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Disclosure of HIV status among patients new to HIV care in Southern Ethiopia: role of perceived social support and other factors

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ABSTRACT
Reports from Sub-Saharan Africa, with a large HIV-infected population, vary widely in how often HIV status is disclosed to others, including spouses and other partners. We surveyed 1799 Ethiopian HIV patients newly enrolled in care within the previous 3 months at one of 32 local hospitals and health centers about disclosure of HIV status and two perceived social support domains: emotional/informational (EI) and tangible assistance (TA) support. Disclosure to another person was reported by 1389 (77%) persons. Disclosure rates to specific persons were: spouses or other partners = 74%; mothers = 24%; fathers = 16%; children = 26%; other family members = 37%; friends = 19%, and neighbors/other community members = 13%. Disclosure to another person was associated with higher social support scores on both EI and TA domains, marriage, and a longer time knowing HIV status. In multivariate adjusted models, disclosure to any person, as well as disclosure specifically to a spouse or partner, were associated with higher EI and higher TA social support scores. Provision of knowledgeable and emotionally supportive assistance can be an important factor in facilitating HIV disclosure. Helping persons with HIV decide who to disclose to and how to do so in the most positive manner is an essential component of HIV care and support.

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HIV disclosure; social support; sub-Saharan Africa; Ethiopia

Introduction

For persons living with HIV (PLHIV), the decision to share their HIV status with others can have many positive outcomes, but may also be associated with concerns about negative reactions (Bott & Obermeyer, 2013; Deribe et al., 2010; Dessalegn et al., 2019; Dessie et al., 2019; Gadisa et al., 2017; Gari et al., 2010; Kiene et al., 2018; King et al., 2008; van Lettow et al., 2019; Wong et al., 2009). Disclosure to sexual partners or others can have benefits including adopting measures to prevent HIV transmission, psychological and emotional support, reduced feelings of depression, and positive impacts on treatment adherence and other health outcomes. However, PLHIV may be concerned about potential negative consequences of disclosure, including social rejection, isolation and physical violence.

Reports from Sub-Saharan Africa (SSA), with the greatest numbers of PLHIV, vary widely in how often HIV status is disclosed to others, including sexual partners. In one systematic review of pregnant and post-partum women in SSA, disclosure rates to any person ranged from 5.0% to 97%, and to husbands or partners from 30% to 93% (pooled estimate = 64%) (Tam et al., 2015). In another systematic review of Ethiopian PLHIV, disclosure rates to sexual partners varied from 42% to 93% (pooled estimate = 73%) (Mekonnen et al., 2019). Other recent studies from Ethiopia and elsewhere in SSA also reported diverse HIV status disclosure rates to sexual partners and others (Abdool Karim et al., 2015; Damian et al., 2019; Dessalegn et al., 2019; Gadisa et al., 2017; Molemans et al., 2019; van Lettow et al., 2019).

Given the potential benefits of disclosing HIV status and variable rates reported in SSA, it is important to identify factors associated with disclosure in this population. In this analysis, we report the rate of disclosure to different persons among 1799 Ethiopian PLHIV newly entering care within the previous three months, and the association of disclosure with demographic characteristics, perceived social support, and other psychosocial factors. We first report on disclosure to any other person, and then (given potential risks of sexual transmission) specifically focus on disclosure to spouses or other partners.

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Methods

Participants were recruited for a randomized trial of community support workers for newly diagnosed PLHIV (Lifson et al., 2018). We hypothesized that social support from such workers would improve retention in HIV care and other health outcomes. Patients were enrolled from HIV clinics at 32 local hospitals or health centers in Ethiopia's Southern Nations, Nationalities, and Peoples' Region, which has a large rural population. Inclusion criteria included age ≥18 years, and new enrollment in HIV care at participating clinics within the previous 3 months.

Measurements

Baseline health surveys, verbally administered in Amharic by trained staff, included two multi-part questions assessing disclosure: "Have you told the following people you are HIV-positive?" (asked individually about disclosure to mothers, fathers, and spouses/primary partners), and "How many of the following people have you told that you are HIV-positive?" (asked individually about disclosure to children, other relatives, friends, neighbors, and community members).

