Prevalence and Predictors of HIV Disclosure to Adult Family Members: A Cross-Sectional Survey Among People Living with HIV in South Africa

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Abstract: Disclosure in the context of HIV is the sharing of information about one's HIV-positive status, and many factors influence the decision to do so. This study examined the prevalence and predictors of HIV disclosure to adult family members using data collected from the South African 2014 People Living with HIV (PLHIV) Stigma Index. A purposive sample consisting of 10 473 PLHIV were recruited into the study from 18 districts across all of the nine provinces (two districts per province) out of a total of 52 districts found in South Africa. All respondents were linked to an institution for PLHIV accessing support or care related to HIV. Bivariate and multivariate logistic regression models were used to assess the association between HIV disclosure to family members and selected explanatory variables. A large majority (85·1%) of the 9874 PLHIV who responded to the question on disclosure to adult family members reported that they had done so. Significant positive predictors of HIV disclosure to adult family members included reporting an age between 25 - 49 years [OR=1·5: 95% CI (1·2-1·8), p<0.001], aged 50 years and older [OR=1·5: 95% ·CI (1·1 - 2·0), p=0012], unemployment [OR=1·3: 95% CI (1·1 - 1·5), p=0.002] and living with HIV for 5 and more years [OR=1·6: 95% CI (1·2 - 2·0), p<.0.001]. On the other hand, significant negative predictors of disclosure included HIV testing decision taken under pressure from others [OR=0.6: 95% CI (0.5-0.8), p<0.001], testing without own knowledge [OR=0.3: 95% CI (0.2-0.5), p<0.001], only receiving pre-test HIV counselling [OR=0.4: 95% CI (0.3-0.5), p<0.001], and not receiving any counselling when testing for HIV [OR=0.6: 95% CI (0.4-0.9), p=0.012]. Overall, the majority of study participants had disclosed their HIV positive status to family members. However, there is a need to equip younger PLHIV and those who were recently diagnosed with HIV with the necessary positive coping mechanisms and self-esteem strategies in order to facilitate disclosure among this population group. Involuntary or forced HIV testing and poor/lack of pre- and post-test counselling should be discouraged since they have been shown to have negative consequences for disclosure.

Keywords: HIV disclosure, Adult family members, People living with HIV, Survey, Prevalence, Predictors, South Africa.

INTRODUCTION

HIV disclosure is a planned and selective process that balances the potential risks and benefits, and is considered as a crucial step towards ending stigma and discrimination against people living with HIV (PLHIV) [1]. Disclosure of HIV positive status is encouraged as a way to reduce sexual risk behaviour and transmission of HIV, decrease HIV-related stigma and increase access to support and care [1, 2]. Consequently, HIV disclosure is an important public health strategy with potential benefits for PLHIV and their sex partners, family and friends.[2] In this way HIV disclosure is crucial to considerations about HIV because of its direct link to increasing chances of HIV prevention [3].

Despite the public health benefits of HIV disclosure, there is also the potential threat of exposing oneself to social rejection, isolation and stigmatisation. It is well known that HIV stigma has been shown to be negatively related to the decision to disclose [4-7]. Thus HIV disclosure can be an extremely challenging experience as it can expose one to discrimination from partners, friends, family and /or community [8-12]. Evidence shows that gender plays an important role on whether or not to disclose one's HIV status, and females tend to experience more serious consequences of disclosure such as physical and sexual assault [6]. Nevertheless, research regarding disclosure to family and friends in sub-Saharan Africa is limited.

There are several factors influencing the decision of PLHIV to disclose ranging from having access to psychosocial support and to anti-retroviral (ARV) treatment and care [10]. The nature of HIV disclosure also varies depending on whom disclosure is made to,

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and can include self-disclosure, mediated disclosure or disclosure without consent [3]. Voluntary HIV disclosure to family members has been described in previous studies as challenging for PLHIV [13, 14]. The decision to disclose or not to family members is mitigated on both trusting that family members will not reveal their HIV status to others without permission and that family members would provide support and care when needed [15, 16].

There are several benefits of HIV disclosure to family members. In the first instance, HIV disclosure to family members has the potential to strengthen family relations and support for medical care and counseling [5]. HIV disclosure can provide an opportunity for PLHIV to express thoughts and feelings about their status and develop a sense of self, and is therefore advantageous to the overall well-being of PLHIV [2]. However, in South Africa few studies have explored the determinants of HIV status disclosure to family members [17-19].

