

Characteristics of Psychosocial Support Seeking During HIV-Related Treatment in Western Kenya

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Abstract

While the characteristics of those who seek psychosocial support following an HIV diagnosis have been well documented in western countries where linkages between HIV-related treatment and psychosocial support programs are well established, little is known about those who become engaged with such services in countries of the world where comprehensive HIV-related care and prevention systems are continuing to develop. Data were collected from 397 individuals who had enrolled in HIV-related psychosocial support groups in western Kenya in November 2005. Demographic and HIV-related characteristics, as well as assessments of psychological distress, were collected from each participant and analyzed by gender in order to document the characteristics of those seeking psychosocial care in conjunction with their participation in an HIV-related treatment and prevention program. Those seeking psychosocial support were primarily female (72%), living with HIV for an average of 2.5 years, and unemployed (70%). Women were younger and more likely to be either widowed or never married; while men were more likely to have advanced HIV disease, including lower CD4 counts and an AIDS diagnosis. Across all participants, HIV serostatus disclosure was rarely reported to sex partners, family members, and friends. Symptoms of psychological distress were more prevalent among women on multiple measures, including depression, anxiety, paranoid ideation, interpersonal sensitivity, and somatization. An increased understanding of the characteristics of those likely to seek psychosocial support groups will help HIV program managers to develop protocols necessary for facilitating linkages to psychosocial support for those enrolled in HIV-related treatment programs. Patient engagement in psychosocial support may facilitate improvements in psychological function and support an individual's maintenance of HIV treatment and prevention behaviors.

Introduction

THE IMPACT OF THE HIV pandemic in sub-Saharan Africa has been devastating to the region and has accounted for 68% of the HIV infections in the world to date. The Joint United Nations Program on HIV/AIDS (UNAIDS) estimated that by the end of 2007, those in Africa represented 76% of AIDS deaths in the world. In Kenya, it is estimated that just over 5.2% of the adult population (15–49) is living with HIV, with infection rates being higher among women (8.7%) than men (4.5%), as is the case in many African countries.¹

Medical advances in both the nature of, and access to, HIV-related treatments have fueled the development of comprehensive HIV care programs in many countries, with an estimated 1 million individuals actively on antiretroviral med-

ications in sub-Saharan Africa.¹ While these advances have been significant, they also have presented care providers with complex quality of life issues among those receiving an HIV diagnosis and treatment, among them challenges associated with psychological health status and impacts to one's ability to maintain functional social interactions.^{2–4}

The psychosocial consequences of HIV infection vary over the course of HIV disease and can be as diverse as the HIV disease spectrum itself.^{5–12} Additionally, those facing psychological distress following an HIV diagnosis, including depression, general anxiety disorder, panic disorder, and drug use disorders, have been shown to be less likely to engage in care and prevention behaviors and could therefore challenge their own health and that of their sexual partners.^{13–16}

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In a recent study conducted in a primary care facility in Kenya, researchers found that 45% of adult patients expressed symptoms of psychological distress, 20% of children patients, and up to 75% among HIV-infected adults.¹⁷ Furthermore, among those seeking psychosocial support care, men expressed their distress in somatic terms, which was also found in a Ugandan study where depressive symptomatology somatically expressed.¹⁷⁻²⁰

Formal systems of mental health care have been described as being scarce throughout countries like Kenya, although they are more likely to be available only in large cities such as Nairobi, due to the increased availability of resources in urban areas.²¹⁻²³ Managing psychosocial distress symptoms has been systematically and culturally marginalized and stigmatized, which has been facilitated further by the limited establishment of more formal systems of mental health care.²⁴ These cultural factors are also important in considering the mechanisms that support one's engagement with psychosocial support when it is available. One study found that significant others have been reported to encourage such care seeking only upon the onset of more severe symptoms such as attempting suicide, being extremely socially withdrawn, hearing voices or talking to oneself.¹⁷ Health care providers have the potential to refer patients to seek mental care upon expression of distress symptoms, or even upon HIV diagnosis.⁸