Perceived social support was assessed using two domains from the Medical Outcome Study Social

Table 1. Number and proportion of HIV patients who disclosed their HIV status to one of more persons, among those newly enrolling in care at HIV clinics in Southern Ethiopia, 2015–2017: relative risk by selected characteristics or responses (*N* = 1799).

	Did Not Disclose (*N* = 410)	Disclosed (*N* = 1389)	Relative Risk (95% CI)
Gender			
Male (*N* = 733)	184 (25%)	549 (75%)	Referent
Female (*N* = 1066)	226 (21%)	840 (79%)	1.05 (1.00–1.11)
Age (years)			
≤25 (*N* = 435)	101(23%)	334 (77%)	Referent
26–44 (*N* = 1108)	268 (24%)	840 (76%)	0.99 (0.93–1.05)
≥45 (*N* = 221)	38 (17%)	183 (83%)	1.08 (1.00–1.17)
Marital status			
Single (*N* = 274)	85 (31%)	189 (69%)	Referent
Married (*N* = 888)	124 (14%)	764 (86%)	1.25 (1.15–1.36)
Widow, divorced, separated (*N* = 632)	199 (31%)	433 (69%)	0.99 (0.90–1.09)
Education			
No School (*N* = 471)	105 (22%)	366 (78%)	Referent
Some Primary School (*N* = 852)	196 (23%)	656 (77%)	0.99 (0.93–1.05)
Above Primary School (*N* = 475)	109 (23%)	366 (77%)	0.99 (0.93–1.06)
Total social support score on MOS-SSS EI and TA domains combined			
Lowest (12–20) (*N* = 473)	196 (41%)	277 (59%)	Referent
Middle (21–47) (*N* = 840)	164 (20%)	676 (80%)	1.37 (1.26–1.49)
Highest (48–60) (*N* = 479)	50 (10%)	429 (90%)	1.53 (1.41–1.66)
Total score on MOS-SSS EI support domain			
Lowest (8–11) (*N* = 458)	184 (40%)	274 (60%)	Referent
Middle (12–31) (*N* = 835)	176 (21%)	659 (79%)	1.32 (1.21–1.43)
Highest (32–40) (*N* = 500)	50 (10%)	450 (90%)	1.50 (1.39–1.63)
Total score on MOS-SSS TA support domain			
Lowest (4–7) (*N* = 417)	174 (42%)	243 (58%)	Referent
Middle (8–16) (*N* = 965)	189 (20%)	776 (80%)	1.38 (1.26–1.51)
Highest (17–20) (*N* = 415)	47 (11%)	368 (89%)	1.52 (1.39–1.66)
Responses to HIV knowledge questions			
<6 correct responses (*N* = 709)	176 (25%)	533 (75%)	Referent
6–8 correct responses (*N* = 1090)	234 (21%)	856 (79%)	1.04 (0.99–1.10)
Chronic disease symptoms			
1–6 symptoms (*N* = 1511)	347 (23%)	1164 (77%)	Referent
None (*N* = 288)	63 (22%)	225 (78%)	1.01 (0.95–1.08)
WHO clinical stage			
Stage I or II (*N* = 1058)	252 (24%)	806 (76%)	Referent
Stage III or IV (*N* = 723)	157 (22%)	566 (78%)	1.03 (0.98–1.08)
CD4+ (cells/mm^3)			
≥200 (*N* = 867)	199 (23%)	668 (77%)	Referent
<200 (*N* = 554)	107 (19%)	447 (81%)	1.05 (0.99–1.11)
Able to carry out activities of daily living			
Unable to carry out (*N* = 282)	57 (20%)	225 (80%)	Referent
Able to carry out (*N* = 1513)	352 (23%)	1161 (77%)	0.96 (0.90–1.03)
Significant depression (CES-D-10 score >10)			
No (*N* = 807)	176 (22%)	631 (78%)	Referent
Yes (*N* = 991)	234 (24%)	757 (76%)	0.98 (0.93–1.03)
Length of time since first learned HIV status			
0–2 months (*N* = 1157)	296 (26%)	861 (74%)	Referent
3–12 months (*N* = 313)	64 (20%)	249 (80%)	1.07 (1.00–1.14)
>12 months (*N* = 285)	43 (15%)	242 (85%)	1.14 (1.08–1.21)

