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Psychosocial Characterization of HIV Clients with Potential To be Change Agents for HIV Prevention in Uganda

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Abstract

New research suggests that people living with HIV have the potential to be strong advocates for HIV prevention by passing on HIV prevention messages within their social networks. However, there is a paucity of research into the nature and prevalence of HIV prevention behaviours engaged in by HIV clients, and the psychosocial correlates of such advocacy, which are the goals of this analysis. We examined engagement in HIV prevention advocacy among 602 new HIV clients at two clinics in Uganda. Eighty nine percent reported encouraging others to get tested for HIV, 79% told people they know to use condoms when they have sex, and 61% reported discussing HIV more generally with friends and family. A client was classified as fully engaged in HIV prevention advocacy if they reported engaging in all three of the measured HIV prevention advocacy behaviors. In the bivariate analysis, being from the rural study site ($p<0.001$), higher levels of HIV disclosure to friends ($p<0.001$), greater hopefulness ($p<0.001$), and lower levels of depression ($p<0.001$) and internalized HIV stigma ($p<0.001$) were associated with full engagement in HIV prevention advocacy. In the multivariate analysis, being from the rural study site (OR=5.461, 95% CI=3.11-9.61), lower levels of internalized HIV stigma (OR=0.524, 95% CI=0.39-0.70) and higher levels of HIV status disclosure to friends (OR=2.040, 95% CI=1.23-3.38) remained significantly associated with full engagement in prevention advocacy. These data suggest that psychosocial adjustment and functioning may play a key role in empowering HIV clients to be advocates for prevention.

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Running title: CHARACTERICTICS OF HIV CLIENTS LIKELY TO ENCOURAGE HIV PREVENTION

Key Words: psychosocial, HIV/AIDS, change agents, prevention with positives, disclosure, stigma, Uganda

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Introduction

Although few interventions have sought to activate people living with HIV (PHAs) to reach out to their social network members and communities with HIV prevention messages, studies such as by Paxton [1] and Tumwine and colleagues [2] show that HIV clients without external motivation do pass on prevention messages to their network and community members. This prevention advocacy initiated by clients targeting their network members can help to reduce the spread of HIV in the community. Although PHAs without any clear external motivation reach out to their social network members with HIV prevention messages (encouraging condom use, abstinence, faithfulness, serosorting), available studies have not clearly presented the characteristics of those likely to engage in this HIV prevention advocacy. The purpose of this analysis is to examine the prevalence of the naturally occurring HIV prevention advocacy among HIV clients in care, and the characteristics of HIV clients most likely to engage in this HIV prevention advocacy. Findings from this analysis could contribute to HIV prevention for positives initiatives [3-5] by informing who to target as likely clients who might be motivated and ready to engage in prevention advocacy, and what barriers need to be addressed that impede some clients from engaging in HIV prevention advocacy.

HIV prevention advocacy generally involves encouraging persons in one's social network or community to adopt HIV protective behaviours. Few and only qualitative studies have so far been conducted to examine how those who have publicly disclosed their HIV status are engaging in HIV prevention advocacy [1]. In a recently completed qualitative study of prevention advocacy among PHAs, Tumwine and colleagues [2] found that 39/40 participants reported having engaged in HIV prevention advocacy with someone. Prevention advocacy to HIV-negative or persons of unknown HIV status tended to consist of encouragement of behaviors to prevent the person from contracting HIV, such as faithfulness, abstinence, and condom use, as well as HIV testing. Prevention advocacy to HIV positives included encouragement of behaviours that can enable them to avoid re-infection and/or passing on the infection to others (e.g., seeking HIV care, adherence to treatment, faithfulness, abstinence, condom use). Further research, including quantitative studies, are needed to better understand the characteristics of the HIV clients who are engaging in prevention advocacy, so as to inform interventions aimed at enhancing the benefits of such actions for both those engaging in such advocacy and the recipients.