The focus has been on the continued development of care systems to provide HIV-related medical treatments in sub-Saharan Africa.²⁵ As a result, the needs for development of psychosocial support programs, their linkage to medical treatment, and medical providers' encouragement of one's engagement in such services have typically not been addressed.^{21,26,27} Psychosocial support programs offer opportunities for individuals to develop coping strategies for a challenging medical condition like HIV.²⁸⁻³⁰ Psychosocial support group members have been found to experience lower levels of depression, hostility and somatization,³⁰ improved cognitive function and levels of perceived social support.³¹⁻³⁴ Furthermore, groups have been successful at addressing the challenges associated with behaviors that impact immune function and overall health status,³¹⁻³⁴ which can play an important role in addressing HIV prevention behaviors such as serostatus disclosure, condom use, and reductions in alcohol use.^{34,35}

In addition to the availability and accessibility barriers^{31,36,37} to seeking psychosocial care, those who report higher levels of psychological distress tend to report higher levels of barriers to care and stigma associated with seeking such support.³⁸⁻⁴¹ These factors have been documented as such in the United States, different barriers may exist in other countries, specifically when the infrastructure is just beginning to develop. Given that little is known about the nature of those likely to seek psychosocial support during their engagement in an HIV-related treatment programs in countries like Kenya, this study was conducted to document these characteristics to help medical providers identify those most likely to seek psychosocial support.

Methods

The aim of this study was to demographically and medically characterize individuals who had self-enrolled into psy-

chosocial support group in western Kenya. This study was conducted by Kenyan and U.S. researchers who are affiliated with the Academic Model for the Prevention and Treatment of HIV/AIDS (AMPATH) in Eldoret, Kenya which began in late 2001.^{42,43} AMPATH was developed as part of a collaborative partnership between the Moi University and Indiana University Schools of Medicine and delivers HIV-related treatment via 19 clinic sites across western Kenya. One of the core components of this program is the AMPATH Support Network, a series of HIV-related psychosocial support groups that were established in 2002 as a response to the expressed need of AMPATH patients for an ongoing means to discuss psychosocial issues related to their HIV infection.

All study protocols were approved by both the Institutional Review Board at Indiana University-Bloomington and by the Institutional Research and Ethics Committee at Moi University School of Medicine in Kenya.

Study participants

Study participants were 397 individuals living with HIV who had self-enrolled into one or more psychosocial support groups of the AMPATH Support Network being held at the Moi Teaching and Referral Hospital in Eldoret, Kenya. During the two weeks preceding the study, group facilitators made announcements that the study would be conducted during a particular week and flyers were also posted in the psychosocial support group area. One hundred percent of those coming to routinely scheduled support groups during the study week agreed to participate when asked by a research assistant. However, given that a range of factors could have influenced whether a participant attended a group during either the recruitment period or the actual week of the study, it is impossible to calculate a valid response rate based on the total number of patients who were exposed to recruitment messages or flyers.

Measures

Data were collected using a self-administered, cross-sectional, paper-based questionnaire administered over a 1-week period in November 2005.

Demographic characteristics. The demographic measures included: age, gender (male/female), tribal affiliation, religion (Catholic, Protestant, Muslim, atheist, other), relationship status (married, divorced, widowed, significant other/partner, single), number of children, highest level of education attained (none, standard 1-3, standard 4-8, form 1-2, form 3-4, university), sexual behaviors (number of sexual partners), condom use (during previous sexual encounter), and employment status (unemployed, part-time work, full-time work).

HIV-related characteristics. HIV-related measures included: presence of HIV diagnosis (yes/no), length of time since HIV diagnosis (months, years), presence of AIDS diagnosis (yes/no), length of time since AIDS diagnosis, primary partner's serostatus (positive/negative/don't know), and to whom the participant had disclosed their serostatus (spouse, parents, children, other family members, friends). Medical chart abstractions were conducted to obtain the most recent CD4 count for each participant.

