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## ASHA-Life Intervention Perspectives Voiced by Rural Indian Women Living With AIDS

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## **ASHA-Life Intervention Perspectives Voiced by Rural Indian Women Living With AIDS**

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*In this focus group study, we explored the experiences of 16 rural women living with AIDS (WLA) who participated in the Asha-Life (AL) intervention to gain an understanding of the environmental, psychosocial, and cultural impact of the AL on their lives. Four themes emerged among AL participants: (a) the importance of tangible support, (b) need for social support, (c) ongoing challenges to accessing antiretroviral therapy (ART), and (d) perspectives on future programs. Our research findings support the development of future programs targeting mother–child dyads which emphasize nutritional knowledge, while reducing barriers to receiving ART, and physical, emotional, and financial support.*

The Joint United Nations Programme on HIV/AIDS (2010) reported that India has the third largest population of individuals living with HIV/AIDS in the

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world, with 1.7 to 2.6 million affected with HIV/AIDS (UNAIDS, 2014). In 2012, the National AIDS Control Organization (NACO) estimated India's HIV prevalence to be .25% among adult women and .36% among adult men (NACO, 2011). Andhra Pradesh (AP) is one of four high prevalence states (National AIDS Control Organization, 2013), with an adult HIV prevalence of 0.90% (NACO, 2011). Given the prevalence of HIV in AP, the authors explored the experiences of rural women living with AIDS (WLA), who participated in a 6-month social support and adherence intervention between 2008 and 2011.

The authors present the findings from an exploratory study conducted with rural WLA in AP, India. Four important themes emerged from the focus group discussions: (a) the importance of tangible support; (b) need for social support; (c) ongoing challenges to accessing HIV treatment; and (d) perspectives on future programs. Health care providers internationally may utilize the authors' findings to develop future programs targeting mother-child dyads in similar settings that reduce barriers to obtaining antiretroviral medication and deliver physical, emotional, and financial support and sustainability. Further, emphasizing nutritional knowledge and family support promotes the positive behaviors needed to sustain positive outcomes.

#### WOMEN LIVING IN RURAL INDIA: RISK FACTORS FOR HIV TRANSMISSION AND CHALLENGES FOR HIV ACCESS AND TREATMENT

Unlike India's north-east regions where HIV transmission is mainly seen among injection drug users (IDUs) and sex workers (NACO, 2009), in southern states, HIV is primarily spread through sexual contact. HIV prevalence is likewise increasing in certain groups that were previously deemed low risk, such as pregnant women in the rural areas, where 60% of India's HIV affected population live (NACO, 2008). In South India, 81% of HIV positive women seeking treatment were housewives (Newmann et al., 2000).

Because India is rooted in patriarchal cultural values, where conservative gender roles are in place (Panchanadeswaran & Koverola, 2005), it is clear that women lack control in sexual decision-making (Gupta et al., 2008). Likewise, in both urban and rural enclaves, high rates of domestic and sexual violence have been noted by the National Crime Records Bureau (2013). Rural Indian women's lack of transmission knowledge regarding HIV further places them in a vulnerable position. While a significant portion of women in India are aware of HIV, rates of transmission and prevention knowledge are much lower (Pallikadavath, Garda, Apte, Freedman, & Stones, 2005). Women Living with AIDS (WLA) experience ongoing barriers to HIV testing and treatment, placing them at further risk for HIV. The women cited the

factors that limited their treatment seeking, including transportation, child-care, and finances (Nyamathi, Sinha, et al., 2011). For those WLA who undergo treatment, misinformation regarding antiretroviral therapy (ART) and lack of social support diminish adherence to ART (Nyamathi, Sinha, et al., 2011). Further, India's cultural values have been seen to dictate a pattern wherein treatment is typically first sought for men in the household, after which limited resources are available for the care of women (Pallikadavath et al., 2005).

## ASHA-LIFE AND USUAL CARE PROGRAMS

### Asha-Life (AL)

Between 2008 and 2011, a multidisciplinary team of researchers from the United States and India conducted a 6-month comprehensive HIV wellness intervention study, termed Asha-Life (AL). The program was designed in a culturally sensitive manner, with the support of a Community Advisory Board (CAB) composed of WLA, government-paid reproductive health community supports, nurses, physicians, and government officials. The AL intervention consisted of group education sessions focused on the importance of adherence to ART, parenting skills, coping and stigma strategies, and ways to maintain psychological strength, along with monitoring of physical and mental health. The AL program was coupled with support from newly HIV-trained village women, Asha (Accredited Social Health Activists), who served as a bridge between the community and the health care system.

