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Change in Patterns of HIV Status Disclosure in the HAART Era and Association of HIV Status Disclosure with Depression Level among Women

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Abstract

Whether widespread use of HAART changed patterns of HIV status disclosure among women living with HIV is largely unknown. In addition, the association between time to first HIV disclosure and depression has not been fully explored among women. A retrospective crosssectional survey was conducted among HIV-infected women from the Washington, DC site of the Women's Interagency HIV Study to collect detailed information about their HIV status disclosure behavior. A sample of 202 HIV-positive women, 102 diagnosed prior to and 100 post-HAART era participated in this study. Relationships between treatment era when diagnosed (pre-HAART or HAART era) and patterns of HIV status disclosure, and associations between HIV status disclosure and depression level were examined using generalized linear regression models with generalized estimating equation to adjust for repeated measurements from the same individuals. Our analyses showed that treatment era was not associated with either comfort level of HIV status disclosure or time to first HIV disclosure to either family members or friends. However, women were less likely to disclose HIV status to their family members in the HAART era (P = 0.006) after adjusting for social network type, comfort level of disclosure, time to first disclosure and length of follow-up time. In addition, longer time to first HIV disclosure, but not comfort level or extent of HIV status disclosure, was independently associated with depression levels as measured by CES-D score at study enrollment ("a few months after" vs "within a few days": P = 0.008). More definitive studies utilizing longitudinal designs should be conducted to further examine

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impact of HAART era on HIV status disclosure and effect of HIV status disclosure on mental health.

Keywords

HIV; Disclosure; HAART; Depression; Social network

Introduction

Disclosure of HIV-positive status may be a stressful event. For women living with HIV, the decision to disclose their serostatus involves evaluation of potential benefits and risks. Research has shown that over time people living with HIV typically disclose to different social network groups, such as family members, friends, sexual partners and health care professionals (Sowell, Seals, Phillips, & Julious, 2003). The prevalence of HIV status disclosure among women reported in the existing literature varies substantially. For instance, a systematic review of studies in developing countries reported prevalence of HIV status disclosure ranging from 16.7% to 86.0% (Medley, Garcia-Moreno, McGill, & Maman, 2004). Another study in Zimbabwe found that prevalence of disclosure ranged from 19% to 78%. The reception of disclosure was positive in most cases, with rates ranging from 72% to 95% (Patel et al., 2012). However, disclosure remains difficult for some individuals (Sowell et al., 2003); between 3.5% of women in Kenya and 14.6% in Tanzonia reported experiencing a violent reaction from a partner following disclosure (Medley et al., 2004).

Studies have shown that many factors may independently affect HIV status disclosure. Significant positive predictors of HIV disclosure for women include motherhood (Iwelunmor, Zungu, & Airhihenbuwa, 2010), older age (Ross, Stidham, & Drew, 2012), employment (Ross et al., 2012), being married (Patel et al., 2012), and social support (Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003; Rice, Comulada, Green, Arnold, & Rotheram-Borus, 2009; Ross et al., 2012). Factors impeding disclosure of HIV status include perceived negative consequences of disclosure (Kalichman et al., 2003) and not receiving antiretroviral treatment (Menon, Glazebrook, Campain, & Ngoma, 2007). The widespread use of highly active antiretroviral therapy (HAART) since 1996 has turned the HIV/AIDS from a disease of high mortality to one that can be managed through medication. Research has begun to explore the impact of HAART era on HIV disclosure patterns; so far, two qualitative studies have shown somewhat contradictory results (Klitzman et al., 2004) (Siegel, Lekas, & Schrimshaw, 2005). Klitzman et al (Klitzman et al., 2004) identified several avenues through which the use of HAART affects patterns of HIV disclosure. HAART allows some individuals to refrain from or delay disclosing through retaining their pre-infection physical appearance and ability to "pass" as HIV-negative. Moreover, HAART can lead to unintentional disclosure if individuals are seen taking the medication. Siegel et al. compared factors related to disclosure among women diagnosed pre- and in the HAART era (Siegel, Lekas, & Schrimshaw, 2005), and found participants' beliefs about disclosure did not differ by treatment eras. Further investigation is needed to clarify the effect of HAART on HIV disclosure.