Psychological Distress Symptoms. The Brief Symptom Inventory (BSI) and the Patient Health Questionnaire-9 (PHQ-9) were used in this study to assess levels of psychological distress and depressive symptomatology, respectively.^{8,19,44-49} The BSI measures psychological distress symptoms across nine dimensions and three global indices. The raw scores of the subscales range from 0 to 4. The scale developers also calculated a T-score which is generated to account for gender differences in distress levels.^{46,50} Since this was the first measurement of psychological distress in a western Kenyan population, only the raw scores of the BSI subscales were included to assess any differences among gender to also capture any differences by gender that may be culturally appropriate.

The PHQ-9 is a depression-specific scale where the summative score of nine items ranges from 0-27.^{48,51,52} Assessments of reliability and validity of these instruments among individuals living with HIV in Kenya have found them to be reliable and valid instruments for the measurement of psychological distress among this population.¹⁹

Statistical analyses

Data were analyzed using SPSS for Windows (version 14.0, SPSS Inc., Chicago, IL). Descriptive analyses were conducted among demographic and HIV-related characteristics by reporting the means, standard deviation (SD), and percentages of measures, both overall and separately for males and females. To test gender differences, *t* tests were used for continuous measures and χ^2 test was used for categorical measures except when 25% or more of the cells had expected counts less than 5 in which case a two-sided Fisher exact test was used.

Results

A total of 397 AMPATH Support Network members participated in the study, of which 72% (*n* = 284) were female.

Table 1 provides a summary of the participants' demographic characteristics by gender. Women were significantly younger than men in the sample with a mean age of 35.6 versus 38.6 years, respectively (*p* < 0.001). More men reported being married (66%, *n* = 69), more women reported being widowed (29%, *n* = 82) and not remarried (29%, *n* = 80; *p* < 0.001). The average number of children for participants who had them, which was 93.45% of the sample, was 3.3 (SD = 1.9). The average age of having their first child was 21.6 years (SD = 5.8). The tribal affiliations reported were consistent with the major tribes in the region, and primarily included Kikuyu (22.9%, *n* = 91), Luhya (22.7%, *n* = 89), Luo (18.4%, *n* = 73), and Kalenjin (19.4%, *n* = 77). The majority of the sample reported being one sect of Christianity; either Protestant, (57%, *n* = 226), Catholic, (29%, *n* = 113), or "other" Christian (10%, *n* = 40), while 4% reported being Muslim (*n* = 14), and 0.8% (*n* = 3) of the sample reported being atheist.

The highest levels of education completed were similar for both men and women. Education levels were assessed based on Kenya's system of "Standard 1-8" and "Form 1-4." Most of the sample either completed "Standard 4-8" (40.6%, *n* = 159) or "Form 3-4" (32%, *n* = 124). The majority of the sample were not employed (69.7%, *n* = 277), while 10% (*n* = 40) were employed full time and 8% (*n* = 32) reported working part-time. Employment status did not significantly differ between genders.

HIV-related characteristics

The entire sample was living with HIV (100%, *n* = 397). Table 2 provides a summary of the HIV-related characteristics of the sample by gender. The majority of the sample reported their route of HIV transmission as heterosexual sex (72.0%; *n* = 286); a significant proportion reported not knowing how they became infected (*n* = 62; 15.6%). There were no significant differences between genders with regard to re-

TABLE 1. DEMOGRAPHIC CHARACTERISTICS BY GENDER (*n* = 397)