In this pilot study, the Asha, who were carefully supported by the research team, and local physicians and nurses, were trained to assess and overcome barriers to optimal ART adherence by accompanying WLA to the District Hospital to receive ART, providing transportation, enhancing social support and knowledge of HIV disease progression, and delivering monthly supplies of basic protein supplementation to rural WLA. In addition, women assigned to the AL condition were also educated on the importance of nutrition. Furthermore, the WLA attended life skill classes of their choice to learn sustaining skills such as embroidery, tailoring, and using a computer.

### Usual Care

Women living with AIDS (WLA) assigned to the second intervention arm, which lasted over a 6-month period, received six integrated group classes focused on the importance of adherence, parenting, and keeping healthy; further, basic nutrition was also provided, as well as physical and psychological assessment. Those WLA assigned to the University of California (UC) group, however, did not receive Asha support as part of this intervention, nor the high protein nutritional component.

At 6-month follow-up, the researchers revealed that adherence to ART, CD4 levels, and depressed mood were significantly improved with the AL group as compared with the UC program ( $p < .001$ ; Nyamathi, Hanson, et al., 2012; Nyamathi, Salem, Meyer, et al., 2012). The AL participants also had significantly greater odds of reducing depressive mood than the UC group (Nyamathi, Salem, Meyer, et al., 2012). Moreover, the AL WLA significantly improved ( $p < .01$ ) in body mass index (BMI; Nyamathi, Sinha, et al., 2013). The researchers designed the focus groups to explore the experiences of WLA who participated in the AL program, and to examine additional needs that could be included in future intervention development in similar international settings.

## METHODS

### Design

Two focus groups were conducted with a total of 16 WLA, all of whom had participated in the 6-month culturally sensitive AL intervention study; eight participants were in each group, which lasted between 60 and 75 minutes. The respective Institutional Review Boards for human subject protection in the United States and India approved the study.

### Community Advisory Board (CAB)

Ten members consisting of former WLA participants of the AL intervention ( $n = 3$ ): former HIV-trained Ashas ( $n = 2$ ); an expert in HIV ( $n = 1$ ); an expert in nutrition ( $n = 1$ ); an expert in mental health ( $n = 1$ ); an expert in child development ( $n = 1$ ); and a nurse expert ( $n = 1$ ) comprised the newly formed CAB. The CAB members met for 2 hours over two sessions and assisted in the development of a culturally sensitive semi-structured interview guide (SSIG). The CAB, guided by the use of the SSIG, addressed issues related to the environmental, psychosocial, and cultural impact of the AL program on the lives of the WLA, as well as the conduct of the focus groups and, subsequently, the interpretation of the findings.

### Participants and Setting

The Indian-based project director contacted the former AL intervention WLA participants and invited them to participate in the focus group sessions (FGSs). Among the former AL participants ( $n = 34$ ), three were selected to participate as members of a CAB described above. Another six individuals had relocated to other districts and were not geographically available to participate. Four additional AL WLA were unable to attend the sessions when

offered. In total, 16 of the original 34 AL intervention participants agreed to join the focus group sessions.

### Procedure

After the research team reestablished contact with 16 of the former 34 AL participants, the WLA were informed of the proposed study. After questions were addressed, participants were asked to sign informed consent. Using an SSIG finalized by the CAB, two 60–75-minute FGSs were conducted in Telegu by the trained project director and a research assistant. At the completion of the focus group, the WLA were compensated 592 Indian Rupee (INR), which is roughly equivalent to \$10.00 U.S. dollars (USD). Each taped FGS was subsequently translated into English by the research team.

### Measures

Sociodemographic factors assessed by the research team include: age, birth-place, marital status, education, number of children, and religious affiliation. Frequencies, percentages, and means were then analyzed by the research statistician to describe these sample characteristics.

### Content Analysis

After transcription of the taped sessions, two members of the research team under the direct supervision of the principal investigator (PI) conducted the content analysis utilizing manual methods (Strauss & Corbin, 1990). The data analytical process utilized by the research team represented an inductive content analysis, which included the following methods: (a) selecting the unit of analysis; (b) creating and defining the categories; (c) pretesting the category definitions and rules; (d) assessing the exhaustiveness and exclusivity of the schema; (e) pretesting the category schema; (f) coding all the data; and (g) reassessing the reliability (consistency in coding decisions) and validity (congruence between claims about the data and reality; Strauss & Corbin, 1990). Afterward, the research team categorized and counted the themes that were then presented to the CAB to discuss the intervention adaptation. The credibility of the data to accurately represent the perceptions of the women were supported by rigorous field notes, transcribed FGSs, and discussions of the findings with the CAB (Nyamathi, William, et al., 2011)