Theoretical framework

Sayles and colleagues [6] describe a psychological process that a person living with HIV goes through from the time they are diagnosed HIV positive. First they deal with the stigma of HIV (internalized and societal stigma), and in the process of coming to terms with the diagnosis they begin to regain a sense of self-acceptance. They then renegotiate social contracts which in turn enables them to reconnect with family, friends and the community [7]. These stages are experienced with varying degrees of HIV stigma, discrimination and social support to the HIV positive person, which influence the psychological well-being of the individual. After going through these psychological processes, the individual gains more self-acceptance, and the negative psychological aspects of HIV are reduced, one may feel more comfortable with disclosing their HIV status and gain a sense of empowerment to champion for HIV prevention in the community. In relation to this theoretical framework, we assess PHAs levels of engagement in promoting HIV prevention within their social networks. We also assess the extent to which psychosocial variables such as internalized HIV stigma, discrimination, depression, and social support are associated with PHAs engagement in HIV prevention advocacy. Our guiding hypothesis was: participants who report lower HIV related discrimination, depression, internalized HIV stigma, and higher hope and social support would be more likely to engage in HIV prevention advocacy. The underlying goal of the analysis is to contribute to a better selection of change agents that can work as popular opinion leaders [8, 9] in

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their networks and to highlight the salient psychosocial barriers that need to be addressed in order to achieve a critical mass of change agents for promoting reduction in HIV risk behaviours in their general communities.

The research questions to be addressed in this analysis are: How prevalent are specific HIV prevention advocacy behaviors occurring among PHAs? And what are the demographic and psychosocial characteristics of PHAs who are more engaged in HIV prevention advocacy?

Methods

Study design

Participants were enrolled in a longitudinal prospective cohort study in Uganda to examine the impact of HIV antiretroviral therapy (ART) on multiple dimensions of health.

Sample

The study was conducted between January 2008 and October 2009 at two clinics operated by the Joint Clinical Research Center (JCRC), one in Kampala and the other in Kakira [10, 11]. Kakira is a small town located about 100 km outside Kampala next to a sugar plantation. A client was eligible if he/she was (1) age 18 or older, (2) new to the clinic and had just completed evaluation for ART eligibility, and (3) had CD4 cell count < 400 cells/mm^3 if not eligible for ART. While statistics on eligible clients who refused to participate were not collected, the study interviewers reported few clients declined to participate after being informed of the study.

Eligible clients were informed of the study by a clinic staff member after their eligibility for ART was determined; those who expressed interest were referred to the study interviewer for consent procedures and administration of the baseline interview. Participants were paid 5000 Uganda shillings (~ 2.00 USD) as compensation for the extra time spent at the clinic to complete the interview. The study protocol was approved by the Institutional Review Boards at RAND and JCRC, as well as Uganda National Council for Science and Technology. Participants went on to be scheduled for follow up interviews at month 6 and 12; however, only baseline data are included in the analysis for this paper.

Measures

All measures were translated into Luganda, the most common language in the study settings, and interviewer-administered.

Information about the patients' ***demographic and background characteristics*** including age of the participant, gender, education level (highest level of formal schooling including primary grades, secondary, technical/trade school, and university) and HIV test date were collected.

We developed three items to measure engagement in ***HIV prevention advocacy***. Respondents were asked to indicate their level of agreement with the following statements on a 4-point Likert scale from '1 strongly agree' to 4 'strongly disagree': "I like to talk to friends and family about HIV"; "I encourage others to use condoms every time they have sex"; and "I encourage others to get tested for HIV". For analysis, the three prevention advocacy variables were dichotomized with strongly agree and agree merged into one category defining engagement in the behavior, and strongly disagree and disagree merged into the category of non-engagement.

Internalized HIV stigma was assessed with an 8-item scale developed by Kalichman and colleagues [12]. Participants were asked to rate their level of agreement with statements such as "I feel guilty that I am HIV positive" using a 5 point rating scale; mean item scores were computed and higher scores represent greater stigma.

HIV discrimination was measured using an 8-item scale developed by Berger and colleagues [13].

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Participants used a 4-point scale to rate their level of agreement with statements indicating the presence of discriminatory events due to their HIV status such as loss of friends, people avoiding touching them, and people not wanting them around their children; mean item scores were computed and higher scores represent greater discrimination.

Hope was assessed using 2 items from the Beck Hopelessness Scale. Participants were asked to indicate their level of agreement with the following statements: "I look forward to the future with hope and enthusiasm", and "I might as well give up because there's nothing I can do about making things better for myself" [14]; a 4-point rating scale was used for each item and a mean item score calculated (after the latter item was reverse coded), with higher scores representing greater hope.

General social support was assessed using a single item: "I can count on my family and friends to give me the support I need", and a 4-point rating scale with higher scores representing greater support.