Research has investigated the relationship between HIV disclosure and mental health among women and the results seem to be consistent. Menon et al showed that disclosure of HIV status did not have a negative effect on mental health (Menon et al., 2007). Patel et al reported that believing in the positive consequences of disclosure was related to fewer depressive symptoms (Patel et al., 2012). Vyavaharkar et al. revealed that total number of disclosures was inversely correlated with depression (Vyavaharkar et al., 2011). However, no study was conducted to examine time to first disclosure on mental health.

In this study, we examined associations between treatment era at enrollment (pre-HAART or HAART era) and HIV status disclosure patterns, and associations between disclosure patterns and depression level in a cohort of women living with HIV at the DC site of the Women's Interagency HIV Study (WIHS).

Methods

Women's Interagency HIV Study

WIHS is an ongoing cohort study focusing on women's natural and treated history of HIV/AIDS (Bacon et al., 2005; Barkan et al., 1998). Two thousand eight hundred and thirteen (2,813) women living with HIV and 953 HIV-negative at-risk women were enrolled during three phases, 1994–1995, 2000–2001 and 2010–2011 in 6 regions, including Chicago; the San Francisco Bay Area; Brooklyn and the Bronx in New York City; and the Washington DC and Los Angeles metropolitan areas. Data have been collected through participant interviews approximately every 6 months. The data collected include sociodemographic characteristics, substance use, sexual behaviors, HIV treatment and clinical manifestations. Biomedical samples are also collected and stored for future use. Informed consent was obtained from each participant and the study proposal was approved by local institutional review boards. For this study, 202 women living with HIV from the Washington DC site of the WIHS were interviewed at one visit between Oct 1, 2011 and Sep 30, 2012 to investigate their HIV status disclosure behaviors.

HIV status disclosure questionnaire

Questions about patterns of HIV status disclosure covered three aspects: (1) comfort level in disclosure of sexually transmitted diseases such as HIV, (2) time to first HIV status disclosure, and (3) extent of HIV status disclosure to social networks. The survey included questions about social network groups including family members, friends, main sexual partner (i.e. husband/boyfriend/main partner), casual sexual partners, church members and others. Preliminary data exploration showed relatively small sample size for casual partners, church members and others groups. Some questions asked information about main sexual partners, while others combined main sexual partners into family members group. Thus, for consistency, main sexual partners were combined into the family member group for all analyses, and our analyses focused on the two major groups: family members and friends.

Comfort level of disclosure to social network

Questions such as "How comfortable is it for you to disclose a sexually transmitted disease (STD) such as HIV to a family member?" were asked. Responses included (1) very

comfortable; (2) comfortable; (3) somewhat comfortable; and (4) not comfortable. Identical questions were asked for other social network groups;

HIV status disclosure to the very first person

Questions asked included "Who was the very first person to whom you disclosed?" and "When did disclosure occur". Time from HIV diagnosis to first HIV status disclosure was categorized into 3 exclusive categories: (1) within a few days; (2) a few weeks after; (3) a few months after.

Extent of HIV status disclosure to social network

A set of questions on extent of HIV status disclosure were asked with regard to different social network groups. For instance, for family members, the questions included "How many of your family members have you told that you are HIV-positive?" Responses included (1) all or nearly all, (2) most of them, (3) about half, (4) some of them, (5) very few and (6) none.

Depression measurement scale

Depression was assessed at study enrollments using the Centers for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1977). The CES-D scores range from zero to sixty, with higher scores indicating a higher frequency of depressive symptoms during the last week.