	Female		Male		p
	Mean	SD	Mean	SD	
Age	35.6	8.0 (18-61)	38.6	7.0 (23-58)	0.001
Marital status	<i>n</i>	%	<i>n</i>	%	
Married	78	27.8	69	65.7	0.01
Divorced	38	13.5	4	3.8	
Never Married	80	28.5	11	10.5	
Widow/er	82	29.2	20	19.0	
Education level					
No formal education	16	5.6	2	1.9	0.116
Standard 1-3	22	7.7	3	2.8	
Standard 4-8	118	41.5	41	38.3	
Form 1-2	41	14.4	18	16.8	
Form 3-4	82	28.9	42	39.3	
University	5	1.8	1	0.9	
Employment status					
Full-time	25	9.7	15	15.5	0.096
Part-time	22	8.5	10	10.3	
Unemployed, looking	184	71.0	62	63.9	
Unemployed, not looking	22	8.5	4	4.1	
Other	6	2.3	6	6.2	

TABLE 2. HIV-RELATED CHARACTERISTICS BY GENDER ($n = 397$)

	Female		Male		p
	Mean	SD	Mean	SD	
Length of time in support group, in months	16.3	14.8	15.1	14.7	0.200
Length of time with HIV, in months	27.3	25.9	30.2	34.5	0.391
CD4 counts, cells/mm ³	369.6	221.8 (2–1321)	287.8	206.2 (7–1113)	0.002
Length of time with AIDS in months	23.2	25.9	17.4	18.8	0.136
Overall health	276	2.8 (1.1)	98	3.0 (1.1)	0.198

ported transmission routes. Both genders reported participating for similar lengths of time in the AMPATH Support Network (ASN) with a mean in the total sample of 15.9 months since enrollment (SD = 14.8). The mean time of knowing of one's HIV infection was 2.3 years (SD = 2.5 years) and time since receiving an AIDS diagnosis was 1.8 years (SD = 1.8 years), neither of which significantly differed by gender. Overall, 43% of the sample reported being diagnosed with AIDS ($n = 202$), although a greater percentage of men (42.9%, $n = 114$) reported being diagnosed with AIDS than women (55.3%, $n = 57$; $p < 0.05$). The mean CD4 cell count of the participants ($n = 346$) was 345.4 cells/mm³ (SD = 219.3 cells/mm³; 2–1321) with a median CD4 cell count of 310.0 cells/mm³. Women had significantly higher CD4 cell counts than men with a mean of 369.4 versus 283.0 cells/mm³, respectively ($p = 0.001$). A measure of overall health was used which was adopted from the SF-12 (Ware, Kosinski, and Keller, 1996) was analyzed; answers range from a high score of 1 for "excellent" and a low score of 5 for "poor". Men and women responded similarly to this question with a mean response of 2.8 (SD = 1.1). While this study did not collect data regarding current antiretroviral therapy and medication adherence, the related clinic study found 36% of the population had been started on ARVs as of 2003.⁵³

Disclosure patterns

Men and women had similar trends in disclosing their HIV serostatus to others. Approximately one-third of the men and women reported disclosing their HIV status to their parents. Most participants who were parents did not report disclosing their status to their children (81%, $n = 316$), with no significant difference between genders. Of those reporting being married, only 35% ($n = 27$) of the women and 46% ($n = 32$) of the men reported disclosing their HIV status to their spouse. More men (58%, $n = 58$) reported knowing their sex partner was HIV-infected, than women (42%, $n = 104$, $p < 0.05$). A substantial proportion of participants reported disclosing their serostatus to an aunt or uncle, (21.0%; $n = 82$). Seven percent ($n = 28$) of the sample reported not disclosing their HIV status to anyone. Disclosure patterns are detailed by gender in Table 3.

Sexual behavior patterns

When asked to report condom usage the previous time they had sex, women reported significantly lower rates of

usage than men (58.7% versus 76.9%; $p < 0.001$). The majority of the female sample reported have sex with one partner in the last 3 months ($n = 135$; 51.7%). A large majority of women also reported not having any sex partners in the same time period ($n = 114$; 43.7%). Men has similar patterns with 39.4% ($n = 41$) reporting no sex partners in the past 3 months and 49.0% ($n = 51$) having sex with one partner. A total of 12 women reported having more than one sex partner in the past 3 months (4.2%) and 12 men reported the same (11.5%).

