Social Support and Disclosure as Predictors of Mental Health in HIV-Positive Youth

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ABSTRACT

The purpose of this study was to describe mental health symptoms in a sample of 66 HIV-positive youth (ages 16–25) and to evaluate social support, disclosure, and physical status as predictors of symptoms. Data were collected from January 2002 to May 2003. As measured by the Brief Symptom Inventory (BSI), 50% of the youth scored above the cutoff for clinically significant mental health symptoms, thus highlighting the need for mental health services. Lower social support, higher viral load, HIV-status disclosure to acquaintances, and being gay/lesbian/bisexual (GLB) were all significantly correlated with more mental health symptoms, but disclosure to family and close friends and contact with service providers were not. Furthermore, regression analysis showed that social support, viral load, and disclosure to acquaintances predicted 32% of the variance in mental health symptoms. Being GLB was no longer significant, most likely because of shared variance with low social support. Results suggest the importance of mental health interventions, and the potential of social support interventions to improve mental health. Further research addressing the role of HIV-related stigma and homophobia is warranted.

INTRODUCTION

BY THE END OF 2004, there were 39.4 million individuals living with HIV across the world, with 950,000 living with HIV in the United States.[1] Youth between the age of 15 and 24 years account for nearly half of all new HIV infections worldwide, that is, more than 7000 new infections daily.[2] Because of the proliferation of newly infected youth, there is significant concern as to the psychosocial issues unique to this population. With the advent of highly active antiretroviral therapy (HAART), the entire course of HIV disease has been revolutionized.[3–6] HAART has prolonged life allowing further attention to issues around quality of life and psychosocial functioning. Furthermore, mental health concerns may impact illness management and health outcomes.

Enduring serious psychosocial distress during a critical developmental stage, such as adolescence, may have more enduring consequences. HIV-positive youth are not only undertaking the inevitable biologic, cognitive, and social developmental challenges of adolescence and young adulthood, but are also enduring the challenges of managing a chronic illness with a myriad of physical and psychosocial barriers. However, there is a paucity of literature on HIV-positive youth to date. There is a need to fill in the gaps with regards to the mental health concerns in HIV-positive

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youth, but also more importantly, what are the risk and protective factors that account for varied outcomes. The purpose of the present study is to describe mental health symptoms in a sample of HIV-positive youth (ages 16–25) and to evaluate potential predictors of symptoms as a foundation for intervention.

MENTAL HEALTH AND HIV DISEASE

Individuals living with HIV experience significant amounts of mental health concerns.[7–10] Symptoms may include mood disturbance, anxiety, social problems, suicide ideation/attempts, and hopelessness.[7–11] There has been a considerable amount of published literature that has studied the psychological effects of HIV disease in adults; however, less is known about mental health symptoms in HIV-positive youth.[10,12–15] One qualitative study suggested that HIV-positive youth identified psychological distress, peer and family relationships, and HIV-status disclosure as primary areas of difficulty.[13] Another study of psychiatric diagnoses in HIV-positive adolescents reported 44% of adolescents with ongoing depressive disorders.[14]

Similar to other chronic illnesses, the mental health concerns associated with HIV disease may have physiologic and psychosocial determinants. In HIV-positive adults, HIV health outcomes (HIV symptomatology) have been associated with higher levels of mental health symptoms[16,17]; although the direction of this relationship is unclear. HIV-related physical symptoms become a perpetual indication of disease progression and reminder of HIV status thus causing distress.[18] It is also plausible that mental health symptoms affect HIV medication adherence and consequently an increase in physiologic symptoms (increase in viral load). Interestingly, one study found that HIV-positive individuals who were diagnosed with depression also had impaired innate cellular immunity.[19] This decreased immunity affects the delaying of the progression of HIV disease. A published study by the same authors on the same population of adolescents in this study found that youths who were more psychological distressed also had poor medication adherence (as assessed by self-report adherence measures and laboratory viral load).[15] There is a paucity of literature examining the relationship between mental and physical health in HIV-positive youth.