Abbreviations: RR = Relative Risk, CI = Confidence intervals, MOS-SSS = Medical Outcome Study Social Support Survey, EI = emotional/informational support, TA = Tangible assistance support, CESD-10 = Centre for Epidemiologic Studies Depression Scale (10 item)

Table 2. Multivariate analysis*: RR of Disclosure of HIV Status to any person (A) and to spouses and other Partners (B) by scores on the MOS-SSS EI and TA social support domains, among those newly enrolling in care at HIV clinics in Southern Ethiopia, 2015–2017.

(A) Disclosure of HIV Status to Any Other Person (*N* = 1799)	RR (95% CI)
Total score on MOS-SSS EI support domain	
Lowest quartile (8–11) (*N* = 458)	Referent
Middle two quartiles (12–31) (*N* = 835)	1.31 (95% CI: 1.20–1.42)
Highest quartile (32–40) (*N* = 500)	1.48 (95% CI: 1.36–1.61)
Total score on MOS-SSS TA support domain	
Lowest quartile (4–7) (*N* = 417)	Referent
Middle two quartiles (8–16) (*N* = 965)	1.33 (95% CI: 1.22–1.45)
Highest quartile (17–20) (*N* = 415)	1.45 (95% CI: 1.33–1.59)
(B) Disclosure of HIV Status to Spouse or Other Partner (*N* = 966)	
Total score on MOS-SSS EI support domain	
Lowest quartile (8–11) (*N* = 215)	Referent
Middle two quartiles (12–31) (*N* = 458)	1.17 (95% CI: 1.03–1.31)
Highest quartile (32–40) (*N* = 292)	1.22 (95% CI: 1.08–1.38)
Total score on MOS-SSS TA support domain	
Lowest quartile (4–7) (*N* = 166)	Referent
Middle two quartiles (8–16) (*N* = 549)	1.29 (95% CI: 1.12–1.48)
Highest quartile (17–20) (*N* = 250)	1.27 (95% CI: 1.10–1.48)

*Models are adjusted for gender, marital status, age, knowledge, depression and time between HIV diagnosis and survey date.

Support Survey (MOS-SSS): emotional/informational (EI) support (8 items assessing emotional support and guidance/advice), and tangible assistance (TA) support (4 items assessing material aid or assistance) (Sherbourne & Stewart, 1991). For analysis, EI, TA and total scores were categorized into three levels: the lowest quartile, two middle quartiles, and highest quartile, allowing for comparison of groups with higher and lower support levels. Other survey items included: demographics; month and year participant first learned their HIV-positive status; presence of six physical symptoms lasting > 1 month; ability to carry out normal activities (e.g., work, family care); knowledge about HIV treatment (8 agree/disagree questions); and the 10-item Centre for Epidemiologic Studies Depression Scale (CES-D-10) (Andresen et al., 1994). CD4+ count and WHO HIV clinical stage were abstracted from medical records.

Analysis

Crude associations between factors of interest and disclosure are presented using relative risks (RR) with 95% confidence intervals (CI). We used multivariable logistic regression to estimate associations between perceived social support and disclosure; estimates were used to compute marginal adjusted relative risks (Muller & MacLehose, 2014; Norton et al., 2013). Regression models were fit for each combination of dependent and independent variables. All models were adjusted for gender, marital status, age, HIV knowledge, depression, and time between diagnosis and baseline survey. Data were analyzed in Stata V15.1 (StataCorp, 2017).

Ethics

All participants provided signed informed consent after verbal explanation of consent provisions. Ethiopia's Ministry of Science and Technology National Research Ethics Committee and the University of Minnesota Institutional Review Board approved this study.

