... I will not share your information with any one; not even my family or neighbors. I will keep all the information you share in my heart. No need to worry about anything; you are just like any other normal person.

I [will] first support her emotionally and then support her physical health needs. I will even take her to the midwives for any major advice. I will accompany her to the PHC (primary health center) and help her get medicines and inform her how to take medicines properly, and eat right food like eating an egg, green leafy vegetables, drinking milk etc.

Consistent with the needs expressed by the WLA previously, the major tasks that the reproductive health ASHAs considered important for the HIV-trained ASHA included a focus on providing emotional support, assistance with travel and referrals to other health care providers, and information related to health. As one ASHA confirmed, offering emotional support to the WLA was an important factor in building their confidence. The WLA would feel more comfortable sharing confidential information, and thus improved assistance could be provided. For another ASHA, there was also an expressed need to “support her to become emotionally strong. I should help her to lead her remaining life healthy in all aspects.”

Characteristics of the ASHA—When the WLA and health care providers were asked what type of women would make an ideal HIV-trained ASHA, two female reproductive health ASHAs replied that a WLA would make an ideal ASHA, as “they understand the problem better than me.” Other characteristics that emerged included knowledgeable, empathetic, and “an overall good human being.”

Compensation—Another issue the reproductive health ASHAs raised related to financial compensation for the work. In the current system, these ASHAs work on an incentive basis and are paid by the government. A point made by one nurse was that while HIV-trained ASHAs would be very interested in working, there would be a need for compensation. At the time of this study, reproductive health ASHAs were receiving Rs.300/- per month, equivalent to approximately \$6 per month for full-time work. As one ASHA replied, “We request to decide the reward according the work you allot to us.”

Training—WLA, reproductive health ASHAs, nurses, and physicians discussed the ideal training that should be required for HIV-trained ASHAs. One WLA felt that ASHAs should understand issues related to sexual health. This was validated by an ASHA, “We talk about personal hygiene and gynaec [gynecology] problems. If you teach us important aspect of sexual health, then we will impart it to the WLA.”

One of the nurses added that ASHAs should also be trained in basic knowledge on HIV/AIDS, as well as communication skills related to empathy. In addition, ASHAs need to be trained on the side effects of ART as well as other areas of symptom support. Four ASHAs supported these content areas. Another ASHA identified nutrition and personal hygiene as areas of importance. In addition, training related to diminishing stigma was identified. As one ASHA stated, “We need complete knowledge about HIV/AIDS, a great strength that makes stronger from inside. We need training to eliminate stigma.”

Midwives and physicians were named as professionals who might be best suited to train this new group of ASHAs. Books and supplementary readings were requested for self-training.

DISCUSSION

A strength of this study is the use of WLA, nurses, reproductive health ASHAs, and physicians to offer input into how the implementation of a program with HIV-trained ASHAs might be crafted. This is the first study of its kind, investigating the perceptions of rural woman to gain an understanding of the perceived benefits and challenges regarding care delivered by paraprofessionals in the community. Our findings show that WLA would like HIV-trained ASHAs to provide emotional support, assistance with travel, and support with ART adherence. These findings are supported by the theoretical model, Comprehensive Health Seeking and Coping Paradigm ([CHSCP], Nyamathi, 1989), and were validated by the community advisory board. This is the first study designed to assess the benefits and challenges to receiving care and support from this new paraprofessional, as perceived by WLA. While the idea of using dedicated HIV-trained ASHAs to provide support, care, and other services to WLA is novel, community members have previously been used in India to provide support for women with other health conditions (e.g., child-bearing). The Indian Local Initiatives Program, piloted from 1999 to 2003, showed that community health volunteers could be successfully used to provide reproductive and child health services (Paxman, Sayeed, Buxbaum, Huber, & Stover, 2005).

Surprising to the community advisory board members was the finding that while WLA believe stigma might be accentuated by having an HIV-trained ASHA visit their homes, they felt this could be overcome if ASHAs can offer support and assist WLA in accessing needed care. While reproductive health ASHAs and nurses in the focus groups also recognized that stigma could be an issue, they felt that stigma could be reduced by engaging ASHAs from the same village as the WLA. An ASHA from an outside village might promote suspicion among village members and perpetuate stigma. Health care providers must continue to address and reduce stigma when caring for HIV-infected people (Ghosh, Wadhwa, & Kalipeni, 2009). HIV and AIDS continue to be highly stigmatized within India (Excler et al., 2008; Steward et al., 2008), and stigma has been cited as a major concern among WLA (Tarakeshwar et al., 2007; Thomas et al., 2005; van Hollen, 2007).

Poor ART adherence can result in the development of resistant strains of HIV (Gazzard, 2002). Our analysis shows that WLA believe ASHAs can help them with ART adherence. van Rompay et al. (2008) found that empowering the community by way of HIV peer education resulted in improved health awareness among residents of rural India. This is consistent with the beliefs of our focus group participants that use of peer education by ASHAs could result in improved ART adherence.