Psychological distress

Participants presented for psychosocial care with moderate levels of psychological distress symptoms, with women presenting with higher symptoms of anxiety ($p < 0.001$), depression ($p < 0.001$), interpersonal sensitivity ($p < 0.05$), paranoid ideation ($p < 0.001$), somatization ($p < 0.05$), and overall distress ($p < 0.05$) than men. Men were more likely to present with somatic symptoms than women ($p < 0.05$).

Additionally, 9.7% of men ($n = 9$) and 11.1% ($n = 29$) of women met criteria for major depressive disorder.⁵⁴ More detailed descriptions of the nature of psychological distress among these individuals and the psychometric properties of the scales used during assessment are provided in other publications.^{19,54}

Discussion

The purpose of this study was to characterize the individuals who had sought psychosocial support care in conjunction with their HIV-related treatment in western Kenya.

TABLE 3. PROPORTION OF HIV SEROSTATUS DISCLOSURE PATTERNS BY GENDER

	Female ($n = 283$)		Male ($n = 107$)		p
	n	%	n	%	
Spouse	27	36.4	32	46.4	0.10
Parents	103	36.4	38	35.5	0.91
Children	57	20.1	16	15.1	0.31
Uncle/Aunt	55	19.4	27	25.2	0.21
Friend	97	34.3	35	32.7	0.81
No one	19	32.1	9	8.4	0.66

^a $p < 0.05$.

The findings of this study therefore, offer a description of the participants who may be more likely to participate in psychosocial support programs in conjunction with their HIV-related treatment. Understanding these characteristics provides insight into the mechanisms that may be helpful to providers who have the opportunity to link such individuals to psychosocial support services. These findings are also important, in that they suggest the specific topics that may need to be addressed in order to enhance the effectiveness of psychoeducational groups, including issues related to disclosure, sexuality, and stigma.

The majority of the sample was female, which reflects the overall AMPATH Support Network membership and patient population.⁵³ Women were younger than their male counterparts, also reflected in the AMPATH patient population, and the samples were both very similar in age.^{42,53} Age seemed to have a limited effect on help-seeking behaviors. In contrast, to published descriptions of the patient population in AMPATH, where women in HIV-related medical care were mostly married, women in this support-seeking study more often had never been married or widowed. One-fifth of the patient population did however report being widowed.⁵³ The difference between patient and support group population in marital status may highlight an elevated need for social support for women who do not have a spouse or significant other. Although women were reportedly more often to be living with HIV without a current spouse, these demographic characteristics reflect the patterns of infection for women.¹ In research conducted in Uganda, those seeking mental health care seemed to be significant others seeking care on behalf of their spouse or family members; this also does not reflect the same pattern, although that sample was not HIV-infected.¹⁷

Most of the participants in the support network had children; the larger patient population sample had slightly more children than those in the support groups. This difference may be reflective of the larger proportion of women who were never married.

With high levels of unemployment in the sample and in the region,¹ there were no differences by gender based on employment status among those who seek mental health care. The highest levels of education obtained mostly converged around either completing primary or secondary schooling, and this did not differ by gender of the psychosocial support group members. Education and employment are typically correlated due to the limited resources in the region for both. These factors do not seem to reveal different health seeking patterns given the limited variance. The high levels of unemployment, having children, and being a single woman with lower levels of education may mean those who self-enroll into care feel a larger burden and higher needs associated with HIV and psychological distress.