Depression was assessed with the 9-item Patient Health Questionnaire (PHQ-9) [15]. The 9 items are the 9 DSM symptom criteria for Major Depression; a "past 2 weeks" time frame is used and each item is scored from 0 'never' to 3 'every day'. Total score ranges from 0-27 and is the sum of all the items. Higher scores represent greater depression.

HIV disclosure was assessed with regard to friends and response options for this were 'none,' 'some' or 'all.'

Data Analysis

Statistical analyses

In bivariate analysis, factors associated with engagement in HIV prevention advocacy were analyzed using the Chi-square test of significance for categorical variables and independent t-tests for continuous variables. All p values were two tailed and considered significant at $p < 0.05$. Multivariate logistic regression analysis was conducted to analyze the psychosocial factors that were independently associated with engagement in HIV prevention advocacy (non full engagement vs. full engagement). Independent variables included in the regression model consisted of HIV clients' self reported levels of hope, HIV status disclosure to friends, internalized HIV stigma, depression and demographics (age, gender, level of education, marital status and study site). All analyses were performed using SPSS version 18.0.

Results

Sample Characteristics

Enrollment consisted of 602 clients, 300 from JCRC Kakira and 302 from JCRC Kampala. The demographic and background characteristics of the total sample are listed in Table 1. The majority 68.3% (411) of the participants were female, mean age was 36 (SD = 8.5) years (range of 20 to 75 years), 45.9% (249) had attained some secondary level of education or higher, 44.9% (270) were married or in a committed relationship, and 73.9% (445) had disclosed to some or all of their friends.

Engagement in Prevention Advocacy Behaviors

We first examined the proportion of study respondents who reported engaging in the three prevention advocacy behaviors; 89% reported encouraging others to get tested for HIV, 79% encouraged people they know to use condoms every time they have sex, and 61% reported talking to friends and family about HIV. The three dichotomous variables representing whether or not the participant engaged in each of the three HIV prevention advocacy behaviours were summed (possible range of 0 to 3) into one four level composite variable: 4.5% (27) of participants reported never engaging in any of the three behaviours, 11.8% (71) engaged in just one of the behaviours, 33.6% (202) in two behaviours, and 50.2% (302) of the participants engaged in all three prevention advocacy behaviours. The 4 level composite variable was then also dichotomized; participants who

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Table 1: Demographic and background characteristics of the total sample, as well as by level of engagement in HIV prevention advocacy

		Engagement in HIV Prev. Advocacy		
Demographic and Background characteristics	Total sample (N=602)	Not fully engaged (N=300)	Fully Engaged (N=302)	p-value (x^2)
Study Site				
JCRC Kampala	50.2%	75.7%	24.8%	0.000
JCRC Kakira	49.8%	24.3%	75.2%	
Male gender	31.7%	31.8%	31.7%	0.974
Mean (SD) age (years)	36 (8.5)	35.3 (8.8)	36.1 (8.2)	0.282 (t- test)
Relationship status				
Married/ in a committed relationship	44.9%	44.1%	45.7%	0.703
Single/divorced/separated/widowed	55.1%	55.9%	54.3%	
Education				
Primary School or less	54.1%	53.3%	54.9%	0.704
Secondary school or more	45.9%	46.7%	45.1%	
Disclosure to some or all friends	73.9%	66.3%	81.5%	0.000

reported engaging in 0, 1 or 2 prevention advocacy behaviours were classified as "not fully engaged" in HIV prevention advocacy, while those who reported engaging in all three behaviours were classified as "fully engaged" in HIV prevention advocacy. On the basis of this classification, 50.2% (n=302) of the participants were fully engaged in HIV prevention advocacy. Table 1 lists the demographic and background characteristics of the subgroup of participants who were fully engaged in prevention advocacy, as well those not fully engaged. The two variables that differentiated the two subgroups were HIV disclosure to friends, as those who were fully engaged in prevention advocacy were more likely to have disclosed to some or all of their friends; and study site, with clients from JCRC Kakira/the rural site, more likely to have engaged in HIV prevention advocacy.