Variable definitions

Our study consisted of two sets of analyses: (1) Association between treatment era at enrollment and HIV status disclosure patterns. For this set of analyses, the study outcomes were patterns of HIV status disclosure, including comfort level of disclosure, time to first disclosure, and extent of disclosure to social network groups. The exposure variable was treatment era at study enrollment: pre-HAART (<1996) or HAART era (1996). Covariates included types of social network group and disclosure target characteristics such as gender; (2) Association between HIV status disclosure patterns and CES-D score at study enrollment. For this set of analyses, the CES-D was used as a continuous variable in order to increase study power. The exposure variables included comfort level of HIV status disclosure, time to first disclosure, and extent of disclosure to the social network groups. Covariates were selected because of their potential associations with CES-D score and HIV status disclosure, including race (White, African-American, Hispanic and Others), age, income (\$12000+ or not), education (less than high school, completed high school, and above high school), quality of life score (measured on a scale from 0 to 100 using a modified SF-36 form) (Bozzette, Hays, Berry, Kanouse, & Wu, 1995), CD4+ T cell counts and HIV viral load at study enrollment.

Statistical analysis

Analysis of variance was used to assess mean differences for continuous variables, and Chisquare tests were used to examine proportion differences for categorical variables. Generalized linear model with generalized estimating equation was used to explore the quantitative relationship between outcome variables and main exposure variables after

adjusting for repeated measurements from the same individual (Hardin & Hilbe, 2003). We examined univariate associations first and only variables with significant univariate associations were included in the multivariate analyses. Estimated statistics and their corresponding 95% confidence intervals were used to assess magnitude and range of the associations. All analyses were carried out using SAS 9.3 (Cary, NC).

Results

Participant characteristics at study enrollment

The participants had a mean age of 36 years (Table 1), and the majority of the sample was African-American (76.7%). Among all participants, only 45% had education levels above high school, and about 39% had annual income less than \$12,000. At the enrollment, the mean CD4+ T cell counts was 477 cells/ml, the mean HIV RNA level (log10) was 3.6, the mean quality of life score was 68.7 and the mean CES-D score was 15.2. Comparing to the pre-HAART group, the HAART group had more African-Americans and lower HIV RNA level.

Association between HAART era and HIV status disclosure to social network groups

- Comfort level with disclosure of STD status: comparing comfort levels of disclosing STD such as HIV between the pre-HAART and HAART groups, no significant difference was observed for disclosure to either family members or friends groups (see Table 2).
- 2. Time to first HIV status disclosure: After diagnosis, 77% of the participants chose a family member or relative as their very first person to disclose HIV status. Among family members, mother, sisters, and husband/boyfriend/main partner were the most frequent persons to whom participants first disclosed. About 60% of the women first disclosed their HIV status to females. No difference was found in the distributions of first HIV disclosure to different genders between the treatment eras (see Table 2). The majority of participants disclosed their status within a few days (see Table 2). For both family and friend groups, no significant difference was observed in comparing time to first HIV status disclosure between the treatment eras (see Table 2).
- 3. Disclosure level to social networks: The overall disclosure levels to family members and friends can be found in Table 2. About 61% and 30% of participants reported disclosure of their HIV status to all/most family members or friends respectively. Comparing disclosure level between the treatment eras, a significant difference was observed for family members, with women disclosing more in the pre-HAART era (*P*= 0.010, see Table 2); this difference was not observed for the friend group. To further examine whether the association between treatment era at enrollment and extent of HIV status disclosure is independent from other risk factors, a multivariate analysis was carried out, with social network type (family vs friend), comfort level of disclosure, time to first disclosure and length of follow up time being the covariates. Our results showed that treatment era at enrollment remained significantly associated with extent of

HIV status disclosure to family members (P= 0.006) even after adjusting for these covariates.

Association between patterns of HIV status disclosure and CES-D score

We examined the associations between different HIV disclosure variables, as well as a number of covariates, with CES-D score at the study enrollment. Univariately, comfort level of disclosure and extent of disclosure to social network were not associated with CES-D. However, an association between time to first HIV status disclosure and CES-D score was found (see Table 3). Participants who disclosed their HIV positive status sooner had lower CES-D scores ("a few months after" vs "within a few days", P = 0.008). In the multivariate model, time to first disclosure of HIV status remained significantly associated with CES-D score ("a few months after" vs "within a few days", P = 0.008) after adjusting for those covariates (income level, HIV RNA level and QOL) significant in univariate analysis.