MENTAL HEALTH AND SOCIAL SUPPORT

In the past two decades, research has consistently shown that family ties and friendships can offer a psychological buffer against life stress, anxiety and depression.[20,21] This is particularly relevant for youth since establishing a network of social support is one of the primary tasks of adolescence.[22] Social support is fundamental for normal development, but this is crucial for those who have to also endure the complexities of a chronic illness.[20,21] Research has revealed that social support has an effect on an individual's immune system, mortality risk, and survivability when faced with crises or serious illness.[20,21,23]

For HIV-positive adults, research has shown that an association exists between the magnitude of social support network and mental health symptoms.[24,25] Social support can enhance emotional well-being and also becomes vital for buffering HIV-related psychological distress and physical symptoms.[10,26,27] Social support can increase the sense of belonging, intimacy, competency, and self-worth that can promote positive mental health.[21] One published study of social support and mental health symptoms in HIV-positive adolescents showed that satisfaction with social support was associated directly with depression.[28] However, this cohort was mostly female and younger (ages 12–19) than current clinic populations of HIV-positive youth.

Finally, the Ryan White Care Act has provided an infrastructure of supportive services for persons with HIV infection and may be an important source of social support. The receipt of ancillary services such as case management, mental health and advocacy has been associated with increased retention in medical care in adults[29] and youth.[30] Furthermore, support groups for individuals can lessen feelings of isolation and stigmatization.[31] While the provision of multidisciplinary ancillary services

has become the standard of care in the treatment of HIV-positive youth, the relationship of these services to mental health has not been addressed.[32]

THE ROLE OF DISCLOSURE IN SOCIAL SUPPORT

There are many benefits of receiving social support related to HIV disease management, but this also requires disclosing HIV-status.[33] Research suggests that HIV-positive adults, who disclose their HIV-status to family and friends, do so because they want to preserve honesty in the relationship, to gain social support, and to avoid the anxieties of concealing their HIV-status.[34] Kalichman et al.[27] found that HIV-positive adults who disclose their HIV-status to family and friends experience greater social support from those relationships. Furthermore, depressive symptoms were most related to low social support when it involved relationships with individuals with whom they are the least to disclose their HIV status to (fathers, brothers, and extended family). Although disclosure has potential benefits, there are also potential social, emotional, and physical costs (ostracism, abandonment/isolation, anxiety) that accompany the full disclosure of an individual's HIV status.[35] One study of disclosure to perinatally infected children found that adolescents exhibited distress in response to their status being disclosed, such as pessimism about their HIV care, their future, and their health. [36] There are no published empirical studies of the role of disclosure in the social support and mental health symptoms of HIV-positive adolescents and young adults, and this study is a first attempt to fill this gap.

We hypothesized that HIV-positive youth would show high levels of mental health symptoms compared to the general population of youth based on published norms. Further, we hypothesized that mental health symptoms would be positively associated with poor health status while HIV-status disclosure and social support from family, friends, and service providers would be protective factors (negatively associated with psychological distress).

MATERIALS AND METHODS

Participants

Participants were enrolled in a larger clinical intervention trial, and this present paper reports on baseline data. Baseline data were collected from January 2002 to May 2003. Participants were recruited from an adolescent HIV clinic within a tertiary care children's hospital located in a major metropolitan area. The clinic offered medical and ancillary services in a one-stop-shopping model. Potential participants were eligible for the study if they (1) were HIV-positive; (2) were 16 to 25 years of age; (3) were English-speaking; and (4) were without a thought disorder that would interfere with questionnaire completion. The sample comprised 66 HIV-positive youth between the ages of 16 and 25 years of age, with a mean age of 21.2 years (standard deviation [SD] = 2.71). Fifty-one percent of the sample were male, 47% were female, and 2% were male to female transgendered. Eighty-seven percent were African American, 3% were European American, 2% were Hispanic, and 8% were mixed ethnicity. Thirty-one percent of the participants were employed, with 88% of the participants reported incomes less than $1000.00 per month, and 61% reported incomes less than $500.00 per month (incomes ranged from $0 to $2500.00 per month). Only 13 participants were school-aged (18 years and under), although it is not certain if they are currently in school because this was not asked in the demographics questionnaire. The mean education level was 11.35 (SD = 1.62), with more than half of the participants (56%) with less than a high school education. Fifty-seven percent of the sample were heterosexual, and the remainder were gay/lesbian/bisexual (GLB). As reported by the participant's primary care physician, 36% of participants were prescribed HIV medication ($n = 24$). The viral load for all participants ranged from undetectable to 475,000, with an average of 66,906 while the median was at 15,000 ($n = 66$, SD = 119,103).