Evidence shows that disclosure of HIV status to family was associated with greater social support, utilization of health care facilities and improved initiation and adherence to ARVs [19]. Given the scaling up of HIV testing and treatment in South Africa, it is therefore important to understand the determinants of HIV disclosure especially to family members. Moreover, as the country scales up HIV testing, counselling, and treatment, better evidence is needed to inform laws and policies, particularly regarding how best to facilitate disclosure while protecting confidentiality and privacy. These are key human rights issues that have a potential impact on HIV prevention, and a better understanding of social determinants of disclosure in diverse setting like South Africa is vital for informing policy.

The South African National AIDS Council (SANAC) commissioned the Human Sciences Research Council (HSRC) to conduct the first PLHIV Stigma Index in South Africa [17]. This study was conducted to address the key priority area of reducing HIV-related stigma and discrimination as outlined in the National Strategic Plan on HIV and AIDS (2012-2016) to systematically measure the extent to which stigma and discrimination affect PLHIV [17]. The predictors of HIV disclosure to adult family members is key to understanding the level of stigma and discrimination experienced by PLHIV in South Africa. Thus this study, using the PLHIV Stigma Index data, examined the prevalence and predictors of HIV disclosure to adult family members.

METHODS

Study Sample and Procedure

A purposive sample consisting of 10 473 PLHIV were recruited into the study from 18 districts across all of the nine provinces (two districts per province) out of a total of 52 districts found in South Africa. The districts were identified on the basis of balancing the prioritization of districts implementing the National Health Insurance (NHI) pilot programmes in the country with the need to have representation of urban and rural districts included in the study. Institutions that provide services for PLHIV included organisations working with PLHIV were identified in each of the participating districts. The majority (77·4%) of study respondents were recruited through their participation in the support group networks of the National Association of People Living with HIV and AIDS (NAPWA), the Treatment Action Campaign (TAC) and Positive Women's Network (PWN) and the rest of the study sample were recruited through the public health services that they provide to PLHIV. Fieldwork took place over 13 weeks, starting from September to December 2014. The survey involved interviewing PLHIV who were 15 years of age and older using the Stigma Index.

The Stigma Index questionnaire consists of 12 modules as follows: Demographic information, experiences of HIV-related stigma and discrimination from other people, access to work, health and education services, internalized stigma, rights, laws and policies, effecting change, testing/diagnosis, disclosure and confidentiality, treatment, having children, TB-related stigma, and problems and challenges. The current analysis focuses on disclosure where individuals who self-reported a HIV-positive status were asked to describe how different groups of people were first told about their HIV status.

Measures

The outcome of interest is HIV disclosure with a focus on disclosure to adult family members based on the following item: "Please describe how adult family members were first told about your HIV status, if they have been told". The responses were as follows: "I told them"=1, "Someone else told them with my consent"=2, "Someone else told them without my consent"=3, "They don't know my status"=4, "They saw my test results"=5. The responses were then recoded and dichotomized into binary outcome whereby "Self-disclosed of HIV result=1", and "None self-disclosure=0".

Socio-demographic characteristics included age in years (15-24, 25-49, 50+), sex (male and female), marital status (unmarried and married), education level (no formal education, primary school, secondary school, technical college/university), employment status (employed and unemployed), and locality type (rural area, small town or village, large town or city). HIV-related factors included length of time living with HIV since diagnoses (0-1 year, 2-4 years, 5+ years), HIV testing decision ("I took the decision myself to be tested", "I took the decision to be tested but under pressure from others", "I was made to take an HIV test", "I was tested without my knowledge"), and HIV testing and counselling ("I received both pre- and post-test counselling", "I only received pre-test counselling", "I only received post-test counselling", "I did not receive any counselling when I had a HIV test").

Statistical Analysis

Descriptive statistics were used to summarize the distribution of participants across the different categories of variables. Cross-tabulations of HIV disclosure by each of the independent variables were performed. Differences between cross-tabulated categorical variables were tested using Pearson's Chi Square ($\chi 2$) test. Bivariate logistic regression models were used to assess the association between HIV disclosure to family members and selected explanatory variables. Statistically significant variables were entered into a multivariate logistic regression model to identify independent predictors of HIV disclosure to family members. All variables with a p-value < 0.05 in were considered statistically significant. Statistical software Stata13 (StataCorp, College Station, TX, USA) was used for analyses.

RESULTS

Sample Characteristics

A total of 10 473 PLHIV (*i.e*. individuals who self-reported a HIV positive status and who were 15 years and older on the day of the interview) were recruited into the study. Of the 10 473 PLHIV, 9874 (94·3%) participants responded to the question: "Please describe how adult family members were first told about your HIV status, if they have been told?"

