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Social support, stigma, and HIV disclosure among parents living with HIV in Guangxi, China

Yuchen Mao^a, Xiaoming Li^a, Shan Qiao^a, Qun Zhao^b, Yuejiao Zhou^c, and Zhiyong Shen^c

^aDepartment of Health Promotion, Education, and Behavior, University of South Carolina, Columbia, SC, USA;

^bSchool of Public Administration, Nanjing University of Information Science & Technology, Nanjing, China;

^cInstitute of HIV/AIDS Control and Prevention, Guangxi CDC, Nanning, China

Abstract

Both stigma and social support have been identified to be associated with HIV status disclosure among people living with HIV. This study aimed to examine cross-sectional associations of perceived social support and multiple types of stigma with both disclosure to various target groups and timing of disclosure among parents living with HIV (PLHIV) in Guangxi, China.

Cross-sectional data from 1,254 PLHIV in Guangxi, China were analyzed. Measures included demographics, disclosure to specific groups (steady partner/spouse, children, family and others) and timing of disclosure, perceived social support, and three types of HIV-related stigma (perceived, internalized, and enacted stigma). Logistic regression analyses were performed to identify the associations of interest.

The participants who reported higher levels of perceived social support were more likely to have disclosed to steady partner/spouse, family or others. Those who experienced enacted stigma were more likely to have disclosed to children or family. Those who were married/cohabitating were more likely to have disclosed to steady partner/spouse, and less likely to have disclosed to children, family or others. Older PLHIV were less likely to have disclosed to steady partner/spouse, or family. Those who had a job were more likely to have disclosed to steady partner/spouse. Perceived social support appeared not to be associated with timing of disclosure. Those who disclosed within a shorter time after diagnosis were more likely to be women or have disclosed to steady partner/spouse, and less likely to have higher perceived stigma or have disclosed to family.

Interventions are needed to help reduce the negative effect of perceived stigma at both family and community levels and to help enhance perceived social support in general and emotional support in particular among PLHIV, especially males and older adults.

Keywords

stigma; perceived social support; target-specific disclosure; timing of disclosure; parents living with HIV

Introduction

The 2015 China AIDS Response Progress Report estimated there were 501,000 people living with HIV in China at the end of 2014, and Guangxi Autonomous Region (Guangxi) had the third largest number of HIV cases among all Chinese provinces (Ministry of Health of China, 2015).

Three types of HIV stigma including perceived (anticipated or perceived prejudice or discrimination in the community), internalized (feeling shame or blame because of HIV status), and enacted stigma (experiencing discrimination because of HIV-positive status) were often mentioned among people living with HIV in previous studies (Logie & Gadalla, 2009; Valenzuela et al., 2015). HIV disclosure is a prerequisite for acquiring social support for access to health care (Maman, van Rooyen, & Groves, 2014; Vyavaharkar et al., 2011), and can also help facilitate HIV prevention and safe sexual behaviors (Deribe et al., 2008; Miller & Rubin, 2007). However, stigma was shown to have impeded disclosure among various populations (Arnold, Rebhook and Kegeles, 2014; Overstreet et al., 2013; Przybyla et al., 2013). On the other hand, social support can help facilitate disclosure (Lyimo et al., 2014; Smith, Rossetto, & Peterson, 2008).

HIV can be disclosed to specific groups such as spouses, children, family, and friends, and timing of disclosure can vary from instantly to years after diagnosis (Eustace & Ilagan, 2010; Moses & Tomlinson, 2013). However, few studies have simultaneously examined associations of social support and multiple types of stigma with HIV disclosure.

Our previous studies have explored the roles of stigma and social support in target-specific disclosure (e.g., parental or partner disclosure) among parents living with HIV (PLHIV) in Guangxi, China (Qiao et al., 2015; Xiao et al., 2015). Built upon them, the current study focused on examining associations of multiple types of stigma and perceived social support with both disclosure to various target groups and timing of disclosure.

Methods

Study design and participants

Data used in the current study were derived from a cross-sectional survey conducted from 2012 to 2013 in Guangxi, China. The detailed sampling and survey procedures were reported elsewhere (Qiao et al., 2015). We randomly selected 10% from 29,606 people living with HIV in the 12 sites with the largest number of cases and finally recruited 3,002 participants, among whom 2,987 completed the survey. A subsample of 1,254 PLHIV who had children aged 5–16 and responded to the questions regarding HIV disclosure were included in the current study.