Procedures

The clinical care team of the adolescent HIV clinic referred those interested in participating

to the researchers for more information. The protocol was approved by the university's Institutional Review Board, and a certificate of confidentiality was obtained from the National Institutes of Health. Informed consent was obtained from all participants, and a waiver of parental consent was permitted for youth under age 18. After completing informed consent, participants provided baseline data through an interviewer-administered questionnaire. The average length of time to complete the research interview was 60 minutes. Interviewers were clinically trained in research ethics, in giving all study measures, and in emergency protocols for clinical care (such as suicide or medical referrals). During this baseline research visit, participants completed a demographic form (included disclosure of HIV status), and a battery of measures that included psychological distress, social support, health status, and service utilization measures. Health outcome was also obtained by a chart review of the participant's current viral load. The study provided transportation for the participants, and they also received $25.00 for compensation of their time.

Study variables

Mental health symptoms. The 53-item Brief Symptom Inventory (BSI) measured psychological distress and symptom patterns (nine primary symptom dimensions of physical and mental status), and has been used extensively in medical, psychiatric, and non-patient populations, including HIV patients.[37] Analyses in the present study utilized the Global Severity Index (GSI), Depression Index, and the Anxiety Index of the Brief Symptom Inventory, which showed good internal consistency in the present sample ($\alpha = 0.97$). As a result of the high correlations between the three indexes (range, 0.83–0.93), the GSI was the only index used in the present study. Furthermore, when the depression and anxiety indexes were incorporated in the correlation and regression analyses, the results were similar to the results when only the GSI was used. The GSI is one of the BSI's global indices, which measures general psychological distress level. The indexes are calculated by the sum of the symptom dimensions and any additional items, than divided by the total number of responses. A higher participant-reported index score indicate a higher level of psychological distress. Internal consistency for the subscales (dimensions) ranged from 0.71 to 0.85. The 5-point response scale ranges from not at all to extremely. Non-patient–age-appropriate norms as published in the BSI manual are used as a comparison to the participants in this study. There have been studies that used the BSI in non-HIV chronically ill patients, and they have all consistently found that BSI scores were generally higher than the nonpatient norms. [37,38] One study found that 23.8% of patients with cancer met clinically significant criteria for psychological distress on the BSI.[38]

Social support and disclosure. Participants reported how much they agreed with 12 items from a shortened Social Provision Scale regarding their relationship with people in their lives.[39] The scale was shortened during previous pilot work and showed good reliability within the current sample ($\alpha = 0.86$). Youth also reported the frequency of utilization of health care (ancillary and regular health visits) and support services (e.g., nurse, support group, mental health, case management, and transportation) over the previous 3 months. The participants responded yes or no to whether or not they disclosed their HIV status to immediate family, extended family, close friends, and acquaintances.

Viral load. The health index used in this study was viral load. This was utilized because it is the primary health outcome linked to adherence in the adult and pediatric HIV literature.[40,41] Viral load was collected at baseline. If viral load was obtained in the previous month as part of clinical care, the result was gleaned from medical records and utilized instead of a new blood draw.

