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Correlates of Depression among Rural Women Living with AIDS in Southern India

Adeline Nyamathi, Anisa Heravian, Jessica Zolt-Gilburne, Sanjeev Sinha, Kalyan Ganguly, Yihang Liu, Padma Ramakrishnan, Mary Marfisee, and Barbara Leake

Abstract

While depression may be commonly experienced by persons living with AIDS, it may be challenging for health care providers to identify persons who are suffering from these symptoms, particularly if they are living in the more isolated rural areas of India. The purpose of this study was to assess correlates of depression among women living with AIDS in rural Andhra Pradesh. A total of 68 rural women living with AIDS (WLA) who were completed baseline data were assessed by means of structured instruments. Regression modeling revealed that disclosure avoidance and making at least six health care visits in the last six months were all associated with depression. Further, living with a spouse was associated with lower depressive symptom scores. Stigma was not found to be associated with depression. Understanding correlates of depression can lead the way to the designing culturally-tailored intervention that mitigates disclosure avoidance and improves the health of women. A more comprehensive health focus may be needed to empower the women to seek quality care for both physical as well as mental health symptomatology.

Keywords

Accredited Social Health Activist (ASHA); HIV/AIDS; Women; Depression

In India, women account for 40% of the almost 2.9 million HIV-positive persons living with HIV (NACO, 2008); the majority of these women share the common risk factor of being married to men who transmitted the disease to them via sexual activity. Depression is the most common psychiatric condition that afflicts persons with HIV (Chandra, Desai, & Ranjan, 2005). Among 51 HIV-seropositive heterosexual men and women living with HIV in South India, 40% met the criteria for depression listed in the Hospital Anxiety and Depression Scale (Chandra, Ravi, Desai, & Subbakrishna, 1998).

Depression and Living with HIV/AIDS

One of the important consequences of depression may be non-compliance to antiretroviral treatment (ART). In a study of HIV-positive men and women receiving ART in India, severe depression was associated with lower adherence (Sarna et al., 2008; Safren et al., 2005). While depression may be viewed as a normal reaction to HIV, barriers to recognition of depressive symptoms exist and include inadequate discussion between patients and health-care providers, and mistakenly attributing somatic symptoms of depression to HIV (Chandra et al., 2005). Thus, it may be challenging for health-care providers to identify persons who are suffering from depressive symptoms, particularly if they are living in the more isolated rural areas of India.

The purpose of this study is to investigate correlates of depression among women living with AIDS in Andhra Pradesh, the fourth largest state in India. These correlates include stigma and coping; sociodemographic factors, such as age and education; and clinical factors, such as number of clinic visits and length of time on ART.

Stigma and Avoidant Coping

HIV-positive individuals in India are stigmatized and fear being discriminated against by society (Krishna, Bhatti, Chandra, & Juvva, 2005). The stigma of HIV in India is multifactorial and includes enacted stigma, which is the direct experience of discrimination, and felt stigma, which is the perception of discrimination. While enacted stigma has been reported less often, perceptions of stigma are often influenced by stories of discrimination against other HIV-infected persons (Steward et al., 2008). Individuals may then internalize the stigma and accept it as legitimate.

A survey of people living with HIV in South India demonstrated that enacted, felt and internalized stigma were associated with higher levels of depression (Steward et al., 2008). Furthermore, the associations of depression with felt and internalized stigma were mediated by the use of coping strategies designed to avoid disclosure of HIV serostatus. Disclosure avoidance was also associated with higher levels of depression (Steward et al., 2008). However, in another study, disclosure variables did not relate to significant psychological morbidity (Chandra, Deepthi, Jairam, & Thomas, 2003).

Sociodemographic Factors

Women living with HIV in India face a double burden of stigmatization being both female and HIV positive. While women are frequently provided care, it is not as comprehensive as that received by their male counterparts (Sinha, Peters, & Bollinger, 2009). Often after the death of the husband, the in-laws no longer provide women with housing and support (Bharat & Aggeleton, 1999). Among male and female clients at voluntary HIV testing and counseling centers in Pune, India, depression was associated with having never been married and repeat test-seeking behavior; and women with higher levels of education also had higher anxiety and depression scores (Sahay et al., 2007). In a study of HIV-positive men and women in Bangalore, India, the following factors were significantly associated with depression: current alcohol abuse/dependence, AIDS in the spouse, and poor relationship with family (Chandra, Ravi, Desai & Subbakrishna, 1998). Studies of people living with AIDS in Peru and West Africa have demonstrated the following correlates of depression: poverty; socioeconomic vulnerability, including food scarcity; less than secondary school educational level; and not having disclosed seropositivity to their partner (Wu et al., 2008).

