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Women living with AIDS in rural Southern India: Perspectives on mental health and lay health care worker support

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Abstract

In this study, focus groups were conducted with 16 rural Women Living with AIDS (WLA) from Andhra Pradesh, India who had previously participated in a clinical trial wherein 68 WLA were randomized into either an Accredited Social Health Activists (ASHA) – Life (AL) intervention or a Usual Care program. Findings are discussed in terms of: a) mental health issues, b) perceived stressors, c) individual resources for coping with mental health issues, and d) role of Asha support in coping with mental health issues. These findings highlight the salience of mental health issues in the lives of WLA and the role played by Asha in addressing some of these issues. The discussion section makes a case for increased emphasis on mental health care in future community-based interventions for this population.

Keywords

AIDS; Mental Health; Women; India; coping resources

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INTRODUCTION

As of 2015, estimates of HIV prevalence in India reported by the National AIDS Control Organization (National AIDS Control Organization, 2015) indicated a rate in the range of 26%. In absolute terms, this statistic suggests that between 1.7 and 2.6 million people are living with AIDS in India (National AIDS Control Organization, 2015). This represents a decline of 0.28% since 2012. Despite the overall decrease in HIV prevalence in India, there exist regional and cross-sectional disparities in HIV prevalence trends. To illustrate, while high prevalence states such as Tamil Nadu have experienced a marked drop in HIV prevalence, Andhra Pradesh maintains its position as one of the four states deemed as “high” in HIV prevalence (Choudhury & Prabakaran, 2015; National AIDS Control Organization, 2015). Furthermore, 60% of India’s HIV affected population lives in rural areas (National AIDS Control Organization, 2013).

Though research thus far has indicated high HIV prevalence rates among sex workers, long distance truck drivers, men having sex with men, and injection drug users, married women are increasingly at high risk (Mothi, Lala, & Tappuni, 2016). The majority of new HIV cases in India – 87% – are a result of heterosexual contact (Mothi et al., 2016). However, routes of transmission for heterosexual men and women are distinct. While risky sexual behavior, such as having multiple partners is associated with HIV transmission in the adult male population, the majority of adult WLA in India contract the virus through one of two paths: having a monogamous sexual relationship with a husband who has engaged in unsafe sex outside of marriage, or engaging in sex work (Chakrapani, Newman, Shunmugam, & Dubrow, 2010; Mothi et al., 2016).

The experience of HIV is gendered from the point of contraction through the course of the illness. WLA in India are less likely than men to access and adhere to ART due to financial constraints (Tarakeshwar et al., 2006). Additionally, they face unique forms of stigma: married WLA in India commonly report harassment from in-laws as they are held responsible for their husband’s HIV infection (Bharat, Aggleton, & Tyrer, 2001). Lower levels of education and limited mobility, as compared to that of men, compound the impact of gender on access to support and adherence to treatment (Nyamathi, Salem, Ernst, et al., 2012). An examination of women’s needs in this context, separate from those of men, is necessary.

Comorbid psychological problems among individuals living with HIV in India are consequential for several reasons. Firstly, a wide body of literature posits that mental health issues such as depression and anxiety influence the HIV illness trajectory through multiple pathways including suppression of the immune system, diminished adherence to anti-retroviral therapy (ART), increased sexual risk behavior, and deteriorated quality of life (Kemppainen et al., 2012). These outcomes bear social ramifications. For example, studies suggest that increased sexual risk behavior and lower adherence to ART are factors tied to the spread of HIV (Global Initiative on Psychiatry, 2006). Studies in the United States (US) indicate that mental illness in conjunction with an HIV diagnosis is also associated with greater hospital visits and increased needs post-discharge (Cheng, Mijch, Hoy, Wesselingh,

& Fairley, 2001). This is of particular concern in rural India, where medical systems which are already highly strained.