Data collection

Participants were asked about socio-demographic characteristics including gender, ethnicity, marriage, original residence, work status, monthly household income, age and year of schooling.

Three types of HIV stigma were measured using modified items from the Berger HIV Stigma Scale (Berger, Ferrans, & Lashley, 2001) (Table 1). Mean scores were computed for both perceived and internalized stigma based on responses ranging from 1 (Strongly Disagree) to 4 (Strongly Agree) for each item. Reliability was satisfactory with Cronbach's α of 0.90 and 0.91, respectively. Their enacted stigma score was coded as "1" (Yes) if they indicated they had experienced either of the 2 items asking about experiences of some stigmatized action and "0" (No) otherwise.

Perceived social support was measured using a modified, Chinese version of the Zimet Multidimensional Scale of Perceived Social Support for people living with HIV (Zimet et al., 1988; Zimet et al., 1990). It contains 28 items asking how often PLHIV believe they can receive the needed support on a 5-point scale from "almost never" to "almost always". Mean score was computed to indicate perceived availability of support. The Cronbach's α in our study was 0.98.

Two aspects of disclosure were measured, including whether some target group was being disclosed to and timing of general disclosure. The target groups we examined included steady partner/spouse, children, family, and others. The timing of general disclosure categories we evaluated included instantly following diagnosis with HIV, within a week, within 3 months, and beyond 3 months.

Data analysis

Statistical analyses were conducted using SAS 9.4. All potential correlates were evaluated in univariate logistic regression for their unadjusted associations with each target-specific disclosure. Those variables with a p-value of less than 0.2 were selected and entered into multivariate logistic regression for their adjusted associations with each target-specific disclosure. Similarly, all potential correlates including various types of target-specific disclosure were evaluated in univariate ordinal regression for their unadjusted associations with timing of disclosure. Those variables with a p-value of less than 0.2 were selected and entered into multiple ordinal logistic regression for their adjusted associations with timing of disclosure.

Results

Socio-demographic characteristics

The sample in the current analysis included 1,254 participants (742 males and 512 females). The average age of the participants was 38.9 years (range 19.6–59.4 years, SD=8.33). A majority of them were Han (71.7%), local residents (94.3%), had a full-time or part-time job (78.0%), had a monthly household income less than 2,000 yuan (85.4%), and reported being married or cohabitating (78.2%). The average year of formal schooling was 7.04 (range 0–17 years, SD=2.70) with a majority of the participants completing no more than middle school (Table 2).

Target-specific disclosure and timing

Two-thirds of the participants disclosed to steady partner/spouse (67.9%), and one-third disclosed to family (32.2%). Only a small portion disclosed to children (5.3%) or others (4.7%). Among 949 participants who reported having disclosed, more than half disclosed immediately following diagnosis (51.3%). Less than 20% disclosed within a week or three months. Those who disclosed beyond three months after diagnosis only accounted for 13.9%.

Stigma, social support and target-specific disclosure

Those who reported higher levels of perceived social support were more likely to have disclosed to steady partner/spouse (aOR=1.33, 95% CI=1.12, 1.59), family (aOR=1.61, 95% CI=1.39, 1.87), or others (aOR=1.55, 95% CI=1.16, 2.07). Those who experienced enacted stigma were more likely to have disclosed to children (aOR=3.06, 95% CI=1.36, 6.90) or family (aOR=1.91, 95% CI=1.11, 3.29). Those who were married/cohabitating were more likely to have disclosed to steady partner/spouse (aOR=13.52, 95% CI=9.54, 19.16), and less likely to have disclosed to children (aOR=0.47, 95% CI=0.27, 0.80), family (aOR=0.38, 95% CI=0.28, 0.52), or others (aOR=0.52, 95% CI=0.29, 0.95). Older PLHIV were less likely to have disclosed to steady partner/spouse (aOR=0.93, 95% CI=0.91, 0.94), or family (aOR=0.94, 95% CI=0.92, 0.96). Those who had a job were more likely to have disclosed to steady partner/spouse (aOR=1.79, 95% CI=1.26, 2.54) (Table 3).