Data analytic plan

Bivariate analyses were first conducted to test associations between mental health symptoms (using the Global Symptom Index from the BSI), demographic characteristics, and hypothesized predictors. While means of viral load are reported, viral load data were highly

skewed. Thus, a log transformation of viral load was utilized in the analysis. Service utilization data were also highly skewed; therefore, this variable was categorized into youth who had contact with service providers in the previous 3 months and those who did not. Because there was only one transgendered youth, gender was recoded to capture biologic gender, and the one transgendered participant was recoded as a biologic male. To reduce the number of variables, measures associated in the bivariate analysis at $p < 0.10$ were then entered into multivariate analysis. Regression analysis was used with backwards elimination to identify measures independently associated with mental health symptoms.

RESULTS

Descriptive and bivariate analyses

Of the 66 participants in the study, 88% ($n = 58$) of the youths reported that they disclosed their HIV status to their immediate family, 32% ($n = 21$) disclosed to their extended family, 42% (n = 28) disclosed to their close friends, 18% ($n = 12$) disclosed to acquaintances. Only 3% ($n = 2$) did not disclose to anyone at all. Majority of youth (64%, $n = 43$) had contact with a service provider in the previous 3 months. Table 1 shows the percent of those participants who are above the clinical cutoff for mental health symptoms on the BSI, and that this percentage was higher than published norms (nonpatient age appropriate norms). As stated in the BSI manual, a t score of 63 or higher corresponds to 10% of the normative population.[37] In our study population, 50% scored above the clinical cutoff for the General Severity Index, 32% for Depression, and 29% for Anxiety.

Correlations between demographic vari-

TABLE 1. MENTAL HEALTH SYMPTOMS ABOVE CUTOFF

Mental health symptoms	% Above cutoff cutoff
BSI Subscales	
General Severity Index	50 ($n = 33$)
Depression	32 ($n = 21$)
Anxiety	29 ($n = 19$)

BSI, Brief Symptom Inventory.

ables, hypothesized predictors and mental health symptoms are presented in Table 2. Age, biologic gender, education, age at diagnosis, and duration of diagnosis were not associated with mental health symptoms. When age was categorized into those 18 years and younger ($n = 13$) and those 19 and older ($n = 53$), there were no significant associations with hypothesized predictors. Those individuals who endorsed that they were heterosexual (coded as a one) had significantly more social support ($r(66) = -0.25$, $p < 0.05$) and a trend to have lower levels of mental health symptoms ($r(66) = -0.22$, $p < 0.10$) than those who endorsed being GLB (coded as a two). Biologic gender was not associated with mental health symptoms. Two of the hypothesized predictors were associated with increased symptoms in the expected direction: lower social support ($r(66) = -0.54$, $p < 0.01$) and higher viral load ($r(66) = 0.31$, $p < 0.05$). Contrary to hypotheses, disclosure to family and close friends and contact with providers were not associated with mental health symptoms, but disclosure to acquaintances was associated with increased distress ($r(66) = 0.25$, $p < 0.05$).

Multivariate analyses

The four measures that were correlated with mental health symptoms in the bivariate analysis at $p < 0.10$ (social support, viral load, HIV status disclosure to acquaintances, and sexual orientation) were entered into a multiple regression model with backwards elimination. The final model ($F(3,64) = 11.10$, $p < 0.001$) contained three measures, social support (standardized β of -0.44, $t = -4.21$, $p < 0.001$), viral load (standardized β of 0.24, $t = 2.28$, $p < 0.05$), and disclosure to acquaintances (standardized β of 0.22, $t = 2.07$, $p < 0.05$). Sexual orientation was eliminated from the model. The adjusted R^2 for this model was 0.32. Table 3 summarizes the multiple regression analyses of all variables that may predict psychological distress.