Studies assessing prevalence of depression among HIV-affected individuals in several Western countries report high rates: 42% of women in the HIV Epidemiology Research Study (HERS) indicated symptoms of chronic depression, while 50% of HIV positive women in the Women's Interagency HIV Study (WIHS) were found to have symptoms of clinical depression (Ickovics et al., 2001). Recent studies in India have noted similar trends – Selvaraj, Ross, Unnikrishnan, & Hegde, (2013) reported that 49% of adults living with HIV in India experience symptoms of clinical depression. Among WLA in India, a depression prevalence of 54.4% was reported at baseline (Nyamathi et al., 2011).

Research in Western contexts indicates that anxiety, as well, is a prevalent and concerning phenomenon among people living with HIV. For example, in an international, multi-site study conducted by the International Network of Nurses, findings revealed that 44% of adults in their sample reported anxiety symptoms (Kemppainen et al., 2012). Further, evidence points towards an increased risk of suicidal ideation and completed suicide among individuals affected with HIV. Studies in the US have indicated an increase in risk for attempted suicide in adult HIV-affected population in the range of 13.3% to 18.9%, as compared to risk for attempted suicide in the general population (Schlebusch & Vawda, 2010).

It is worth mentioning that women in India experience internalizing mental health disorders, such as depression and anxiety, at approximately 2–3 times the frequency observed in the male population (Thara & Patel, 2001 p 24–25). Further, India is one of two countries where rates of completed suicide are higher among adult women than men (Malhotra & Shah, 2015). It is clear that women in India face significant vulnerabilities towards mental illness; an investigation into the mental health of WLA in India, who are subject to unique and severe forms of abuse and stigma, is certainly worthwhile (Mothi et al., 2016).

Inadequacies of the health care system in India largely leave the mental health needs of WLA unmet. Health service use among WLA in India is generally limited due to challenges such as lack of resources and barriers to mobility, as well as due to negative experiences within the health care system such as refusal of providers to administer services (Nyamathi et al., 2016; Women of the Asia Pacific Network of People Living with HIV, 2012). Further, available health services are grossly limited and largely confined to urban areas (Das & Leibowitz, 2011).

Accordingly, community-based interventions that train lay health care workers to provide emotional and practical supports play a critical role in serving the mental health needs of WLA in rural India. In this qualitative study, women who participated in such a community-based intervention were interviewed about mental health issues they faced and the support they received from Asha, or lay health care workers trained to assist them.

Within focus groups, women discussed their experiences with mental health issues, the factors they perceived to influence mental health, and strategies they employed in addressing their mental health needs. Additionally, the WLA shared their perspectives on working with

Asha, thus shedding light on lay health care workers' role and impact in helping this population cope with psychological distress.

Though literature exists on the prevalence of mental health issues among people living with HIV/AIDS in India, there is limited research on how this population copes with psychological distress. Further, though the ASHA-Life intervention has been evaluated in previous studies, there is no research on how this and other community-based interventions are experienced specifically in terms of their impact on mental health. It is hoped that participants' subjective accounts in this study may help in developing future interventions that are grounded in WLA's perspectives on their mental health needs and what they feel is helpful to their coping process.

The Comprehensive Health Seeking and Coping Paradigm (CHSCP; Nyamathi, 1989) was used to organize variables of interest presented in this paper. The CHSCP incorporates the thoughts and behaviors individuals rely on to overcome threats to health, life crises, and to retain or attain optimal health. Additionally, it includes situational factors, such as environmental constraints, which may impact the coping process. This paradigm was deemed most appropriate in guiding the literature review as it encompasses a broad range of coping strategies directed towards dealing with significant health issues, such as HIV/AIDS. Further, it is client-centered and culturally sensitive in that it recognizes coping to be a transactional process mediated by environmental, social, and personal influences.

METHODS

The aim of this study was to explore perspectives of WLA on their mental health and the role and impact of Asha support on mental health after participation in a community-based intervention that aimed to improve health outcomes among WLA. Accordingly, participants were asked about their mental health needs and experiences and their perspectives on what in particular about Asha support was helpful to participants in coping with ongoing mental health issues.