Stigma, social support, disclosure target and timing

Perceived social support appeared not to be associated with timing of disclosure. Those who disclosed within a shorter time after diagnosis were more likely to be women (aOR=0.72, 95% CI=0.56, 0.92), have higher internalized stigma (aOR=0.55, 95% CI=0.40, 0.76), or have disclosed to steady partner/spouse (aOR=0.62, 95% CI=0.40, 0.98), and less likely to have higher perceived stigma (aOR=1.73, 95% CI=1.28, 2.34) or have disclosed to family (aOR=1.46, 95% CI=1.12, 1.91) (Table 4).

Discussion

The current study examined disclosure to various target groups and the timing in relation to social support and multiple types of stigma among PLHIV in Guangxi, China, and identified correlates.

The finding that disclosure to steady partner/spouse, family or others was associated with higher levels of perceived social support is corroborated by previous studies that identified mutual influences between social support and disclosure (Lyimo et al., 2014; Xiao et al., 2015). Using cross-sectional data enables explanation of causality in either direction. Higher prevalence of disclosure to steady partner/spouse among those who were married/cohabitating may be the result of desiring to maintain a trusting and intimate relationship (Hirsch Allen et al., 2014; Lyimo et al., 2014). Quicker disclosure to steady partner/spouse and women's quicker disclosure identified may be due to the similar interpersonal reason that earlier disclosure to trustworthy people can help access support and healthcare services (Sowell et al., 2003; Hirsch Allen et al., 2014). The finding that age was negatively

associated with disclosure to family and spouse is consistent with some previous studies that found older people used non-disclosure to reduce anticipated stigma (Gaskins et al., 2011; Wallach and Brothman, 2012)

Those who reported having experienced enacted stigma were more likely to have disclosed to children and family, which is partially consistent with our previous study (Qiao et al., 2015). It might be the sense of responsibility to inform or educate that motivated disclosure to children and family. The potential explanation for higher internalized stigma corresponding to quicker disclosure is that those who disclosed early might have experienced a negative reaction from their receivers that led to a higher level of internalized stigma. The association of delayed disclosure with higher perceived stigma may be the result of strategies used by PLHIV to cope with perceived stigma. Similarly, delayed disclosure to family may be the result of PLHIV's managing anticipated stigma from their family members.

There are limitations to be aware of in the current study. First, the 2-item measure of enacted stigma may not truly capture PLHIV's experience of stigma, especially from family members, which could be the reason for the low prevalence of enacted stigma (5.3%) in the current study. A better measure in future studies may help improve the exploration of associations between stigma and disclosure. Second, this study was cross-sectional in design, and hence, causal relationships between HIV-related stigma, perceived social support and HIV disclosure cannot be inferred. Further research is warranted to identify causality between variables employing longitudinal study designs. Finally, data gathered through the questionnaire may be subject to recall and social desirability bias.

Despite the limitations mentioned above, the findings still inform future intervention efforts. Interventions are needed to help reduce the negative effect of perceived stigma at both family and community levels and to help enhance perceived social support in general and emotional support in particular among PLHIV, especially males and older adults.

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Table 1

Modified items used to quantify multiple types of HIV-related stigma

Questionnaire items
Perceived stigma
People with HIV can lose their jobs when employers find out
People with HIV are treated like outcasts
Most people believe a person who has HIV is dirty
Most people think a person with HIV is disgusting
Most people with HIV are rejected if others are aware of their positive status
Most people are uncomfortable around people living with HIV
Internalized stigma
I feel guilty because I have HIV
People's attitudes make me feel worse about myself
I feel I'm not as good as others because I have HIV
I avoid making new friends because I have HIV
Having HIV makes me feel unclean
I feel isolated from the rest of the world
Having HIV makes me feel I'm a bad person
I feel disgusted with having HIV in my body
Enacted stigma
I was rejected because I have HIV (e.g., from job, school, or social welfare, etc.)
My family members were excluded by others because I have HIV

Table 2

Sociodemographic characteristics

	Analytic sample n (%) or mean (SD)
Gender	
Male	742 (59.2)
Female	512 (40.8)
Ethnicity	
Han	899 (71.7)
Non-Han	354 (28.3)
Local	
Yes	1181 (94.3)
No	71 (5.7)
Marital status	
Married/cohabitating	950 (78.2)
Other	264 (21.8)
Work status	
Full-/part-time job	973 (78.0)
No job	275 (22.0)
Income (yuan)	
0–999	694 (55.9)
1000–1999	366 (29.5)
2000–2999	119 (9.6)
3000	63 (5.1)
Age (years)	38.90 (8.33)
Year of schooling	7.04 (2.70)