Clinical Factors

The symptoms most commonly reported by 103 adult men and women with advanced AIDS in South Africa, in decreasing order of prevalence, were pain, weight loss, loss of appetite, weakness, dry skin, diarrhea, nausea and vomiting, cough and fatigue. Almost three quarters (70%) of the interviewees reported "low mood". Females reported significantly more anxiety, genital sores and pain than males (Norval, 2004). Among seropositive women and men in Bangalore, 55% reported painful symptoms, with 31% reporting severe pain; pain was significantly associated with depression (Chandra, Ravi, Desai, & Subbakrishna, 1998).

Length of time on ART may also be correlated with depression. Among women in Zimbabwe, depression was less common among those who were on ART for a median of 13 months compared to those who were not receiving treatment (Patel et al., 2009). In West Africa, exposure to efavirenz was a risk factor for depression (CES-D score = 16), but this

risk decreased with increasing time on treatment (Marcellin et al., 2008). Depressive symptoms in South Africa were associated with internalized AIDS stigma and depression remained high six months after initiation of ART and even slightly increased after 12 months (Peltzer & Ramlagan, 2011). Levels of depression have also been shown to be increased among male and female HIV-positive people from Mozambique 12 months after initiation of ART; all of which suggests the need for incorporating the assessment and treatment of depression in long-term HIV care (Pearson et al., 2009).

Methods

Design

This study provides baseline cross-sectional data on 68 rural women living with AIDS in India who were enrolled in a pilot prospective, randomized clinical trial intervention. The study was designed to assess the impact of having trained lay village women, Asha (Accredited Social Health Activists), provide in-depth physical and emotional support to a group of women living with AIDS in rural India as compared to providing minimal care to a control group of similar women. Human Subjects Protection Committee clearances were obtained both in the US and in India.

Sample and Setting

Women living with AIDS (WLA) were eligible for the study if they met the following inclusion criteria: a) between the ages of 16-45; b) screened as receiving or eligible to receive ART, with CD4 cells < 100; and c) not a participant of an earlier qualitative study. Two high prevalence HIV/AIDS villages in rural Andhra Pradesh that were demographically alike and served by a Public Health Center (PHC) were randomly selected from a pool of 16 villages. One village was randomly assigned to the intervention condition, while the other village served as the control.

Screening Procedure

The study was announced by means of flyers posted in the PHCs of the two villages. A full description of the study was provided by the research team to interested WLA in a private setting in the PHCs. After a full discussion about the study and its requirements, interested WLA signed an initial informed consent. This was followed by the administration of a brief two-minute structured questionnaire that elicited information about socio-demographic characteristics, including age, and HIV and ART status. These questions helped to determine eligibility for the proposed study and provided basic sociodemographic information on refusals.

To complete the eligibility review, blood was drawn to assess CD4 levels. Research staff stationed at the designated site four days later provided test results. All respondents were paid \$5 for completion of these screening procedures. Individuals with self-reported or visibly apparent health problems were referred to the PHC. WLA who met eligibility criteria and wished to participate then underwent another informed consent procedure and were enrolled in the study. The administration of the baseline questionnaire followed, prior to any intervention.

Instruments

Several of the instruments have been previously tested with WLA in the U.S. (Rotheram et al., 2000, 2001; Whitbeck, Hoyt, & Bao, 2000) and in India (Ekstrand et al., 2006).

Socio-Demographics—A structured questionnaire was used to collect sociodemographics which included age, birthday, education, employment status, marital status and number of children.

Health History—We collected self-reported HIV-and TB-related physical symptoms from the women in the baseline questionnaire, as well as history of opportunistic infections (OIs) and other illnesses, as assessed by a licensed physician. We also assessed history of health care access and utilization, including number of medical visits in the past three months. Number of pills left in WLA's medication bottles was also checked at baseline by the research staff prior to beginning the program.