DISCUSSION

The purpose of the present study was to describe mental health symptoms in a sample of

TABLE 2. BIVARIATE CORRELATIONS AMONG STUDY VARIABLES ($n = 66$)

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Demographic														
1. Age	—													
2. Age diagnosed with HIV	0.66[a]	—												
3. Duration of illness	0.00	-0.75[a]	—											
4. Highest grade completed	0.39[a]	0.44[a]	-0.26[b]	—										
5. Biologic gender	0.03	-0.15	0.23[c]	0.09	—									
6. Sexual orientation	0.09	0.21[c]	-0.20	-0.00	-0.59[a]	—								
Predictors–Social Support														
7. Viral load	0.13	0.02	0.08	-0.18	-0.02	0.14	—							
8. Total social support	-0.16	-0.14	0.05	0.16	0.17	-0.25[b]	-0.18	—						
9. Contact with support staff	0.08	-0.03	0.11	0.00	-0.08	-0.05	0.14	0.03	—					
10. Disclosure—immediate family	0.03	-0.15	0.23[c]	-0.22[c]	0.17	-0.24[c]	-0.11	0.22[c]	0.11	—				
11. Disclosure—extended family	-0.01	-0.18	0.23[c]	-0.06	-0.20	-0.00	-0.25[c]	-0.08	-0.06	0.06	—			
12. Disclosure—close friends	0.09	0.05	0.01	0.25[c]	-0.15	0.18	-0.01	0.07	0.13	0.04	0.26[b]	—		
13. Disclosure—acquaintances	0.18	0.21[c]	-0.12	0.20	-0.14	0.15	-0.05	-0.10	-0.12	0.06	0.43[a]	0.39[a]	—	
Psychological distress														
14. BSI Global Severity Index	0.12	0.16	-0.11	-0.11	-0.10	0.22[c]	0.31[b]	-0.54[a]	0.05	-0.07	-0.00	0.11	0.25[b]	—

[a] $p < 0.01$.
[b] $p < 0.05$.
[c] $p < 0.10$.
BSI, Brief Symptom Inventory.

TABLE 3.   MULTIPLE REGRESSION ANALYSES PREDICTING PSYCHOLOGICAL DISTRESS ($n = 66$)

| Variables | *Mental Health Symptoms (GSI)* | | |
	β	*Standardized β*	p
Total social support	−0.54	−0.44	0.00[a]
Disclosure—acquaintances	0.41	0.22	0.04[b]
Viral load	0.16	0.24	0.03[b]
Sexual orientation	0.04	0.03	0.79
Contact with providers	0.17	0.11	0.34

[a]$p < 0.001$.
[b]$p < 0.05$.
GSI, Global Severity Index.

HIV-positive youth (ages 16–25) and to evaluate potential predictors of symptoms as a foundation for intervention. Consistent with other studies of adult cancer patients[42,43] and HIV-positive youth,[13–15] youth in the present study had higher levels of mental health symptoms than the normative population. It is striking that half the sample scored above the clinical cutoff for self-reported symptoms, highlighting the need for mental health services. As hypothesized, social support was a potential buffer for mental health concerns in HIV-positive youth. These results are consistent with research on HIV-positive adults[18,24,25,27] and the one study of younger adolescents in the REACH cohort.[28] Contact with providers was not related to mental health. It is possible that youth maintained regular contact with providers regardless of mental health status as majority of youth had contact with providers in the previous 3 months. At least one study suggests that youth may have more contact with providers than adults[30] as quarterly appointments (versus every 6 months for adults) are often recommended.[32] Clearly intervention development is necessary to boost social support in the natural ecology of the youth, and not only from supportive services and support groups.[44] For example, Travers and Paoletti[44] found that most HIV-positive youths in their study reportedly did not know any HIV-positive peers and felt that they were the only one who had HIV; thus leading to reported feelings of social isolation and severe loneliness. Moreover, these youths stated that if they had access to supportive HIV-positive peers, they would be able to cope better with their illness. It is possible that HIV-related stigma may be a barrier to adequate social support for youth, and this is an area warranting further study.[44–48]

Those who endorsed being GLB had more mental health symptoms in the bivariate analysis, but this relationship was no longer significant in the multivariate analysis likely due to the shared variance with social support. That is, the relationship between sexual orientation and mental health symptoms may be accounted for (mediated by) the lower levels of social support reported by youth who are not heterosexual. Again, stigma (i.e., homophobia) may be the source of reduced social support in this population, particularly the stigma associated with being gay in the African American community.[49–52] Further research is necessary to confirm these relationships.