Asha-Life Intervention

The AL intervention was a six month, culturally-sensitive intervention delivered by rural village Asha supported by community physicians and nurses. In 2008, the NIH-funded Nyamathi and her team to provide HIV training for village women to function as Ashas at the village level to promote long-term ART adherence and health outcomes of WLA in Andhra Pradesh, a high HIV/AIDS prevalent state in India. Ashas were carefully supervised and supported by research staff, local nurses and physicians. They were trained to assess and overcome barriers to optimal ART adherence by accompanying WLA to receive their ART, providing transportation, enhancing social support and knowledge of HIV/AIDS progression, and delivering monthly supplies of basic protein supplementation to WLA. The intervention, named Asha-Life (AL), was delivered in eight group sessions, which lasted for 60–75 minutes. The study was approved by the University of California Los Angeles (UCLA) Human Subjects Protection Committee, the Indian Ministry of Health, and the All India Institute of Medical Sciences (AIIMS) ethics committees.

Design

Data collection and analysis in this study was conducted within a Grounded Theory framework. Grounded Theory advocates for the development of theory from qualitative data grounded in participants' perspectives, rather than drawing testable hypotheses from existing theories.

Though grounded theory guided the collection and analysis of data, the CHSCP was used to analyze and frame results in the discussion. Thus, this study did not employ a 'pure' grounded theory design. An existing theory was used for several reasons. For one, the data upon which this study was based was collected from a very small sample – 16 WLA. Thus, a coherent theory may not be developed based on this data. Secondly, it is hoped that by analyzing findings within a framework that is understood by a wide audience of multi-cultural researchers, the findings from this study will have greater translatability. Additionally, it is hoped that discussing the extent to which findings fit within the CHSCP will help highlight characteristics of the coping and health seeking process that are unique to the context of rural India.

Formation of a Community Advisory Board

A Community Advisory Board (CAB) was formed to guide the development of a culturally-sensitive, semi-structured interview guide (SSIG). The CAB was composed of three WLA who received the AL intervention, and 14 other members. These included former HIV-trained Asha, and experts in each of the following areas: HIV, nutrition, mental health, child development, and nursing.

The CAB members met for two hours over two sessions. They developed an SSIG which focused on the environmental, psychosocial, and cultural impact of the AL program on the lives of the WLA. Key questions included: What did you like most about the Asha programs?; How does depression affect your life?; and What do you do to make yourself feel better when you are depressed? This CAB was also involved in the facilitation of the focus groups, and subsequent interpretation of findings. See Appendix 1.

Participants and Setting

WLA who had participated in the former AL intervention were contacted by the Indian-based project director and invited to participate in the focus groups. Among the former AL participants (N=34), three were selected to participate as members of a CAB as described below. Another six 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. Participants were collected into one of two focus groups, each comprised of 8 women. Each focus group met for a session which lasted two hours.

Focus groups were used to give voice to the subjective experiences of WLA. Focus groups were deemed appropriate for this study as qualitative assessment allowed the women to express their feelings in their own voice. In India, mental illness is typically only diagnosed and treated in cases of severe presentation, such as psychosis and dementia (WHO/PAHO,

2010). More common forms of psychological distress, such as depression and anxiety, are typically processed in local, culture-specific terms which may not be reflected in diagnostic tools developed in the West (Weaver & Kaiser, 2015). Thus, qualitative methods, specifically the use of focus groups, were preferred over quantitative methods that have been used in previous studies so as to allow participants to describe their mental health issues and resources for coping in their own terms.