The HIV-related characteristics described in this study were expected to be the primary determinants of participating in psychosocial support groups, primarily due to the somatic factors associated with seeking help.¹⁷ Most participants reported having HIV and not being diagnosed with AIDS. More men had been diagnosed with AIDS and had lower levels of CD4 cell counts at their most recent measure, perhaps indicating men were waiting longer to seek psychosocial support. The pattern of HIV-related medical care in western Kenya still reflects little early HIV counseling and

testing with many patients being diagnosed and entering into care due to medical complications that occur later in the course of disease, which seemed to be reflective of the men who enroll into psychosocial support group care. This pattern is reflected also in the larger patient population and of men's health seeking behaviors.^{1,17,53} The current CD4 cell counts for men in this study and the overall AMPATH patient population were both lower than women and thus, more often reported being diagnosed with AIDS.⁵³

Participants reported being members of the AMPATH Support Network for an average of almost 1.5 years, which did not differ between genders. This is a substantial period of time in which seeking mental health care repeatedly occurred. These findings can also suggest a level of client satisfaction and commitment to improving their mental health care. This may further suggest an opportunity to develop the psychosocial support groups into a psychoeducational support group in which prevention programming may be implemented in a more strategic manner. Serostatus disclosure patterns are complex and may contribute to issues of prevention efforts, support systems, and family planning. There was very little serostatus disclosure reported in this study. Approximately one-third of the sample reported disclosing to their spouses, which is a slightly larger proportion than the findings of the larger patient population where one-quarter of the sample reported know the HIV status of their spouse.⁵³ The large proportion of participants who did not disclose their HIV status to their spouses is of high concern. Combined with low rates of disclosure to parents and children, the results may imply an assumed lack of support from family members. Furthermore, the differences in disclosure patterns between men and women reveal further areas to be addressed, with women reporting less disclosure across all significant others (spouses, family members, friends). These findings highlight the continued stigma and distress with the disease that have been documented in this population.⁵⁵ Additionally concerning are the low levels of disclosure among individuals living with HIV who are already seeking psychosocial support group care and yet still not telling their spouse of their HIV status.

The elevated levels of somatization and paranoid ideation in this study offer insights for how to best recruit and link individuals into care who may not already present for care. For individuals with HIV who have high levels of somatization, it is challenging to discern which symptoms are psychosomatic and which are symptoms of the disease or treatment. Other relevant research, specifically in resource-poor environments, suggests that regardless, somatization is an important indicator for assessing needs of mental health care.^{17,20,56} Symptoms of paranoid ideation are similar to of the physical and psychological manifestations of stigma. Levels of stigma have been known to be high in relation to HIV infection, both in the United States and internationally,⁵⁷ and stigma levels have been documented as being elevated in low-resource areas of the world among people who have lower levels of knowledge about HIV.^{57,58} The effect that stigma or paranoid ideation has on high-risk behaviors demands additional research. Symptoms of paranoid ideation and stigma must also be addressed to help individuals improve their overall health status. Currently, a referral process loosely exists to assist patients seeking medical care who may indicate needing psychosocial support group care. This

linkage must be strengthened to further develop opportunities and resources for individuals presenting for medical care and may be experiencing somatic or stigma-related symptoms. Improving and enhancing the referral system to mental health care needs to be addressed with medical personnel.

Furthermore, this study suggests that these individuals experienced a need for support from others, enough so that they have enrolled and participated in this psychosocial support group structure. The characteristics described in this study offer insight to the types of patients within an HIV care infrastructure that may need social support or other psychological services. As the groups currently function, care is not standardized across groups and there is little quantifiable "therapy" occurring with the patients. However, anecdotal evidence suggests that individuals report "improvements" when they regularly attend psychosocial support group sessions. The groups could serve as a mechanism for assessment. Furthermore, protocols for further assessment and referrals into psychological or psychiatric care need to be incorporated before such assessments become routine even for the support network. If the psychological care was given elsewhere; for example, from a team of mental health care professionals, the support group leaders would be able to utilize their skills more appropriately and effectively.

This study reports on individuals who selected to participate in this study of AMPATH Support Network members in Eldoret, Kenya. The findings suggest that those developing comprehensive HIV-related programs in developing countries may benefit from formulating opportunities for continuing to work toward the delivery of services that support psychosocial well-being, for strengthening linkages between established systems of HIV-related treatment and psychosocial support programs, and for identifying potential patients who might be more likely to enroll in psychosocial support upon the recommendation of an HIV-related provider.

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