Results

From October 2015 through April 2017, 1799 PLHIV enrolled, representing 92% of eligible patients (Lifson et al., 2018); characteristics are shown in Table 1. The mean age was 32.8 years, mean CD4+ count was 322 cells/mm^3, and median time participants knew their HIV status was one month. For the 12 items from the MOS-SSS (possible scores = 12–60), the median score was 35 (interquartile range [IQR] = 20,48). For the EI domain (possible scores = 8–40), median score was 22 (IQR = 11,32). For the TA domain (possible scores = 4–20), median was 12 (IQR = 8,16). Higher scores for each domain reflect greater social support.

Of all participants, 1389 (77%) reported disclosing their HIV status to another person. Of 966 participants married or with a primary partner, 74% reported disclosing to this person. When asked about immediate family members, and excluding those who said this question was "not applicable" (e.g., because a parent was not living), 24% of 1113 persons reported disclosing to mothers and 16% of 785 to fathers. Twenty-six percent of 1114 persons reported disclosing to a child, and 37% of 1759 to another relative/family member (e.g., sibling, aunt, uncle, grandparent). Of all 1799 participants, 19% reported disclosing their status to a friend, and 13% to a neighbor or other community members.

In univariate analysis, those who reported disclosing HIV status to another person were significantly more likely to have higher social support scores on both EI and TA domains, to be married vs. single, and to have known their HIV status >12 months (Table 1). In multivariate adjusted models, reported disclosure remained more likely among those with higher EI and TA perceived social support scores (Table 2).

Table 3. Number and proportion of HIV patients who disclosed their HIV status to a spouse or other partner, among those newly enrolling in care at HIV Clinics in Southern Ethiopia, 2015–2017: relative risk by selected characteristics or responses (*N* = 966).

	Did not disclose (*N* = 252)	Disclosed (*N* = 714)	Relative risk (95% CI)
Gender			
Male (*N* = 485)	133 (27%)	352 (73%)	Referent
Female (*N* = 481)	119 (25%)	362 (75%)	1.04 (0.96–1.12)
Age (years):			
≤ 25 (*N* = 181)	52 (29%)	129 (71%)	Referent
26–44 (*N* = 635)	159 (25%)	476 (75%)	1.05 (0.95–1.17)
≥45 (*N* = 130)	39 (30%)	91 (70%)	0.98 (0.85–1.14)
Marital status:			
Single (*N* = 37)	14 (38%)	23 (62%)	Referent
Married (*N* = 846)	178 (21%)	668 (79%)	1.27 (0.99–1.64)
Widow, divorced, separated (*N* = 82)	60 (73%)	22 (27%)	0.43 (0.28–0.67)
Education:			
No School (*N* = 239)	69 (29%)	170 (71%)	Referent
Some Primary School (*N* = 462)	115 (25%)	347 (75%)	1.06 (0.96–1.16)
Above Primary School (*N* = 265)	68 (26%)	197 (74%)	1.05 (0.94–1.16)
Total social support score on MOS-SSS EI and TA domains combined			
Lowest quartile (12–20) (*N* = 214)	86 (40%)	128 (60%)	Referent
Middle two quartiles (21–47) (*N* = 463)	104 (22%)	359 (78%)	1.30 (1.15–1.46)
Highest (48–60) (*N* = 287)	62 (22%)	225 (78%)	1.31 (1.16–1.49)
Total score on MOS-SSS EI support domain			
Lowest (8–11) (*N* = 215)	82 (38%)	133 (62%)	Referent
Middle (12–31) (*N* = 458)	110 (24%)	348 (76%)	1.23 (1.09–1.38)
Highest (32–40) (*N* = 292)	60 (21%)	232 (79%)	1.28 (1.14–1.45)
Total score on MOS-SSS TA support domain			
Lowest (4–7) (*N* = 166)	71 (43%)	95 (57%)	Referent
Middle (8–16) (*N* = 549)	124 (23%)	425 (77%)	1.35 (1.18–1.55)
Highest (17–20) (*N* = 250)	57 (23%)	193 (77%)	1.35 (1.16–1.56)
Chronic disease symptoms			
1–6 symptoms (*N* = 787)	211 (27%)	576 (73%)	Referent
None (*N* = 179)	41 (23%)	138 (77%)	1.05 (0.96–1.15)
WHO clinical stage			
Stage I or II (*N* = 582)	142 (24%)	440 (76%)	Referent
Stage III or IV (*N* = 376)	108 (29%)	268 (71%)	0.94 (0.87–1.02)
CD4+ (cells/mm^3)			
≥200 (*N* = 483)	128 (27%)	355 (73%)	Referent
<200 (*N* = 304)	75 (25%)	229 (75%)	1.02 (0.94–1.11)
Able to carry out normal activities of daily living			
Unable to carry out (*N* = 133)	33 (25%)	100 (75%)	Referent
Able to carry out (*N* = 831)	218 (26%)	613 (74%)	0.98 (0.88 -1.09)
Responses to HIV knowledge questions			
<6 correct responses (*N* = 362)	97 (27%)	264 (73%)	Referent
6–8 correct responses (*N* = 604)	155 (26%)	449 (74%)	1.02 (0.94–1.10)
Significant depression (CES-D-10 score >10)			
No (*N* = 465)	128 (28%)	337 (72%)	Referent
Yes (*N* = 501)	124 (25%)	377 (75%)	1.04 (0.96–1.12)
Length of time since first learned HIV status			
0–2 months (*N* = 609)	182 (30%)	427 (70%)	Referent
3–12 months (*N* = 168)	43 (26%)	125 (74%)	1.06 (0.96–1.18)
>12 months (*N* = 167)	21 (13%)	146 (87%)	1.25 (1.15–1.35)