Data Collection

Upon re-establishing contact, the researchers informed the former WLA about the proposed study. After questions were addressed, informed consent was signed. Two focus groups were conducted in accordance with the SSIG developed by the CAB. The groups were facilitated by a trained project director, along with two of the Principal Investigators (PIs) of the study. Groups were conducted in Telugu, the local language. The group sessions were audio recorded and subsequently translated into English. At completion of the focus group session, the women were compensated 592.1 Indian Rupee (INR) equivalent to \$10.00 US dollars (USD).

Content Analysis

A rigorous and systematic process of content analysis (Strauss & Corbin, 1990) was conducted on transcriptions of the focus groups. The data used in this study were coded independently by the author of this paper under direct supervision of the PI. Manual methods were used to manage the data. This data analytical process was inductive in nature and entailed counting and categorization of data. Specifically, content analysis encompassed a process of line by line coding, wherein each line of transcription was treated as the primary unit of analysis.

The first stage of content analysis entailed open coding, where each line of data was attached with as many codes as were relevant. Related codes from both focus groups were grouped into families. Subsequently, families of codes were grouped together to develop themes.

Initially, families were grouped into three broad themes: 'providing a descriptive account of a mental health issue,' 'discussing sources of stress,' and 'discussing resources for coping.' In order to highlight the unique role of Asha support, codes concerning WLA's perspectives on Asha support as a resource for coping were categorized into a separate theme. Quotations were selected for inclusion in the results section on the basis of their nuance and complexity.

Certain features of the process of data collection and coding may impact the rigor and credibility of results discussed here. In particular, a significant limitation of the data is that it was translated into English from Telegu (the native language of participants in this study). As the transcripts were translated into English by a local translation service in India, the PI and author of this paper have only engaged with the English transcripts of the interviews. These transcripts thus bear the risk of misrepresenting or reframing the experiences of participants in that certain culture specific nuances in expression may be lost.

The first author of this paper, who also conducted the process of content analysis, is a female graduate student who lived at one time in India. Accordingly, content analysis was

conducted from the perspective of a South Asian woman who identifies with certain aspects of the broader cultural context within which this study was located – for example, gender based discrimination and stigma associated with illnesses such as HIV. However, this data was largely interpreted and coded from an outsider’s perspective.

Sociodemographic Measures

The following socio-demographic factors were assessed: age, birthplace, marital status, education, number of children, and religious affiliation. Frequencies, percentages, and means were calculated to describe these sample characteristics.

RESULTS

The women’s discussions surrounding mental health broadly pertained to the following three themes: a) mental health issues, b) perceived stressors, c) individual resources for coping with mental health issues, and d) role of Asha support in coping with mental health issues.

Sociodemographics

The mean age of the 16 participants 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.

Mental Health Issues

Mental health issues emerged as a salient theme across topics of discussion. Women spoke about their mental health both in response to questions directly pertinent to psychological issues, as well as in the context of other discussions, such as family and relationships. We use the term depressed mood to capture women’s experiences with sadness and low mood. Three mental health issues, in particular, resonated across women’s experiences: depressed mood, anxiety, and suicidal ideation.

Depressed Mood—In both focus groups, women were asked to describe their personal experiences with sadness or feelings of depression prior to their participation in the AL study. Out of 16 women, 9 (57%) responded to this question, sharing subjective accounts of mood consistent with experiences of depression in the general population. One woman expressed her feelings at that time as follows:

“I feel why should I live in this world, or for what am I living? Sometimes I am completely down, depressed emotionally. Sometimes I have feeling of even killing myself or committing suicide.”

Another woman said she had “...always felt depressed with this disease.” When asked to describe her experiences, a third woman said that she “... [could] not express [it] in words as that feeling is very difficult to bear.”

Anxiety—Anxiety is characterized (and distinguished from depression) by worry surrounding future events or uncertain outcomes (American Psychological Association,

2014). While anxiety was not explored in isolation from depression, several women did report feeling anxious, particularly with regard to the well-being of their children. For example, when discussing how HIV has impacted her children's lives, one woman shared:

“I fear what will happen to them when I am not there in this world. I feel my kids are fatherless kids because of the disease, [and] I am a widow.”