Stigma—Stigma scales developed by Ekstrand and her team (Ekstrand et al. in press, Stewart et al., 2008; 2011), provided four constructs: a) Heard Stigma; b) Felt Stigma; c) Enacted Stigma; and d) Internalized Stigma. The scale items were based on previous research (Berg & Arnsten, 2001; Berger, Ferrans, & Lashley, 2001; Chesney, 2006; Herek, Capitanio, & Widaman, 2002; Simoni et al., 2006), and were subsequently modified based on qualitative interviews in India (Bharat, Aggleton, & Tyrer, 2001, Stewart et al., 2008) to ensure that the content was relevant and appropriate. The process of developing these scales has been described in detail by Stewart et al. (2008).

Heard Stigma—Items measure whether participants have heard stories about other people living with HIV/AIDS being mistreated because of their infection. A sample item is: “How often have you heard stories about people being refused medical care or denied hospital services because of their HIV.”

Felt Stigma—This scale measures perceived levels of stigma in one's community, such as the attitudes that people living with HIV/AIDS deserve their infections or have brought shame on their families. A sample Felt Stigma item is: “In your community, how many people think that HIV-infected people have brought shame on their families.”

Enacted Stigma—Assesses whether participants have experienced specific discriminatory acts due to their HIV infection, such as being asked not to share utensils or plates with other family members. An example of an item in this scale is: “Have you been told not to share your food or utensils with your family because of your HIV”.

Internalized Stigma—This scale parallels the Felt Stigma scale, but assesses the extent to which participants believe that, as HIV-infected people, they deserve to be stigmatized. For example, an item in this scale is: “How much do you feel that you deserve to have HIV?”

Avoidant Coping—A strategies scale was utilized to assess coping responses to HIV stigma. This eight-item scale assesses the frequency with which participants use various coping strategies to avoid disclosing that they have HIV. Examples of avoidant coping were based on qualitative research (Stewart et al., 2008) and included coping strategies such as hiding one's HIV medications and describing one's illness as TB, rather than HIV. A sample item from this scale is: “How often have you described your illness as tuberculosis instead of HIV?” Responses vary from (1) never to (4) often. Cronbach's alpha for this scale was .90. Scale scores for all stigma measures and for stigma coping were constructed by summing the individual item responses.

Depressive Symptomatology—The CES-D, a 20-item scale, was used to measure frequency of depressive symptoms on a 4-point continuum. The CES-D has well-established reliability and validity and has been used with a variety of populations (Radloff, 1977).

Scores on the CES-D range from 0-60, with higher scores representing greater depressive symptomatology. Internal consistency for the scale in this sample was .94. Scale scores were dichotomized for analysis at 16 or more, a well-established cut-point suggesting a need for psychiatric evaluation of depression (Radloff, 1977).

Data Analysis

Summary statistics, including means and percentages, were presented to describe participants' demographic and clinical characteristics, as well as other independent variables. Preliminary analyses, including chi-square and t tests were used to identify unadjusted correlates of depression. Stepwise multiple logistic regression analysis was used to create a model of depression; predictors included variables that were associated with depression at the 0.15 level in preliminary analyses. Covariates that were significant at the 0.10 level were retained in the final model. Multicollinearity was assessed and model fit was examined with the Hosmer-Lemeshow test. All statistical analyses were conducted using SAS, version 9.1.

Results

Sociodemographic Factors

There were 68 WLA completed the baseline structured questionnaire for our current study. The participants were relatively young (average age of 31.2 years old) Hindus (65.7%) that spoke Telegu (100%) (Table 1). Overwhelmingly, the majority of the women completed less than high school education (94%). Though slightly over half were married, only 44% lived with a spouse. With a mean of 1.57 children reported, more than three-quarters lived with children (76.5%).

Health Descriptors and Utilization of Health Care

On average, WLA had been taking ART for just under two years (22 months) and the average ART compliance rate in the study sample was 53% (Table 2). More than half (54.4%) of the sample experienced depression. The mean number of visits made to health care providers was 7.5 over the past three months. All participants reported visiting the government hospital. Visits to other providers and facilities, including pharmacists (68%), the PHC (65%) and medical assistants (52%) were also frequently reported by the WLA; less than 1 of 5 WLA had visited a HIV care clinic or non governmental organization/ voluntary testing & counseling site for care in the past three months.

Physical Health Symptoms

In terms of physical health symptoms, most WLA (84%) had experienced fever and fatigue (Table 3). Three-quarters of the women also reported experiencing dizziness, frequent headaches and changes in body shape. Over 60% of the sample reported experienced various digestive symptoms. Slightly over half of the women reported difficulty sleeping, skin rashes and depression/mood swings. Less prevalent symptoms included mouth ulcers (31%) and oral numbness (22%).