Jana et al. (2004) reported findings from the Sonagachi Project, a community intervention that recruited peer outreach workers to provide HIV prevention services to sex workers in India. In this study, outreach workers were used as role models and implemented HIV awareness training in the community. This exploratory study on HIV-trained ASHAs could guide a subsequent intervention to implement the use HIV-trained ASHAs in the provision of care and support for WLA in rural India.

Our focus group results revealed that HIV-trained ASHAs should be knowledgeable, open, friendly, and accepting toward WLA. This is consistent with findings from a recent review, which concluded that supportive and accepting health care providers are needed to deliver quality service to people with HIV in India (Bharat & Mahendra, 2007). Our focus group participants also believe that the HIV-trained ASHA should be able to provide travel assistance to WLA. This is also consistent with a report by Pallikadavath and colleagues (2005), who believe that the effect of poverty must be factored into any intervention strategy

and measures must be taken to improve access for the impoverished people with HIV/AIDS. One such issue of access is related to transportation.

With respect to the type of training needed to prepare lay village women to become HIV-trained ASHAs, participants suggested that the training should include information about HIV/AIDS, diet, and hygiene and the side effects of ART. This is supported by other studies concluding that it is essential to provide HIV/AIDS information (including prevention and treatment strategies) to those providing care to people with HIV/AIDS (Kermode, Holmes, Langkham, Thomas, & Gifford, 2005; Mignone, Washington, Ramesh, Blanchard, & Moses, 2007; Nyamathi et al., 2007). Other participants suggested that issues surrounding sexual health should be included in the curriculum. Kambou et al. (2007) likewise called for the assimilation of gender and sexuality content into community-based HIV prevention programs. Sachdev (2005) has also recommended that gender-sensitive content be a part of HIV/AIDS training.

Several of our participants believed that midwives and physicians would be the ideal trainers of the future HIV-trained ASHA. The majority of studies regarding HIV education for health care providers in India do not address method of training. However, Nyamathi et al. (2008) found that a train-the-trainer approach using nurses was useful for the provision of HIV education among nurses. It is possible that once a cadre of HIV-trained ASHAs has been established, they can be used to train other ASHAs as well.

Our focus group results also showed that compensation for future HIV-trained ASHAs was also an issue. The participants questioned the amount of incentive payment that would be used to reimburse the HIV-trained ASHA. In order for a program to be sustainable, it must have an ongoing funding stream (Jana et al., 2004). Based on the perceptions of our focus group, we plan to design an intervention whereby trained HIV ASHAs would be provided with reimbursement for their services similar to that of existing government trained reproductive health ASHAs.

Finally, while there is no documentation to date about the use of WLA as ASHAs, future studies into this idea would be of great interest. Hypothetically, WLA who become ASHAs may more effectively provide HIV care, due to their own personal experiences living with AIDS.

Policy Implications

WLA living in rural India face a number of challenges. Our study shows that WLA believe HIV-trained ASHAs could be very useful in helping them overcome some of the difficulties of living with HIV/AIDS (i.e., supporting adherence and dealing with issues surrounding stigma). This supports the Indian government's desire to train and use ASHAs as a support for rural women (NRHM, 2008) but also necessitates the need for further study on how best this training can be accomplished and how ASHAs can be utilized in the community, specifically for WLA.

In our study, we examined perceptions of WLA regarding the role of the ASHA. Our participants believe that the ASHA could help with key issues WLA face such as optimizing health, bolstering adherence to ART and diminishing stigma. Our findings are consistent with the NRHM (2009) policy of using ASHAs for care and support in rural areas. We believe our findings will be helpful to assist in molding training, practice, and policy for the Indian government as problems related to medication adherence among rural WLA have not specifically been addressed to date.

Nevertheless, limitations existed in terms of generalizability, as the data were collected from a relatively small sample of WLA and health care workers who resided within one rural area in southern India. Furthermore, the participants were not randomly selected. In addition, this study is limited by including only women who are living with AIDS who were taking ART and presented to a primary health center for care. Nevertheless, the findings highlight the perceptions and needs of this very challenged population.

Conclusion

In this study, we have solicited the perceptions of WLA, reproductive health ASHAs, nurses, and physicians regarding the development of a future program of care for WLA living in India. This program would guide HIV training for ASHAs, enabling them to go into the community and provide support, care, and counseling for WLA. Our focus groups have provided us with new insights. In particular, we have learned that WLA are willing to accept an HIV-trained ASHA, especially if the ASHA lives within the local village community. WLA are likely to accept HIV-trained ASHAs if these community workers can provide emotional support, travel assistance, and ART adherence support.

Reproductive health ASHAs, nurses, and physicians recommend that HIV-trained ASHAs be well trained and able to offer emotional support, promote access to care, enhance nutritional health, and enhance assistance with obtaining ART. All of our participants recommend that future HIV training should include information regarding HIV pathogenesis and treatment issues. The results of these focus groups provide insight into a community program design using ASHAs to provide support to WLA. According to this exploratory study, such a program would be well received.

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