In the same vein, another woman voiced that she “...feel[s] mentally depressed whenever she [thinks] about her daughter's future life.”

Suicidal Ideation—Though the women were not directly questioned with regard to suicidal thoughts or feelings, a little over one-third (35%) of the women reported feelings of suicidal ideation as a feature of their depression prior to the start of the AL study

One woman expressed:

“My mental illness affects my physical health; [I] felt like committing suicide.”
Another woman shared how mental illness and suicide had touched not only her own life, but that of her husband: “My husband died committing suicide because he too suffered mental illness. I also feel the same way.”

Yet another woman articulated concrete suicidal thoughts: “I feel like taking some sleeping pills or eat some things to end my life.”

Perceived Stressors

The following are three major factors women reported as being significant sources of emotional distress prior to participation in the AL program. It is of note that the women were not directly questioned with regard to perceived triggers or sources of stress. Rather, these themes were gleaned from the course of general discussion surrounding topics such as experiences within medical settings, the impact of Asha support, and concerns regarding the experiences of children.

HIV-Related Stigma—Experiences of being isolated or discriminated against due to HIV-related stigma were common among the women, and typically associated with stress and other depressive symptoms. Women reported discrimination due to their HIV status in multiple settings, including the family, community/village, and medical institutions.

For example, one woman shared that she felt “shame and guilt” when receiving treatment at her Primary Health Care (PHC) site, while another woman voiced: “I feel stigmatized when my relatives and friends of the village know my HIV status.”

Approximately one-third of the women revealed that their own families had isolated or excluded them due to the stigma associated with their HIV status. One woman shared her painful story:

“For me, neighbors are relatives. When I visit occasionally, my husband's side of the family never respects me well. My husband's sister throws a plate on my face and keeps me away from everything.”

Two women shared that while they were included by their own families in family events, their husband's families excluded them from social gatherings. Such experiences of isolation were cited as a source of distress for all the women.

Abuse within the Medical System—Several women reported negative, abusive experiences within the medical system as a source of stress. In particular, almost two-thirds of the women shared that practitioners at their PHC site had displayed apathy towards their experiences, or had engaged in overtly abusive behavior. One woman's account of her experience at the District Hospital (DH) captured the extent of verbal and physical abuse and the impact it had on her:

“Even I experienced bad treatment at the DH. I felt very depressed when Doctors and counsellors at the DH treated me with disrespect throwing ART books ... (at us) and occasionally shouting loudly ... in front of other patients.”

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

Additionally, several women voiced that they were met with an attitude of disregard when interacting with their practitioners. According to one woman:

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

Concern for Children—Women's feelings of depression, anxiety, and suicidal ideation, were commonly linked with concerns regarding the well-being of their children. More than half the women reported that their mental health issues were directly tied to, or exacerbated by concern for their children.

For example, one mother shared: “I cry sometimes when I am not able to provide enough food for them or when they are sick.” Another had similar feelings:

“I feel bad and cry sometimes when I am unable to protect them from opportunistic infections or diseases.”

A third woman voiced concerns about resources available to her children and their treatment within the community:

“I have AIDS and other children are living with healthy parents. I feel my children are not receiving equal status in the community. There is lot of difference between my children and other children, our children are weaker health wise and sometimes depressed also.”

Individual Resources for Coping with Mental Health Issues

Religious Beliefs and Practices—When asked in a direct question how they coped with their depressed mood, seven of the nine women who reported experiencing depression shared that they coped by relying on their religious beliefs and practices. It is important to note that the women were not asked when they started to draw upon spirituality as a coping

resource – thus, it may not be assumed that this practice is an outcome of the AL intervention. However, given that a significant number of women cited religious beliefs and practice as a significant and potent tool for coping, they are discussed here. As one woman said:

“I think of God’s help and spirituality whenever I am depressed and I always end up feeling lighter in my heart.”