Correlates of Depression

Table 4 presents unadjusted correlates of depression with socio-demographic characteristics, AIDS-related variables and measures of stigma. WLA who were depressed were less likely than those who were not depressed to be living with their husbands and more likely to have visited the health clinics at least six times in the past 3 months. In addition, those who were depressed reported being on ART for a longer period of time than those not depressed. None of the physical symptoms were associated with depression.

After controlling for other potential correlates (Table 5), women living with their husbands were less likely to be depressed. Visiting health clinics at least six times in the past 3 months was positively associated with depression. Women who used disclosure avoidance coping strategies were also more likely to experience depression.

Discussion

It is clear from our findings that WLA in rural India are significantly impacted with depression as measured by a CES-D score of 16 or greater. Among those who participated in our study, more than half (54%) reported high CES-D scores. Interestingly, depression among our sample of WLA was correlated significantly with disclosure avoidance coping mechanisms and not living with one's spouse. In addition, visiting the health center often within the past three months was also correlated with depression. No differences were found in terms of stigma, HIV knowledge, ART adherence, age, and other socio-demographic findings. The common theme between disclosure avoidance and living with one's spouse is that they both speak to the WLA actual relationship to the world around her and to her fear of disclosing her illness despite her need for support and health care.

Disclosure can positively influence one's mental health. Even the desire to disclose one's HIV status is related to improved mental health (Chandra et al., 2005). Prior studies have suggested that disclosure leads to decreased levels of depression because disclosure decreases stigma (Pearson et al., 2009). In addition, disclosure may support WLA's emotional state by helping them connect to treatment and support resources (Emlet 2006; Smith, Rossetto, & Peterson, 2008). Our study supported these findings by revealing a significant correlation between disclosure avoidance and depression; nevertheless, stigma and depression were not significantly related. This difference suggests that the act of avoiding disclosure, rather than experiencing stigma may have a more deleterious impact on the mental health of WLA.

The lack of correlation between stigma and depression in our study may be due to several reasons. For example, WLA in our sample had been on ART for an average of 2 years. This length of time may have enabled the women to adjust to the stigma that may have been experienced. This adjustment may have resulted by not disclosing to friends and the community at large. However, as the WLA become sicker, the ability to mentally control the situation may become more unbalanced. While other studies that found a correlation between stigma and depression (Pearson et al., 2009; Peltzer & Ramlagan, 2011), viewing WLA one year after initiating ART may be a discriminating point. Again, this shorter time period may reflect the lack of time for WLA to adjust to the stigma in her environment.

Living with one's spouse was also found to be an important protective factor against depression. WLA who lived with their spouse experienced less depression than WLA who did not live with their spouse. Previous studies have reported the correlation between marriage and lower rates of "emotional distress" (Sahay et al., 2007) and that lack of familial support can be a risk factor for depression (Chandra et al., 2005). Additionally, previous studies have found depression and social support to be inversely correlated. This is particularly true among WLA who have disclosed their status to others, and are thus freer to seek out social support, even if they perceive less social support available (Pearson et al., 2009). Significant others may be a source of support (Chandra et al., 2005) since WLA who live alone do not have any support for managing the complexities of ART treatment, or the emotional struggles that come with HIV/AIDS.

Our findings also revealed that women who had frequent health care visits were more likely to report high depressive symptom levels. It is possible that the combination of worsening

health and lack of disclosure can have a profound impact on the WLA, particularly as the overwhelming majority was plagued with serious health symptoms such as changes in body shape, dizziness, fatigue and fevers. Such debilitating symptoms may overpower women who find the need to make frequent visits to health care providers; but yet have not disclosed the reason for their illness. Thus, the need for ongoing research which promotes disclosure by the WLA in a safe manner in order that they may be released from ongoing fear and inability to reach out for support by friends and family who are unaware of their illness is pervasive.

This study highlights disclosure avoidance behavior and increasing need for health care as two important issues at the root of depression in these participating WLA. As we know, untreated depression can have significant negative consequences on one's health, such as poor medication adherence (Chandra et al., 2005; Sarna et al., 2008) and lower CD4 levels (Chandra et al., 2005). Yet, until AIDS is disclosed, it is unlikely that depression may not be fully treated. The correlation between disclosure avoidance and depression in the present study portends and underscores the importance of treating depression in order to protect the WLA physical health.