Table 1: Socio-Demographic Characteristics and HIV Disclosure to Adult Family Members (n = 9874)

Variable	Total*	%	Disclosure (%)	p-value
Age in years				
15-24	974	9·9	78·3	<0.001
25-49	7858	79·3	85·6	
50+	1042	10·8	87·5	
Sex				
Males	3350	34·6	82·6	<0.001
Females	6424	65·4	86·3	
Marital status				
Unmarried	7021	71·1	84·9	0.453
Married	2819	28·9	85·5	
Level of education				
No formal education	460	4·8	83·5	0.812
Primary school	1721	18·0	85·1	
Secondary school	6492	66·1	85·1	
Technical college/university	1082	11·1	84·8	
Employment status				
Employed	3000	30·9	83·3	0.001
Unemployed	6758	69·1	85·9	
Locality type				
Rural area	2979	31·2	85·7	0.038
Small town or village	4692	48·4	84·2	
Large town or city	2001	20·4	86·4	

*Sub-totals not equal due to non-response and missing data.

The majority of the participants were between the ages of 25 - 49 years old (79·3%), female (64·4%), unmarried (71·1%), had completed secondary level education (66·1%), were unemployed (69·1%), about half of the households reported not having enough money for basic things like food and clothes (50·3%), and reported living in small towns or villages (48·4%).

Out of the 9874 participants who responded to the question, 85·1% had disclosed their HIV positive status to adult family members. Table **1** shows that the proportion of HIV disclosure was significantly higher (p≤ 0.05) among those 50 years and older (87·5%), females (86·3%), the unemployed (85·9%), and those living in large towns and cities (86·4%).

Table **2** shows that the majority of respondents reported to be living with HIV for 2-4 years (58·5%), reported having taken their own decision to test for HIV (82·2%), and received both pre- and post- test counselling (82·2%). The proportions of HIV disclosure to adult family members was significantly higher (p≤ 0.05) among those living with HIV for 5 years and more (88·7%), those who took their own decision to test for HIV (86·5%), and those who received both pre- and post- test counselling (86·3%).

Predictors of HIV Status Disclosure

Bivariate models of socio-demographic factors (Table **3**) show that an increased likelihood of HIV disclosure to adult family members was significantly associated with age 25-49 years [OR=1·6: 95% CI (1·4-1·9), p<0.001], and 50 years and older [OR=1·9: 95% CI (1·5-2·5), p<0.001] compared to those 15-24 years old, females [OR=1·3: 95% CI (1·2 - 1·5), p<0.001] compared to males, those unemployed [OR=1·2: 95% CI (1·1 - 1·4), p=0.001] compared to those who were employed.

Bivariate models of HIV-related factors (Table **4**) show that the increased likelihood of HIV disclosure to adult family members was significantly associated with respondents living with HIV for 5 years and more [OR=1·5: 95% CI (1·2-1·9), p<0.001] compared to those living with HIV for less than 1year. The decreased likelihood of HIV disclosure to adult family members was significantly associated with those who took the decision to be tested but under pressure from others [OR=0·6: 95% CI (0·5-0·7), p<0.001], those who were made to take an HIV test [OR=0·7: 95% CI (0·6 - 1·0), p=0.019], and those who were tested without their knowledge [OR=0·3: 95% CI (0·2 - 0·4), p<0.001] compared to those who themselves took the decision to be tested. Also included in the bivariate models were those who only received pre-test counselling [OR=0·3: 95% CI (0·3 - 0·4), p<0.001], only received post-test counselling [OR=0·7: 95% CI (0·5 - 1·0), p=0.047], and those who did not receive any counselling when they had an HIV test [OR=0·5: 95% CI (0·4 - 0·7), p<0.001]

Table 2: HIV and Stigma-Related Factors and HIV Disclosure to Adult Family Members (n = 9874)

Variable	Total*	%	Disclosure (%)	p-value
Length of time living with HIV				
0-1 year	1117	17·5	83·5	<0.001
2-4 years	3811	58·5	82·5	
5+ years	1561	24·0	88·7	
Was the decision to be tested for HIV up to you?				
I took the decision myself to be tested	7897	82·2	86·5	<0.001
I took the decision to be tested but under pressure from others	1089	11·2	80·3	
I was made to take an HIV test (coercion)	465	5·0	82·6	
I was tested without my knowledge	143	1·6	63·6	
Did you receive counselling when you were tested for HIV?				
I received both pre- and post-HIV test counselling	8874	91·7	86·3	<0.001
I only received pre-test HIV counselling	359	3·7	67·4	
I only received post-test HIV counselling	205	2·1	81·5	
I did not receive any counselling when I had an HIV test	224	2·4	76·3	

*Sub-totals not equal due to non-response and missing data.