The current study found that there was a relationship between mental health and viral load; although directionality needs to be explored further. One cannot be certain whether it is mental health status that affects health status or that those with poorer health status are more distressed. This naturally leads to the issue of whether HIV medication adherence becomes a mediator between mental health and viral load.[53] One study found that HIV-positive individuals who were depressed also had impaired immunity which then escalates the progression of HIV disease.[19] Preliminary findings from Simoni et al.[54] showed that HIV-positive adults who had more social support were less psychologically distressed and were spiritual, which then affected self-efficacy to medication adherence. In a pilot study by Lyon et al.,[55] HIV-positive youths and their family members

or "treatment buddies" participated in a 12-week program to increase adherence to therapy. Ninety-one percent of youths reported increased adherence upon completion of the program, and indicated that social support was key to their success. Future studies need to explore and establish theoretical models that shed light on these issues.

Contrary to the study's hypotheses, HIV-status disclosure to family and close friends and contact with staff were not associated with psychological distress. The lack of relationship between disclosure to family and close friends and mental health is not consistent with studies of adults. It is possible that in adults, disclosure is more likely to involve partners as adults are more likely to disclose to friends than to family.[27] Youth in this study were more likely to disclose to family members, which are likely to be family of origin who may be less supportive and accepting of the diagnosis. Youth were less likely to disclose to friends which may reflect a normative developmental trend in adolescents where they place high value peer approval,[56] thus more reluctant to disclose their HIV-status. Friends may also be more transient in adolescence than in adulthood which may make disclosure less likely.

Alternatively, the quality of the family's and friends' response to the disclosure (and their subsequent social support) is more important than the disclosure itself. Future research should assess family and friends responses to disclosure. In this study, those who had disclosed their HIV status to acquaintances had more mental health symptoms. Here again, HIV-related stigma is a likely culprit. Clearly, it should not be assumed that disclosure will automatically benefit the youth, and the decision to disclose should be made on a case-by-case basis while informing the youth of the potential risks and benefits.

Limitations

Limitations include the generalizability of our findings because of a small sample from a single site. However, the demographics of this sample are consistent with the epidemic in the local area[57] and other inner city settings such as Washington, D.C.[58] Second, this study did not collect data on whether the youths were presently enrolled in school. This would be a potentially important variable in terms of both HIV disclosure to friends and, possibly, accompanying mental health symptoms.[10] Although in this study, age was not significantly associated with the hypothesized predictors and mental health, this may be due to our small sample size for those 18 years and younger. Third, it should also be noted that a rather conservative approach to data analyses was undertaken in this study owing to the modest sample size. Some of the effects observed in this study, though of reasonable magnitude in terms of effect size, were not considered statistically significant. Future studies with larger samples will provide evidence as to the stability and statistical importance of the bivariate correlations observed here. Fourth, causal implications of the findings must be tempered by the nature of the correlational data. Longitudinal studies with HIV-positive youth will provide important information about the developmental course and predictors of mental health symptoms for HIV-positive youths. Last, this study utilized a single self-report measure of mental health symptoms, social support, and service utilization. Multimethod measurement approaches may help reduce self-report bias.

Implications for intervention

This paper is a first step in characterizing the mental health symptoms of a clinical sample of HIV-positive youth and in demonstrating important role of social support.

Mental health services and interventions to boost social support are critical in the care of HIV-positive youth and may even serve to improve health status. Alternatively, improving the health status of youth, potentially via improved adherence to medications, may also serve to reduce mental health symptoms. There appear to be both cost and benefits to disclosing HIV-status, and youth may benefit from counseling around this issue. Finally, stigma around HIV and around sexual orientation may play a large role in mental health symptoms and social support of HIV-positive African American youth. Interventions to reduce stigma both at the community level (e.g., education, media messages) and at the individual level (peer counseling) may be benefi-

cial. These results suggest that HIV-positive youth have mental health concerns in addition to the physical symptoms which characterize their illness. As HIV has become a chronic illness and more attention is paid to quality of life, mental health services and social support interventions must be integrated into the medical care of HIV-positive youth.

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