Limitations

A number of factors limit the general applicability of our study. Our cohort includes two villages from rural India. There may be different factors that effect WLA in urban environments and in other countries.

Conclusions

The present study provides unique data reflecting a rural population of WLA in India. As more than half of these women reported high depressive symptom scores, understanding correlates of depression can lead the way to the designing culturally-tailored intervention that mitigates disclosure avoidance and improves the health of women. Learning more about the health care interactions of these women may shed light on the quality of care received, the reason for the need for frequent visits and whether psychological health is being considered within a comprehensive care package. Clearly, a comprehensive health focus may be needed to empower the women to seek quality care for both physical as well as mental health symptomatology.

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Table 1

Sample Characteristics (N=68)

Measure	Mean	(SD)
Age	31.21	(5.3)
Number of Children	1.57	(1.0)
	N	%
Less than High School	63	94.0
Education		
Speak Telegu	68	100.0
Marital Status		
Married	35	51.5
Widowed	28	41.2
Other	5	7.4
Religion		
Hindu	44	65.7
Christian	17	25.4
Muslim	6	9.0
People Living with:		
Children	52	76.5
Spouse	30	44.1
Working	52	76.5

Table 2**Health Utilization Measures (N=68)**

Measure	Mean	(SD)
Mean Time Taking antiretroviral therapy (ART) in Months	22.3	(17.6)
Compliance with ART, Last Six Months	53.5	(14.8)
Visits Past 3 Months	7.5	(3.5)
	N	%
Depression *	37	54.4
Reason Tested for HIV:		
Persistent/Severe Illness	25	37.3
Spouse Positive	26	38.8
Facilities/Providers Visited Past 3 Months:		
Government Hospital	68	100.0
Pharmacist	46	67.7
Primary Health Center	44	64.7
Medical Assistant	35	51.5
Private Hospital	31	45.6
Private Practitioner	27	39.7
HIV Care Clinic	11	16.2
Non-Governmental	10	14.7
Organization/Voluntary		
Testing & Counseling Site		

* As determined by CES-D 16

Table 3

HIV Symptoms in the Last Six Months (N=68)

Symptom	N	%
Fevers	57	83.8
Fatigue	57	83.8
Dizziness	53	77.9
Frequent Headaches	51	75.0
Changes in body shape	51	75.0
Nausea	47	69.1
Vomiting	42	61.8
Stomach Pain	41	60.3
Diarrhea	41	60.3
Difficult Sleeping	40	58.8
Skin Rashes	40	58.8
Depression/Mood Swings	36	52.9
Sense of Taste Change/Loss	32	47.1
Color of Skin/Nails change	31	45.6
Mouth Ulcers	21	31.3
Oral/Numbness	15	22.1

Table 4

Unadjusted Correlates of Depression

Measure	Depression				P-Value
	Yes	No	N	%	
Less Than High School Education	35	94.59	29	93.55	0.855
Living with Spouse	11	29.73	19	61.29	0.009
Religion (Hindu)	21	56.76	23	74.19	0.134
Currently Working	30	81.08	22	70.97	0.327
Frequent Health Care Visits in Past 3 Months (≥ 6 times)	21	56.76	10	32.26	0.043

	Mean	Std	Mean	Std	P-value
Age	30.659	4.8	31.87	4.7	0.272
Time Since HIV (+) in Months	54.346	35.7	49.25	27.7	0.882
ART Duration	24.806	20.1	19.40	11.1	0.040
HIV Knowledge	3.35	4.1	2.68	2.5	0.165
Heard Stigma	3.34	0.6	3.20	0.5	0.886
Felt Stigma	3.566	0.4	3.54	0.3	0.717
Internalized Stigma	3.46	0.6	3.33	0.6	0.241
Enacted Stigma	7.11	3.0	7.13	2.7	0.454
Disclosure Avoidance	3.40	0.7	3.02	0.7	0.1487

Table 5

Multiple Logistic Regression Model for Depression (n = 68)

Measure	Beta	STD Error	P Value
Age	-0.06	0.06	.245
Living with spouse	-1.72	0.62	.006
Healthcare Visits in the past 3 months	1.22	0.62	.048
Disclosure Avoidance	1.33	0.50	.008
Adherence Support	0.59	0.32	.063