Table 3: Bivariate Regression Models of Socio-Demographic Factors Associated with HIV Disclosure to Adult Family Members (n = 9874)

Variable	OR	95% CI		p-value
Age in years				
15-24	Ref			
25-49	1·6	1·4	1·9	<0.001
50+	1·9	1·5	2·5	<0.001
Sex				
Males	Ref			
Females	1·3	1·2	1·5	<0.001
Marital status				
Unmarried	Ref			
Married	1·0	0·9	1·2	0.453
Level of education				
No formal education	Ref			
Primary school	1·1	0·9	1·5	0.400
Secondary school	1·1	0·9	1·5	0.336
Technical college/university	1·1	0·8	1·5	0.499
Employment status				
Employed	Ref			
Unemployed	1·2	1·1	1·4	0.001
Locality type				
Rural area	Ref			
Small town or village	0·9	0·8	1·0	0.079
Large town or city	1·1	0·9	1·3	0.461

Table 4: Bivariate Models of HIV-Related Factors Associated with HIV Disclosure to Adult Family Members (n = 9874)

Variable	OR	95% CI		p-value
Length of time living with HIV				
0-1 year				
2-4 years	0·9	0·8	1·1	0.424
5+ years	1·5	1·2	1·9	<0.001
Was the decision to be tested for HIV up to you?				
I took the decision myself to be tested				
I took the decision to be tested but under pressure from others	0·6	0·5	0·7	<0.001
I was made to take an HIV test	0·7	0·6	1·0	0.019
I was tested without my knowledge	0·3	0·2	0·4	<0.001
Did you receive counselling when you were tested for HIV?				
I received both pre- and post-HIV test counselling				
I only received pre-test HIV counselling	0·3	0·3	0·4	<0.001
I only received post-test HIV counselling	0·7	0·5	1·0	0.047
I did not receive any counselling when I had an HIV test	0·5	0·4	0·7	<0.001

compared to those who received both pre- and post-test counselling.

In the final multivariate model (Figure **1**) factors that remained significant positive predictors of HIV

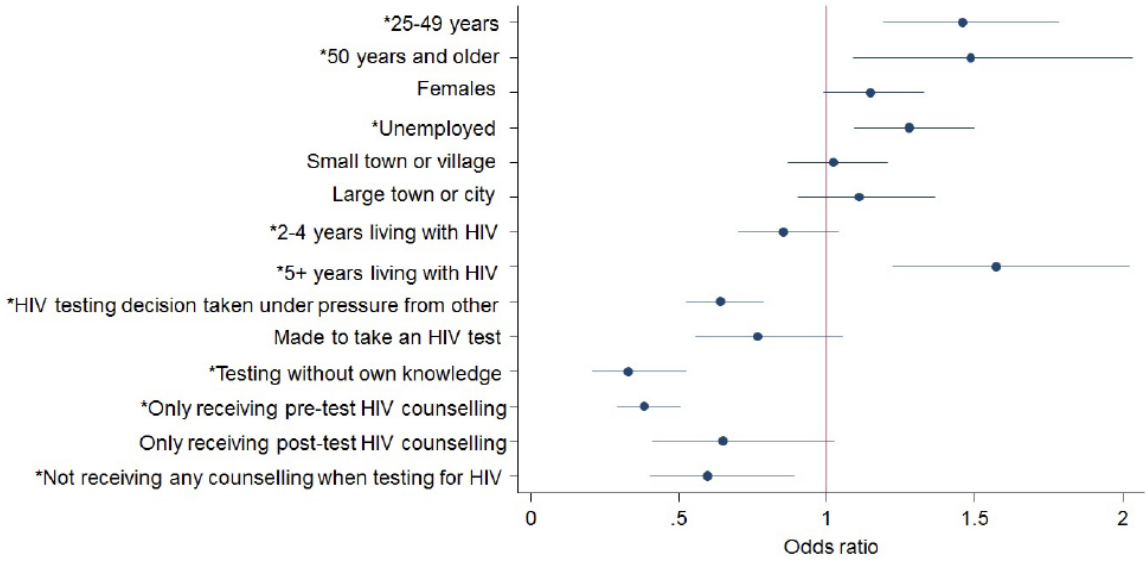

Figure 1: Multivariate model of predictors of HIV disclosure to adult family members (*significant at p-value < 0.05).