Table 3

Multivariate logistic regression of target-specific disclosure

Variable	Disclosure target 1254(100%)							
	Spouse 852(67.9%)	Children 66(5.3%)	Family 404(32.2%)	Others 59(4.7%)				
	cOR(95% CI)	aOR(95% CI)	cOR(95% CI)	aOR(95% CI)	cOR(95% CI)	aOR(95% CI)	cOR(95% CI)	aOR(95% CI)
Stigma and social support								
Perceived stigma	0.99(0.81,1.22)	1.11(0.71,1.74)	0.93(0.75,1.14)		0.81(0.52,1.26)			
Internalized stigma	0.96(0.77,1.20)	1.36(0.86,2.16)	1.22(0.76,1.96)		0.94(0.58,1.52)			
Enacted stigma	1.41(0.80,2.48)	2.64(1.21,5.78)	1.65(1.00,2.72)		1.31(0.46,3.72)			
Perceived social support	1.50(1.29,1.73)	1.06(0.80,1.41)	1.51(1.32,1.74)		1.53(1.15,2.03)			1.55(1.16,2.07)
Sociodemographic factors								
Female	1.22(0.96,1.56)	1.22(0.74,2.01)	1.11(0.88,1.41)		1.24(0.73,2.09)			
Han	1.03(0.79,1.34)	0.97(0.56,1.68)	0.78(0.60,1.01)		0.82(0.47,1.44)			
Married	11.77(8.54,16.21)	0.49(0.29,0.82)	0.49(0.37,0.65)		0.62(0.35,1.09)			0.52(0.29,0.95)
Local residency	0.71(0.41,1.23)	0.93(0.33,2.63)	1.06(0.63,1.78)		1.75(0.42,7.32)			
Full-/part-time job	2.43(1.84,3.20)	1.79(1.26,2.54)	1.00(0.75,1.33)		1.85(0.87,3.94)			1.67(0.77,3.63)
Income(yuan)								
0-999	0.77(0.43,1.37)	0.62(0.23,1.63)	0.92(0.54,1.59)		0.78(0.27,2.28)			
1000-1999	0.75(0.41,1.36)	0.71(0.26,1.95)	0.84(0.48,1.48)		0.54(0.17,1.72)			
2000-2999	0.96(0.49,1.91)	0.51(0.14,1.83)	0.81(0.42,1.55)		0.92(0.26,3.28)			
3000								
Age (years)	0.93(0.92,0.95)	1.02(0.99,1.05)	0.94(0.92,0.96)		0.95(0.92,0.99)			0.96(0.92,1.00)
Year of schooling	1.01(0.97,1.06)	0.89(0.81,0.98)	1.01(0.96,1.05)		0.99(0.90,1.09)			

Table 4

Timing of HIV disclosure in relation to factors

	cOR(95% CI)	aOR(95% CI)
stigma and social support		
Perceived stigma	1.19(0.97,1.48)	1.73(1.28,2.34)
Internalized stigma	0.82(0.66,1.03)	0.55(0.40,0.76)
Enacted stigma	1.48(0.90,2.43)	1.46(0.87,2.47)
Perceived social support	1.00(0.87,1.14)	—————
Disclosure target		
Spouse	0.48(0.34,0.67)	0.62(0.40,0.98)
Children	1.45(0.92,2.29)	1.21(0.74,1.96)
Family	1.70(1.33,2.16)	1.46(1.12,1.91)
Others	1.31(0.81,2.13)	—————
Sociodemographic factors		
Female	0.70(0.55,0.90)	0.72(0.56,0.92)
Han	1.32(1.01,1.72)	1.26(0.95,1.66)
Married	0.60(0.44,0.82)	0.87(0.58,1.32)
Rural residency	0.84(0.51,1.40)	
Full-/part-time job	0.75(0.56,1.02)	0.78(0.56,1.07)
Income (yuan)		
0–999	1.34(0.76,2.36)	—————
1000–1999	1.42(0.79,2.55)	—————
2000–2999	1.59(0.82,3.08)	—————
3000		
Age (years)	1.00(0.98,1.02)	—————
Year of schooling	1.00(0.94,1.07)	—————