## RESULTS

### Sociodemographics

The mean age of the intervention WLA was 32.6 ( $SD = 6.2$ ). The majority had completed less than a high school education (94%), and three-quarters

reported being employed. The majority of the women were widowed (56%), while five (31%) were married and two were separated. All the women reported having children; the average number of children was 1.8. The participants shared a broad range of topics that were categorized into four salient themes: (a) importance of tangible support, (b) need for social support, (c) ongoing challenges to accessing HIV treatment, and (d) perspectives on future programs. Taken together, the information gathered from the focus groups and presented by the researchers permits an understanding of participants' perspective on future intervention programs.

### The Importance of Tangible Support

*Nutritional and financial support.* The majority (88%) of the participants expressed appreciation for the program's emphasis on nutritional support. Participants verbalized the importance of receiving both *knowledge* regarding nutrition, as well as the *nutritional supplements* given to them by the program in the form of local staple foods, namely, channa dal, black gram, oil, and pigeon peas. Participants were clear that the value of the food was important for their health, as one woman stated:

My hope of surviving was very less; but after attending group meetings, receiving nutrition supplement (channa) from you, and also the money you provided, with which I could buy more nutrition supplements, I have gradually gained CD4 count and weight.

Another participant shared her perspective: "Nutrition supplements [were] another big help for me. I received black gram, pigeon peas, oil and money, which helped me to gain weight and health." Another participant expressed that the best part of the intervention was the nutrition supplements.

While relatively fewer participants spoke about the benefit of receiving knowledge regarding nutrition, three participants noted the utility of nutritional knowledge as another specific benefit of the program. In particular, one woman stated, "Basic nutrition counseling helped me to select low-cost and highly nutritious foods."

About one-third of the WLA perceived financial support in the form of regular monetary installments provided during the course of participation in group sessions, and after completion of questionnaires over the 6-month program, to be beneficial. For one woman, money was helpful because it allowed her to buy additional nutrition supplements.

*Medical support and testing.* Participants enrolled in the AL program received enhanced support to engage regularly with a medical support team composed of physicians, nurses, psychiatrists, and psychologists. Close to half of the WLA highlighted the value of medical support. One woman shared her perspectives of the support she received by the medical support



team: “When I [was] very sick on the bed, the project physician and you team saved my life by providing good treatment needed.”

Participants were also provided with information regarding types of laboratory testing. Such testing provided in the program included CD4, hemoglobin, and urine analyses. In addition, the women voiced appreciation for both the knowledge pertaining to testing and opportunities for testing, as one woman shared:

I never knew or understand [understood] that so many blood tests exist [existed] in the hospital; only by being [a] participant in AL, I could learn that [there are] so many tests I [can] get for myself from [the] DH or other sources.

Another woman indicated to her peers that she “liked the BMI . . . check-ups done in the intervention,” while another woman reported that “all [the] blood tests were very useful to evaluate [her] health condition.”

*Group and life skills classes.* In the AL program, WLA attended six group classes that focused on learning about HIV and AIDS, the importance of adherence with ART, parenting skills, improved coping strategies, and the benefits of spirituality:

One woman clearly verbalized what she gained from the classes:

I learned the things which I didn't know before. I learnt about being a good or best parent to my kids in bringing up them properly. Now my kids are at a government school.

Information regarding the importance of consistent adherence to ART was also provided in the program. More than half of the participants spoke about the positive impact this information had on their health, as one woman stated: “The ART information and adherence to it helped me to gain weight.” Another women, as well, mentioned how “timely ART medication,” and understanding the “importance of ART,” led to better overall health.

Another woman shared the following:

The group meeting information helped me to face all challenges related to AIDS. Asha [were] also was very cooperative. I am not thinking that I am AIDS patient. I just feel like [a] normal person.

The life skills classes offered WLA a chance to learn about and practice skills in areas in which they could continue to have a sustainable income to feed themselves and their families after the program ended. About one-third (38%) of the participants shared their views of these classes.

For one woman, life skills had a significant impact on her life: “Life skills helped me to become a good tailor and I am earning Rs.2000/- per month income by stitching blouses and dresses in a nearby shop.”

### Need for Social Support

*Support from Asha.* A number of women spoke about Asha support as a positive aspect of the program. One woman emphasized the companionship provided to her by her Asha: “[My] Asha gave me emotional support; she treated me like a friend and family member. She gave me the strength to live.”