Discussion

For individuals living with HIV, the decision about to whom and when they will first disclose HIV status is an important one. The patterns of disclosure to different social network groups have been shown to depend on the perceptions of how much support individuals in that group will provide. For instance, Maman et al. found that early disclosure to one family member was motivated by the high value they placed on family support. Others found that individuals living with HIV disclosed more often to the groups they perceived more support from (Kalichman et al., 2003)(Zea, Reisen, Poppen, Bianchi, & Echeverry, 2007; Zea, Reisen, Poppen, Echeverry, & Bianchi, 2004). In this study, we did not ask women about their reasons for disclosing HIV status, but our results suggest that they disclosed to their mother and sisters more often than to their father and brothers, which is consistent with previous studies (Kalichman et al., 2003; Maman, van Rooyen, & Groves, 2013).

Our study observed that participants diagnosed in the HAART era were less likely to disclose their HIV status to their family members even after adjusting for length of follow-up time. Two possible explanations are: (1). women diagnosed after HAART became available do not believe they are at risk of impending death due to HAART's proven effectiveness and they may not see disclosure as an urgent necessity; (2). the HIV-infected women may be delaying disclosure to family members because they believe HAART has effectively prevented external signs of HIV infection in their appearance (Kalichman et al., 2003).

Studies have shown that positive beliefs regarding disclosure or overall level of HIV status disclosure was significantly correlated with fewer depressive symptoms among women (Patel et al., 2012) (Vyavaharkar et al., 2011; Woodward & Pantalone, 2012). We did not find evidence of a relationship between CES-D score and comfort level with or extent of HIV status disclosure. However, we did find that individuals who delayed initial disclosure were more likely to report higher CES-D score. Possible reasons for this inconsistency between our findings and earlier studies may lie in geodemographical difference of the study populations and then different levels of perceived social support.

Comparing to previous studies, our study has some strengths. First, our study might be the only quantitative study that examined the association between HAART availability and HIV disclosure patterns thus far; Second but not last, to our best knowledge, our study might be the first study to examine the association between time to initial HIV status disclosure and depression level among women. However, our study has some limitations too. First, we used a retrospective cross-sectional survey, in which women were asked to recall circumstances of HIV status disclosure that occurred years earlier and information collected might be subject to recall and memory bias. However, given the salience of HIV disclosure, the recall bias might be minimal as many participants could still report it vividly after many years. Second, temporal ambiguity between disclosure and CES-D score at study enrollment might be an issue to consider because we could not ascertain with clarity the temporal relationship between HIV status disclosure and depression measurement at study enrollment. However, given that all women in this study were HIV positive already at study enrollment and the majority of disclosure happened within a few days after HIV diagnosis, the impact of this issue might be minimal. Lastly, we grouped the main sexual partners into family member group in our analyses and some might doubt that the disclosure patterns to main sexual partners might be different from those to other family members. However, we did separate analyses for those questions where main sexual partners were asked separately from other family members, and found the examined association remained the same with and without main sexual partners included into the family group (data not shown).

The findings that women who enrolled in the HAART era are less likely to disclose their HIV status to family members and that those who disclosed more quickly reported lower depression score may have implications for interventions for women who have been newly diagnosed as HIV-positive. More definitive studies should be conducted utilizing longitudinal designs that clearly delineate the temporal order of HIV diagnosis, initial disclosure, and depression.