Others shared similar experiences. “I think of God and pray for the mental strength,” said one. Another expressed that “Praying to God helps and visiting church satisfies and fills my heart with peace.”

Role of Asha Support in Coping with Mental Health Issues

Social Support—Once enrolled in the AL program, several women cited the social support fostered by the group sessions as a powerful and transformative experience. 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.

This was summarized by one woman:

“...I could get so many friends in the group session which gave emotional strength and happiness [so that I felt] that I was not alone. I learnt about many things which I didn’t know before.”

Another woman’s experience was similar:

“The group meetings gave me the strength and courage to live and fight AIDS-related challenges.”

Emotional Support & Friendship—A number of women spoke about emotional support and friendship provided by their Asha 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 WLA in the study became best friends.”

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 in Navigating Medical System—Several women highlighted the benefit of Asha collaboration with other practitioners in their medical support network. As one WLA said:

“The psychiatrist’s [support] was very helpful, when my son expired. You, Asha and the psychiatrist... helped me to overcome grief of my son’s death.”

DISCUSSION

The data which this paper draws upon emerged from focus groups discussing women’s experiences one-to-two years after enrolling in the AL intervention. Mental health was a recurrent theme across discussions, reflecting the importance of this issue in the lives of the women interviewed. Further, the discussions gave voice to how the ASHA intervention was experienced by the WLA, particularly in terms of the intervention’s role in supporting women’s coping with mental health issues and perceived sources of stress.

The CHSCP Model helped organize findings. Focus group data revealed two situational factors which may impact women’s coping process prior to the Asha intervention: HIV-related stigma and abuse within the medical system. Discussions also highlighted one social resource, concern for children and family, and one personal resource, spirituality, that may influence women’s cognitive appraisal of their situation, and, in turn, their health outcomes and coping behaviors.

In terms of the CHSCP paradigm, the Asha intervention may provide WLA with additional social resources in the form of community support fostered during group sessions and additional personal resources in the form of individual emotional support, friendship, and advocacy provided by the Asha. Thus, based on the results discussed in this paper, the Asha intervention broadened and strengthened social and personal resources available to WLA, such that the women experienced the intervention as a positive influence on their ability to cope with psychological distress, such as depressed mood, anxiety, and suicidal ideation, that was experienced prior to the intervention. The impact of the Asha intervention on specific coping behaviors and mental health outcomes deserves further examination.

Social support, or support from other WLA’s in the study, was cited by the majority of women as a powerful coping resource introduced by the AL intervention. There are multiple studies that indicate social support to diminish risk for depression among individuals affected with HIV (Klein, Elifson, & Sterk, 2008; Simoni, Pantalone, Plummer, & Huang, 2007). However, a study conducted by Jagannath et al. (2011) in Mangalore, India, found no significant relationship between social support and depression in their sample.

Jagannath et al., (2011) surmise that this may be due to most Indians receive adequate social support from their families, as stipulated by cultural norms. It is worth mention that two-thirds of the sample was comprised of men. It may be that women in rural India, being the providers of social support, receive less support than men on average. Concomitantly, it may be that women have a higher need for social support. An examination of the kind of social support and resources available to WLA in everyday life may help in understanding its value and need in this context.

Participants’ recognition of emotional support, friendship, and support in navigating the medical system offered by Asha’s as a significant resource in the coping process parallels WLA’s accounts in other assessments of the impact of the AL intervention (Nyamathi,

Ekstrand, Salem, et al., 2013). Additional evaluations of the outcomes of the study have ascertained that Asha support is associated with decreased depressive symptomology, diminished internalized stigma, and reduced avoidant coping behavior among women affected with HIV in Andhra Pradesh (Nyamathi, Ekstrand, Salem, et al., 2013; Nyamathi, Salem, Meyer, et al., 2012).