Other women also spoke about the value in feeling as though the Asha working with them were a friend or family member offering emotional support. For example, another woman shared: “Asha and other WLAs in the study became best friends.”

Several women highlighted the benefit of Asha collaboration with other practitioners in their medical support network. One WLA shared her experience: “The psychiatrist’s help was very helpful, when my son expired. You, Asha and the psychiatrist . . . helped me to overcome grief of my son’s death.”

While the home visit aspect of the program was noted as an initial source of stress by a few women, the Asha became a critical part of their lives. One woman professed, “In the beginning there was a little embarrassment, but later on she became my best friend.”

*Support of other women living with AIDS.* Several women cited social support fostered by the group sessions as a powerful and transformative feature of the program. Specifically, women appreciated the therapeutic value of identifying commonalities within the community of WLA who participated with them in the program. The WLA valued the friendships and community support they gained through meeting other women in the program, as summarized by one woman: “I could get so many friends in the group session which gave [me] emotional strength and happiness. . . . I was not alone. I learnt about many things which I didn’t know before.”

### Ongoing Challenges to Accessing HIV Treatment

*Social and physical barriers.* Regardless of program attendance, former WLA easily recalled HIV-related stigma as an ongoing challenge or barrier to accessing HIV treatment. Three women identified experiences with stigma related to their HIV status as a reason why they were disinclined to access treatment at their local PHC site. For example, one woman shared that she felt “shame and guilt” when receiving treatment at her PHC, while another

women voiced, “I feel [felt] stigmatized when my relatives and friends of village know my HIV status.”

Conversely, another woman indicated that in her experience, HIV-related stigma had not been a barrier to HIV treatment, “I am comfortable visiting PHC because I do not fear disclosing my HIV status.” Two women also identified the cost and time invested in travelling to their PHC site as a barrier to receiving regular treatment.

*Systemic barriers.* In both focus groups, women cited negative experiences and limitations within the medical system as a barrier to sustaining or accessing treatment. In particular, 10 women shared that practitioners at their PHC site had displayed apathy toward their experiences, or they had engaged in overtly abusive behavior. One woman’s account captured the extent of verbal and physical abuse:

Doctors and counselors at DH (District Hospital) [treated] me with disrespect. They throw [threw] the ARV books . . . [at me] . . . saying I will die soon. They never listen [listened] to my health problems.

Multiple women, in fact, shared similar disheartening accounts including providers “occasionally shouting loudly [at me] . . . in front of other patients.”

Concomitantly, several women voiced that they were met with an attitude of disregard when interacting with their practitioners, as one woman related:

They [providers] do [did] not listen to our health problems [such as] OIs (opportunistic infections) or side effects. Except for providing ART medications, they are not doing any help to us [were not helping] or listening to us or hearing anything.

Other women noted the lack of availability of sufficient counseling services as a weakness in the system.

### Perspectives on Future Programs

*Additional nutritional support.* When asked what they would appreciate in future programs, about two-thirds of the AL women indicated that life skills and nutritional support should be a continued component of the program. According to one woman, “Life skills and nutrition for long time [are needed]. Persons living with AIDS mainly need good nutrition. Nutrition plays important role in their life.”

Several additional women proposed that future programs should provide further training in life skills such as tailoring and small business management.

*Support for children.* Across both groups, women voiced a shared sentiment that future programs should include additional provisions in support of their children. Aside from nutritional support, women suggested that the program could include support for the education of their children, as one woman admitted:

For our children . . . help is needed. Some children are going to school and some are not going, so two different plans are required for the kids at school and kids at home.

Another woman voiced a common perspective: "In the government school, they are not getting good education; I want to send my kids to good private school."

Further, medical support for their children was also considered to be of value.

## DISCUSSION

In the present focus group study, the authors explored the perceptions of the WLA to develop a richer understanding of the impact of a 6-month Asha-Life (AL) intervention that enrolled rural WLA between 2008 and 2011. A number of themes surfaced during the focus group discussions. These included the following: (a) importance of tangible support, (b) need for social support, (c) ongoing challenges to accessing HIV treatment, and (d) perspectives on future programs. The focus group participants identified many benefits gained from the program.

Primarily, WLA appreciated the nutritional supplements that were offered during the program. Anand and Puri (2013) likewise found that lack of access to proper nutrition is a critical life issue in India. These author findings were also consistent with those of other authors in which mothers living with AIDS could not afford essential nutrition (Nyamathi, Sinha, et al., 2013). These authors also revealed the perception of the women that providing financial support to the AL women, specifically to purchase the needed nutrition, was very beneficial. Duraisami and colleagues (2006) reported the financial burden faced by individuals living with HIV/AIDS living in Southern India, a burden that was also shown to advance the progression of disease.