Table 2 presents the bivariate relationships between the psychosocial measures (hope, general social support, depression, internalized HIV stigma, discrimination) and each of the dichotomous indicators of the three prevention advocacy behaviors, as well as the dichotomized composite variable (fully versus not fully engaged in prevention advocacy). Higher internalized HIV stigma was associated with lower engagement in each of the individual prevention advocacy behaviours, as well as the composite variable. Higher depression was significantly associated with a lower likelihood of generally liking to talk to friends and family about HIV and marginally associated with a lower likelihood of telling people one knows to use condoms when they have sex), as well the composite variable. Higher hopefulness was significantly associated with a higher likelihood of generally liking to talk to friends and family

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Table 2: Bivariate psychosocial correlates of engagement in HIV prevention advocacy

Psychosocial measures	Engagement in HIV prevention advocacy		p-value
	I encourage others to get tested for HIV		
	Not Engaged (N=65) Mean (SD)	Engaged (N=537) Mean (SD)	
General social support	3.3077(0.92)	3.3724 (1.01)	0.623
Depression	0.9192 (0.53)	0.85 (0.54)	0.301
Internalized HIV Stigma	2.8288 (0.92)	2.3689 (0.97)	0.000
Discrimination	1.1692 (0.54)	1.2318 (0.62)	0.436
Hope	3.5462 (0.50)	3.6676 (0.49)	0.060
	I tell people I know to use condoms when they have sex		
	Not Engaged (N=126)	Engaged (N=476)	
General social support	3.3651 (0.95)	3.3655 (1.01)	0.996
Depression	0.9335 (0.55)	0.8329 (0.53)	0.062
Internalized HIV Stigma	2.9276 (0.93)	2.2839 (0.95)	0.000
Discrimination	1.1974 (0.60)	1.2324 (0.62)	0.568
Hope	3.4167 (0.46)	3.7174 (0.48)	0.000
	I like to talk to friends and family about HIV		
	Not Engaged (N=234)	Engaged (N=368)	
General social support	3.4145 (0.95)	3.3342 (1.03)	0.338
Depression	1.0021 (0.59)	0.7597 (0.48)	0.000
Internalized HIV Stigma	2.9573 (0.93)	2.0761 (0.83)	0.000
Discrimination	1.2046 (0.60)	1.2381 (0.62)	0.512
Hope	3.5107 (0.51)	3.7459 (0.46)	0.000
	HIV Prevention Advocacy composite variable		
	Not fully Engaged (N=300)	Fully Engaged (N=302)	
General social support	3.4100 (0.93)	3.3212 (1.07)	0.277
Depression	0.9794 (0.58)	0.7293 (0.47)	0.000
Internalized HIV Stigma	2.8792 (0.94)	1.9611 (0.76)	0.000
Discrimination	1.1988 (0.58)	1.2512 (0.64)	0.292
Hope	3.4917 (0.51)	3.8162 (0.42)	0.000

about HIV, telling one knows to use condoms when they have sex, and moderately associated with a higher likelihood of encouraging others to get tested for HIV), as well the composite variable.

Multivariate Analysis of factors associated with Engagement in HIV prevention advocacy

All psychosocial variables that were significantly associated with at least one individual prevention advocacy item and or the dichotomized composite variable in the bivariate analysis were entered into the logistic regression model to ascertain the independent predictors of full engagement in HIV prevention advocacy. These variables included depression, internalized HIV stigma, and hope. Demographics (gender, age, marital status, and level of education), HIV disclosure to friends and study site were also included in the model as covariates. Table 3 lists the results of the logistic regression model that predicts full engagement in HIV prevention advocacy.

Disclosure to some or all friends, internalized HIV stigma and being from the rural study site (JCRC Kakira) were the only independent predictors of engagement in HIV prevention advocacy. A unit increase in internalized HIV stigma for instance reduced the odds of engagement in HIV prevention advocacy by a factor of 0.52. And disclosure to some or all friends (compared to disclosure to none), increased the odds of engagement in HIV prevention advocacy by a factor of 2.04.

Discussion

Our study findings suggest that most HIV clients convey HIV prevention messages to members in their social networks. When individual prevention messages are considered, 89% reported encouraging others to get tested for HIV, 79% tell people they know to use condoms every time they are to have sex, and 61% talk to friends and family about HIV in general. With full engagement stringently defined (to only include those engaged in all 3 prevention behaviours), 50% of the participants still could be classified as fully engaged in HIV prevention advocacy. Most participants reported

Table 3: Multivariate logistic regression for full engagement in HIV prevention advocacy