Turning to religion as a coping strategy channels similar trends that have been reported in international research. Multiple studies report spirituality as an efficacious and powerful coping resource for HIV affected women (McCormick, Holder, Wetsel, & Cawthon, 2001; Sowell et al., 2000). Further, recent research advocates for the integration of spirituality into therapeutic interventions for this population due to its association with positive mental health outcomes (Dalmida, 2006).

The perceived sources of stress discussed by the women – HIV related stigma, concern for children, and abuse within the medical system – reflect challenges experienced by individuals diagnosed with HIV regardless of cultural and social context. A wide body of research posits HIV-related stigma as a major source of stress for individuals affected with HIV from diverse backgrounds (Ekstrand, Ramakrishna, Bharat, & Heylen, 2013; Nyamathi, Ekstrand, Salem, et al., 2013; Nyamathi, Ekstrand, Zolt-Gilburne, et al., 2013). This being said, stigma may be a particularly imposing challenge when it operates in conjunction with lack of HIV knowledge and scarce resources, as is the case in rural India.

The women's accounts of abuse within the medical system align with the concept of 'enacted stigma,' a category of stigma within Steward et al. (2008) framework which characterizes stigma related experiences of HIV affected individuals (Steward et al., 2011). 'Enacted stigma' refers to "overt and personally experienced instances of hostility and discrimination" (Steward et al., 2011), such as those described by the women within their healthcare settings. Studies have found a positive association between enacted stigma and avoidant coping behaviors such as avoidance of HIV status disclosure (Nyamathi, Ekstrand, Salem, et al., 2013); avoidant behavior, in turn, is known to bear association with negative mental health outcomes (Steward, Bharat, Ramakrishna, Heylen, & Ekstrand, 2012; Steward et al., 2011). In this study, several women reported avoiding particular health care sites after personal experiences with abuse in these settings.

Women's reports of stress tied to concerns over the well-being of their children may be expected when situated within the cultural context of rural India. Studies conducted in India reveal that mothers affected with HIV face multifarious challenges, including inheritance issues, barriers to education access for their children, and discrimination within maternity wards (Thomas, Nyamathi, & Swaminathan, 2009). Further, several researchers such as Bharat, Aggleton, & Tyrer, (2001) have found that women affected with HIV in India continue to prioritize their role as caregivers in the household, typically attending to the needs of their families before their own. Taken together, these experiences are associated with anxiety, avoidance of HIV disclosure, and diminished ART adherence (Nyamathi, Ekstrand, Salem, et al., 2013)

There are a number of studies that implicate depression and other mental health issues as a major concern for men and women affected with HIV across international settings. In a study assessing the prevalence rate of depression among HIV affected individuals on ART in India, (Bhat, Babu, & Abhishekh, 2013) found that almost one in two participants met the criterion for clinical depression. In a comparative study, Jagannath et al., (2011) found a markedly higher prevalence rate of clinical depression among HIV affected women (62.2%), as compared to HIV affected men (33.8%). It is not surprising that nine out of the 16 women interviewed reported symptoms that were typical of depression.

Women's reports of anxiety and suicidal ideation were consistent with experiences captured by multiple studies investigating the mental health of HIV-affected individuals. For example, in a seminal study conducted by Chandra, Ravi, Desai, & Subbakrishna (1998) in probing the psychological health of men and women affected by HIV in India, findings revealed that 36% of adults reported significant feelings of anxiety, and 14% reported serious suicidal intent. Taking into account the substantive literature that indicates higher rates of attempted and completed suicide among women affected with HIV as compared to the general population in the United States (Cooperman & Simoni, 2005), it is within reasonable expectations that a large number (6 out of 16) of the WLA interviewed in this study reported thoughts about suicide.