Participants addressed the impact of the group sessions in fostering social support and gaining knowledge about disease-related information. Other authors have shown that persons who have knowledge about the disease often have reduced stigma, which is pervasive, and related to misinformation about cause of disease and transmission (Nyamathi, Sinha, et al., 2011). Further, WLA who learn life skills in targeted classes can ensure a stable source of income. Programs designed by health care providers that train individuals living with HIV in activities to improve their income was similarly an

essential aspect in other studies based in India (Duraismy et al., 2006) and South Africa (Visser, Mundell, de Villiers, Sikkema, & Jeffery, 2005).

In terms of the group sessions, WLA reported a benefit in their adjustment to the disease and related challenges. Not only did they value information, but they gained a benefit of added social support through interactions with women who were facing similar challenges. This new-found source of social support by the WLA was an unexpected long-lasting benefit. Likewise, South African women living with HIV emphasized the benefits of the group sessions on learning positive coping skills and attaining emotional support and self-acceptance (Visser et al., 2005).

Poor ART adherence among HIV-infected Indians is partially due to insufficient knowledge about the consequences of nonadherence (Anuradha et al., 2013). Another key finding noted by the authors is that the program raised the knowledge level of the WLA about the importance of ART and the value of adherence to treatment. Anuradha and authors (2013) demonstrated that positive beliefs about the impact of treatment strongly facilitate adherence to the drug. Moreover, by being aware of cultural and demographically related barriers to ART adherence, appropriate strategies can be fostered by other researchers to improve ART adherence among persons living with HIV in India (Ekstrand, Chandy, Heylen, Steward, & Singh, 2010; Ekstrand et al., 2011). For example, Patel and colleagues' study of combination therapy in Gujarat revealed that understanding of the barriers and facilitators was necessary to overcoming the challenges, such as commuting to the clinic, high cost, and fear of physical reactions to treatment adherence (Patel et al., 2012).

Mothers living with HIV in rural India are in desperate need of psychological support that helps them to cope with the disease (Joseph & Bhatti, 2004). Women living with AIDS (WLA) in rural India face several challenges that negatively impact their health, including stigma, depression, and parenting-related issues. Those women who participated in this study expressed their experience living with stigma and mistreatment in their homes, villages, and medical clinics. The frequency and commonality of this experience of stigma has likewise been faced by other WLA in India and in other studies (Ekstrand, Bharat, Ramakrishna, & Heylen, 2012; Ekstrand, Ramakrishna, Bharat, & Heylen, 2013; Nyamathi, Ekstrand, Salem, et al., 2013; Nyamathi, Ekstrand, Zolt-Gilburne, et al., 2013; Thomas, Nyamathi, & Swaminathan, 2009). Unfortunately, these women limit their utilization of health care services due to the stigma, discrimination, and denial of care from health care providers (Nyamathi, Ekstrand, Salem, et al., 2013; Nyamathi, Ekstrand, Zolt-Gilburne, et al., 2013).

Similar to South African women living with HIV (Visser et al., 2005), the participants in the present study reported improvement in their mood and their feelings of self-efficacy and a reduction in their sense of social isolation as a result of Asha support, the group sessions, and life-skill classes. The impact of the program on the physical health of WLA was also reported by

the women in terms of CD4 counts and body weight and concur with other research studies (Nyamathi, Hanson, et al., 2012; Nyamathi et al., 2012).

The authors' findings are limited to rural WLA who previously participated in the Asha-Life intervention in AP; thus, the authors are unable to generalize to other populations outside of this local area. Further, the continued development and the role of Asha are necessary because many of the program participants described support that was gained from their interactions. Ongoing challenges that WLA face in accessing HIV treatment include social and physical barriers, along with systemic barriers experienced from providers. Finally, the WLA were very concerned about the future of their children. Parenting classes were considered a benefit of the AL program because the classes focused the women on supporting the children for a better future. Thinking ahead about improved schools for their children was one such hope of the WLA for a better future. Health care professionals can utilize the study findings to tailor future programs for mother-child dyads, which will provide additional nutritional supplements, support children's education, and reduce barriers to ART medication adherence in similar rural international settings. Additional strategies such as including microfinance programs, medical support, clinical testing, and group and life skills classes would further optimize these programs for WLA.

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