Abbreviations: RR = Relative Risk, CI = Confidence intervals, MOS-SSS = Medical Outcome Study Social Support Survey, EI = emotional/informational support, TA = Tangible assistance support, CESD-10 = Centre for Epidemiologic Studies Depression Scale (10 item).

Disclosure to spouse or sexual partner

Of 966 persons with a spouse or other primary partner, those who chose to disclose to this person were again more likely to have higher social support scores on both EI and TA domains and to know their HIV status for >12 months (Table 3). In multivariate adjusted models, disclosure was also more likely among those with higher EI and higher TA social support scores (Table 2).

Discussion

Among 1799 Ethiopian PLHIV newly entering care within a three month period, 77% reported disclosing HIV status to another person, most commonly to spouses or partners. Disclosure was more common among those with high social support scores on EI and TA domains, those knowing their HIV status for longer time periods, and those who were married.

Social support can be provided by multiple sources, including spouses, other family, and friends. In our analysis, social support was positively associated with reported HIV disclosure. We cannot tell whether social support preceded or resulted from disclosure, but both relationships likely exist. Since disclosure may be a stressful event (French et al., 2015; Odiachi et al., 2018), perceived social support could help "buffer" individuals against this anticipated stress (Cohen & Wills, 1985; Thoits, 1986). Disclosure may in turn lead to more positive social support from family and friends (Dessalegn et al., 2019; Gadisa et al., 2017; Odiachi et al., 2018; Wong et al., 2009).

Similar to other studies, we found disclosure rates were higher among those knowing their HIV status for longer time periods (Gadisa et al., 2017; King et al., 2008; Wong et al., 2009). Receiving an HIV diagnosis can be distressing and require major adaptive changes (Workowski & Bolan, 2015). More time allows individuals to better accept their HIV status, additional opportunities for counseling, and more time to prepare for the processes of disclosure.

Study limitations include lack of temporality on the relationship between social support and disclosure. Since behaviors were self-reported, we could not verify whether reported disclosures actually occurred. Associations may be due to other unmeasured confounders; however, the positive relationship between disclosure and social support is consistent with other studies. We achieved high participation rates from this specific target sample, but results may differ for other clinical, demographic or geographic populations.

It is concerning that even among those knowing their HIV status for three months or longer, some persons have not disclosed, even to their spouses or partners. Provision of knowledgeable and emotionally supportive assistance and counseling can be an important factor in facilitating HIV disclosure. As an essential component of HIV care, providers in HIV clinics, support groups, and community organizations can play a valuable role in helping PLHIV decide who to disclose to and how to do so in the most positive manner.

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