disclosure to adult family members included age 25-49 years [OR=1·5: 95% CI (1·2-1·8), p<0.001] and age 50 years and older [OR=1·5: 95% CI (1·1 - 2·0), p=0.012], unemployment [OR=1·3: 95% CI (1·1 - 15), p=0.002] and living with HIV for 5 and more years [OR=1·6: 95% CI (1·2-2·0), p<.0.001]. On the other hand, significant negative predictors of HIV disclosure to adult family members remained HIV testing decision taken under pressure from others [OR=0·6: 95% CI (0·5 - 0·8), p<0.001], testing without own knowledge [OR=0·3: 95% CI (0·2 - 0·5), p<0.001], only receiving pre-test counselling [OR=0·4: 95% CI (0·3 - 0·5), p<0.001], and not receiving post-test counselling [OR=0·6: 95% CI (0·4 - 0·9), p=0.012].

DISCUSSION

Overall the level of HIV disclosure to family members was high (85·1%). Although the levels of disclosure varied across the country the rates were generally high (71·3 – 90.5%), the results also show that the high rates of disclosure varied across the different socio-demographic and HIV-related characteristics. The high overall disclosure rates can be attributed to the fact that families were the most supportive group in terms of both social and emotional support for PLHIV [5]. Consistent with the current findings on social support, especially family support has been previously positively associated with HIV disclosure in South Africa [7, 11, 18].

The final model showed that age 25-49 years, 50 years and above, unemployment, and living with HIV for five and more years were strong positive predictors of HIV status disclosure to adult family members. Consistent with previous findings, our study found older age to be a predictor of HIV disclosure [19, 20]. The likelihood of disclosure among older participants has been attributed to maturity and sense of responsibility [21]. This therefore highlights the need for interventions aimed at equipping young people with coping strategies and communication skills for building resilience and emotional readiness for disclosure.

Sachem and colleagues [22] found that unemployment was a positive predictor of HIV status disclosure to family members. This was attributed to depression due to HIV status coupled with being unemployed and the need of more support and assistance things from family members [22]. Contrary to other previous findings [23], these results suggest that employment which is likely to protect individuals from distresses related to their positive status may not encourage disclosure to family members due to self-reliance and support [22].

In addition, it is not surprising that other studies have shown that the longer the time living with HIV the higher the likelihood of disclosure [24, 25]. Evidence shows that the rates of disclosure increased with time after HIV positive diagnosis [25]. This implies that PLHIV experience a period of struggle before disclosure and take time up to a few years to disclose [26]. Timing of HIV disclosure is therefore an important factor to consider in HIV disclosure promotion strategies.

The final multivariate model also showed that HIV testing decision taken under pressure from others, testing without own knowledge, only receiving pre-test counselling, and not receiving post-test counselling were strong negative predictors of HIV status disclosure to adult family members. These findings reiterate the fact that voluntary testing and counselling is key to HIV disclosure, and that comprehensive pre- and post-test counselling are an essential preparation for coping effectively during and immediately after testing [27].

The study findings should be interpreted in the light of the following methodological limitations. In the first instance the final study sample was biased towards PLHIV belonging to support groups linked to the SANAC PLHIV sector which took part in the study [17]. Not only is this study sample of PLHIV a special group as they were all aware of their HIV-positive status, and may be more likely to have accepted their HIV status due to their participation in support groups, which is a facilitating factor in HIV disclosure [17]. In this way selection bias exists in the current study sample because participants were recruited mainly through support networks. Participation of PLHIV in support groups has been shown to increase self-confidence and made it more possible for PLHIV to disclose [28]. In addition, purposeful sampling does not allow for generalization of the study findings to the general population of all PLHIV. Moreover, the data is self-reported and social desirability bias cannot be totally eliminated.

In conclusion, although the present study revealed that the majority of study participants had disclosed their HIV positive status to family members, there is however a need to equip younger PLHIV and those who were recently diagnosed with HIV with the necessary positive coping mechanisms and self-esteem strategies in order to facilitate disclosure among this population group. This work underscored the importance of understanding factors associated with disclosure and how they differ by disclosure target, which is vital for effective prevention interventions. While there are many advantages for disclosing one's status, there are also several potential negative consequences associated with HIV disclosure such as domestic violence and abuse, abandonment, and discrimination [29, 30]. The current study also clearly showed that involuntary or forced HIV testing and poor/lack of pre- and post-test counselling should be discouraged since they have been shown to have negative consequences for disclosure. Therefore, interventions that seek to promote safe disclosure decisions and positive disclosure outcomes must be targeted and tailored to the social context for them to be effective.

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