Variables	Odds Ratio	p-value	95% CI
JCRC Kakira site (base=JCRC Kampala site)	5.461	0.000	(3.105-9.607)
Female gender	1.025	0.915	(0.649-1.620)
Age in years	0.985	0.272	(0.960-1.012)
At least some secondary school education (base=none or primary education)	1.389	0.137	(0.900-2.143)
Single (base=Married/in committed relationship)	1.138	0.560	(0.737-1.759)
Disclosure to some or all friends (base=no disclosure)	2.040	0.006	(1.233-3.376)
Hope	1.381	0.209	(0.834-2.287)
Depression	1.234	0.373	(0.776-1.962)
Internalized HIV stigma	0.524	0.000	(0.391-0.703)

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engaging in the above HIV prevention messages, and did so without monetary or any other kind of incentive. We believe, with a properly designed intervention, PHAs can pass on more of such HIV prevention messages among their social network and community members.

In the bivariate analysis, most aspects of healthy psychosocial functioning were associated with full engagement in HIV prevention advocacy. In the multivariate analysis too, HIV status disclosure to some or all friends, and lower HIV internalized stigma remained significantly associated with full engagement in HIV prevention advocacy. These findings generally support the framework developed by Sayles and colleagues [6], and which we adopted to provide the lens through which we could interpret our findings. This framework suggests that poor psychosocial functioning (as a result of getting to know that one is HIV positive) among most PHAs is common in the period immediately after receiving HIV results, but HIV clients often adjust and restore psychosocial functioning after this initial period. During the period of poor psychosocial functioning, the HIV client withdraws from community activities, but during the period of better psychosocial functioning and adjustment to being HIV-positive, the client gains self-acceptance and re-engages in community activities.

In the multiple logistic regression analysis, higher internalized HIV stigma was significantly associated with a lower likelihood of engagement in HIV prevention advocacy. Also, disclosure to some or all friends was significantly associated with full engagement in HIV prevention advocacy. The current finding on HIV status disclosure is partly consistent with other studies such as by Calin and colleagues [16] and Patel and colleagues [17], which showed that the psychosocial variable of perceived stigma is a predictor of disclosure among the HIV clients. This finding implies that HIV disclosure has the potential to be a strong moderator between psychosocial functioning and full engagement in HIV prevention advocacy. The more someone is comfortable being open about their HIV status, the more likely they are to feel comfortable discussing HIV, and perhaps the more effective and credible they will be with regard to conveying messages related to HIV prevention advocacy.

The study has limitations that are worth noting. Engagement in HIV prevention advocacy assessed in this analysis was limited to only three behaviors (encouraging condom use, HIV testing and generally talking about HIV/AIDS with family and friends), where as prevention advocacy can include many other aspects such as encouraging other HIV protective behaviours like male medical circumcision, HIV status disclosure, and for the HIV positives –seeking HIV treatment. Some of the variables (social support, disclosure, hope) were measured with only one or two items, which can be prone to poor reliability. The study findings cannot be generalized to all PHAs, since the sample consisted of only those clients just starting HIV care who may be different from clients in care for a longer period of time or those who are not in care at all. Also, no causal inferences can be made as to whether poor psychosocial functioning precedes limited engagement in HIV prevention advocacy since this is only a cross-sectional analysis. There is need for further longitudinal studies that can examine the causal relationships between full engagement in HIV prevention advocacy and psychosocial functioning.

Further research that takes into account the nature of recipients of the prevention advocacy, and more specific descriptions of the prevention advocacy behaviours enacted by PHAs, is needed to enable a more complete assessment of the potential for PHAs to be effective change agents. Also, there is need for further research that strives to determine the factors that explain the different levels of engagement in HIV prevention advocacy between rural and urban areas in Uganda that this study highlights.

In conclusion, these findings reveal a fairly high prevalence level of HIV prevention advocacy among clients attending the two HIV clinics in Uganda. The findings further reveal a strong relationship between healthy psychosocial adjustment and functioning and

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greater prevention advocacy among PHAs. Those with better psychological well-being (lower depression and greater hope) and greater acceptance of their HIV status (lower internalized stigma) were more likely to be fully engaged in prevention advocacy behaviors. Interventions aimed at empowering HIV clients as change agents for HIV prevention within their social networks and communities need to address these psychosocial factors so that PHAs can fulfill their potential to have a critical impact on HIV prevention. Activating PHAs to be agents for HIV prevention behaviors provides HIV clients with an opportunity to see themselves and be seen by others as a vital part of the solution to the HIV epidemic and not just part of the problem.

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