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Table 1Characteristics of Study Participants at Study Enrollment

Characteristic Variables	Total (N = 202)	Pre- HAART Group (n1=102)	HAART Group (n2 = 100)	P - value
Age, mean (SD)	36.0(8.4)	35.0(7.4)	36.9(9.2)	0.113
Race, %				0.008
White	14.9	22.5	7.0	
African-American	76.7	69.6	84.0	
Hispanic and others	8.4	7.8	9.0	
Education, %				0.315
Less than high school	22.0	26.5	18.2	
Complete high school	32.3	32.3	32.3	
Above high school	45.0	41.2	49.4	
Income less than \$12,000 per year, %	39.4	37.0	42.0	0.480
CES-D score, mean (SD)	15.2(11.8)	15.8(11.2)	14.5(12.5)	0.456
CD4+ T cell counts, mean (SD)	477.0(304)	488.0(314)	465.0(293)	0.588
Log10 of HIV RNA, mean (SD)	3.6(1.2)	3.9(1.0)	3.4(1.3)	0.003
Quality of life, mean (SD)	68.7(20.3)	67.1(19.7)	70.7(20.9)	0.230

Table 2
HIV Status Disclosure Patterns in Pre-HAART and HAART Groups

HIV Status Disclosure Patterns	Overall (N=202)	Pre- HAART Group (n1=102)	HAART Group (n2=100)	P- valu
Comfort level of disclosure				
A family member or relative, %				0.368
Very comfortable	34.5	39.2	30.0	
Comfortable	18.8	14.4	23.0	
Somewhat comfortable	17.3	17.5	17.0	
Not comfortable	29.4	28.9	30.0	
A friend, %				0.067
Very comfortable	17.2	20.9	13.7	
Comfortable	18.3	19.8	16.8	
Somewhat comfortable	25.3	29.7	21.0	
Not comfortable	39.3	29.7	48.4	
First person to disclose				
A family member or relative, %				0.170
Female	60.0	63.8	56.9	
Male	40.0	36.2	43.1	
A friend, %				0.103
Female	62.5	75	50.0	
Male	37.5	25	50.0	
Time to first disclosure				
A family member or relative, %				0.564
Within a few days	72.7	75	70.0	
A few weeks after	6.3	4.2	8.5	
A few months after	21.0	20.8	21.1	
A friend, %				
Within a few days	81.1	66.7	94.7	0.089
A few weeks after	2.7	100	0	
A few months after	16.2	27.8	5.3	
Extent of HIV Status Disclosure to Social Netwo	rk Groups			
Family member or relative %				
All or nearly all	43.2	52.0	34.0	0.010
Most of them	17.8	17.0	18.6	
About half	7.6	2.0	13.4	
Some of them	6.1	8.0	4.1	
Very few	14.7	13.0	16.5	
None	10.7	8.0	13.4	
Current Friends, %				0.139
All or nearly all	18.1	21.0	15.0	

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Overall (N=202) Pre- HAART Group (n1=102) HAART Group (n2=100) P- value **HIV Status Disclosure Patterns** Most of them 12.6 16.0 About half 5.0 4.0 6.0 Some of them 11.1 14.0 8.0 Very few 32.7 30.0 35.4 None 20.6 15.0 26.3

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Note: due to missing data, the data within each category may not add up to one hundred percent.

 Table 3

 Association between HIV Status Disclosure and Depression at Study Enrollment

	Univariate		Multivariate	:
Independent variables	Parameter	P-value	Parameter	P-value
Main exposures				
Comfort level				
Not comfortable	3.6237	0.062		
Somewhat Comfortable	1.2402	0.516		
Comfortable	0.8221	0.705		
Very comfortable	0			
Time to first disclosure				
A few months after	5.796	0.008	4.687	0.008
A few weeks after	9.986	0.010	2.687	0.447
within a few days	0		0	
Extent of disclosure to social network				
None	-0.0396	0.985		
Very few	0.644	0.728		
Some of them	2.4244	0.407		
About half	-1.2615	0.609		
Most of them	0.2018	0.920		
All or nearly all	0			
Age	-0.091	0.363		
Education				
Lower than high school	0			
Completed high school	-0.179	0.938		
Above high school	-3.711	0.086		
Income \$12000 or less	5.808	< 0.001	2.659	0.077
Enrollment waves				
Pre- HAART	1.249	0.456		
Post- HAART	0			
Log10 (HIV RNA level)	-1.414	0.046	-1.568	0.011
Quality of life	-0.384	<.001	-0.348	<.001

Note: covariates adjusted for in the multivariate model include income level, Log10(HIV RNA level) and Quality of life.