Implications for Future Interventions

In sum, these findings provide helpful insights for future community based interventions with WLA in rural India. First, given that this population reports substantive mental health concerns, along with the well-established notion that mental health is linked to the prognosis of HIV (Cooperman & Simoni, 2005), it will be of value for interventions to include programs that support women in coping with their psychological distress. This may be done in a direct manner by including groups that educate women about mental health issues such as depression, anxiety, and suicidal ideation. The focus may be on normalizing these experiences and providing women with simple and accessible coping strategies such as breathing and relaxation techniques which have been shown to provide relief from different forms of stress, as well as depression and anxiety (Brown & Gerbarg, 2005; Lazarus & Folkman, 1984).

It will also be beneficial to continue to encourage WLA to draw upon their religious beliefs as a coping strategy. A study conducted by Kemppainen et al. (2012) assessed that a spiritually based intervention wherein participants were allowed to select and practice 'mantras' was effective in helping HIV affected individuals manage stress. Given that a large number of women in the study reported religion as their primary source of strength, it may be helpful for Asha's to encourage WLA to recognize and draw upon their spiritual practices as a powerful and portable coping strategy.

The far reaching implications of stigma in the lives of WLA predicates the need for interventions to assist women in its confrontation. In their study, Steward et al. (2011; 2012) found that psychological distress associated with experiences of enacted stigma is mediated by internalized stigma, or the extent to which an individual endorses stigmatized notions of HIV. As a part of the AL study, Nyamathi, Ekstrand, Salem, et al. (2013) found that 66% of

the WLA they interviewed experienced internalized stigma. Thus, in addition to addressing sources of the abuse itself, which may lie at the intersection of multiple factors including stigma, lack of HIV knowledge, discrimination, competition for limited resources, and inadequate training; it is necessary for interventions to inculcate positive self-appraisal of one's HIV status among participants.

To this end, Asha may be trained to provide additional emotional support to the WLA. Recent research concerning therapeutic interventions for women of South Asian origin in the United States has advocated for approaches that focus on de-pathologizing psychological distress. That is, there is a movement towards therapeutic interventions for South Asian women that recognize their strengths, acknowledge the intersectional nature of their identity, and frame their psychological distress as a normal reaction to the challenges and discrimination they are presented with at multiple social levels (Ali & Lees, 2013; Tummala-Narra, 2013).

It is acknowledged that the experiences and needs of South Asian immigrant women in the United States and may not be parallel to those of WLA in rural India. However, there are similarities in that both populations are minorities, subject to multi-layered oppression, and face barriers in accessing healthcare. An approach wherein the therapist works as an ally in confronting contextual factors, such as stigma and abuse, in which women's mental health issues may be rooted, while honing the unique strengths and multi-dimensional identity of each woman, may well hold potential in working with WLA in rural India.

Limitations

A major limitation of the findings discussed here is that the language used to discuss mental health may not have captured all the unique experiences of the women regarding mental health problems. Further, given the stigma associated with mental health issues in addition to HIV, the group format of data collection may have inhibited many women or given rise to group conformity.

Additionally, in light of the stigma associated with mental health issues, it may be worthwhile for future research in this area to employ individual interviews, in addition to focus groups. Individual interviews enable privacy and minimize pressure to conform to group norms. However, the therapeutic function of focus groups should also be taken into consideration.

Implications for Future Research

These findings provide impetus and direction for future research that examines the mental health of women living with AIDS in rural India. Scope remains for greater nuance in examining coping strategies employed by women living with AIDS in rural India. An understanding of the situational antecedents of different coping behaviors may be helpful in tailoring interventions to the needs and existing patterns of women. Additionally, explication of the strengths and factors that may protect against negative mental health outcomes is imperative to developing a strengths-based approach to treatment.

While current findings have demonstrated helpful perspectives of the WLA in terms of participation in the AL program, these findings plus positive quantitative outcomes of the intervention now require expansion to include a greater understanding of the impact of Asha on improving both emotional and physical health of WLA and their families. If successful, this intervention could then be easily scaled up by integrating Asha training into current infrastructures of the Rural Health Mission of India.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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