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HIV disclosure in rural China: Predictors and relationship to access to care

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Abstract

This study examined the main reasons and predictors of HIV disclosure and its relationship to access to care among people living with HIV (PLH) in a rural area of China. A sample of 88 PLH from three counties was interviewed in 2009. In our sample, the rates of disclosure were higher within and outside family. Trust (31%), needing help (28%), and close relationships (26%) were the three main reasons of selecting the person to disclose by a PLH. Using a multivariate analysis, level of HIV disclosure to partners and members within the community was only significantly associated with use of antiretroviral treatment (ART) (β =2.76; 95% Confidence Interval: 0.77, 4.74). After adjusting for demographics, time since HIV diagnosis and ART, we found HIV disclosure (β =0.07; 95% Confidence Interval: 0.01, 0.13) was a significant predictor for access to care. In order to improve PLHs' access to health services and care, future intervention programs should consider both the potential benefits and risks associated with HIV disclosure (intentional and unintentional), and assist PLHs to prepare for HIV disclosure and reduce potential negative impacts that come with it.

Keywords

HIV/AIDS; antiretroviral treatment; disclosure; access to care; China

Introduction

Disclosure of HIV serostatus is critical because of the significant links to safer sex practices (Crepaz & Marks, 2003; king et al., 2008; Loubiere et al., 2009), active cooperation in vertical transmission prevention (Nebie´ et al., 2001), less anxiety and greater social support (Holt et al., 1998; Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003; Lee et al., 2010), and adherence to antiretroviral treatment (ART) (Do et al., 2010; Stirratt et al., 2006). However, HIV disclosure makes people living with HIV (PLH) open to stigmatization and discrimination. This vulnerability puts PLHs at risk to potential loss of income, blame, threats to personal well-being, rejection, abandonment, verbal abuse, and disruptions in interpersonal and intimate relationships (Black & Miles, 2002; Gielen, O'Campo, Faden, & Eke, 1997; Lam, Naar-King, & Wright, 2007; Medley, Garcia-Moreno, McGill, & Maman, 2004).

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HIV disclosure is a difficult and complicated decision-making process. It consists of many dilemmatic components, e.g., to disclose or not, when to disclose and who should be the first one to disclose, etc (Li, Lin, Wu, Lord, & Wu, 2008). Previous researches on self-disclosure of HIV infection found individuals choose to disclose HIV serostatus depending on the populations and their social relationships (Bairan et al., 2007; Mason, Marks, Simoni, Ruiz, & Richardson, 1995). For example, HIV-positive gay men were more likely to disclose their HIV-status to lovers and gay friends than to their family (Hays et al., 1993). HIV-positive heterosexual men and women were more likely to disclose their serostatus to partners and friends, but lower rates of disclosure were found to their immediate family members, or co-workers (Marks et al., 1992; Petrak, Doyle, Smith, Skinner, & Hedge, 2001; Simoni et al., 1995). Moreover, cultural factor is another influential determinant. Profoundly influenced by Confucianism, Chinese culture is collectivistic by nature, which emphasizes on family as the fundamental unit of social support for individuals (Ko et al., 2007). Therefore, family is another important consideration, which influences a person’s disclosure decision. Previous studies have shown that in China, most PLHs disclose their HIV status first to a close family member, oftentimes a spouse or a sibling if single. They do not normally disclose to their parents initially. Then the close family member will decide when and how to inform the rest of the family members, which in turn, will determine whether to disclose to the community and in what manner (Li, et al., 2007; Li et al., 2008).

Numerous studies have examined reasons associated with HIV disclosure. According to Serovich (2001) consequence theory, HIV disclosure is a process of weighing the costs and benefits. Fear of being stigmatized may prevent HIV-infected persons from disclosing their HIV status (Chesney & Smith, 1999). However, with the progression of the disease, this fear would be overcome by the urgent need of emotional support from significant others to cope with the disease (Holt et al., 1998; Serovich, 2001). The visible signs of disease, use of highly active antiretroviral treatments (HAART), and hospitalization may precipitate the disclosure (Bouillon et al., 2007; Hays et al., 1993; Klitzman et al., 2004; Mansergh, Marks, & Simoni, 1995). Disclosure might also be considered to be an expression of responsibility towards the spouse or sex partners (Holt et al., 1998; Harawa, Williams, Ramamurthhi, & Bingham, 2006; Gorbach et al., 2004; Serovich & Mosack, 2003). In addition, it was reported that factors such as time since diagnosis (Mansergh, Marks, & Simoni, 1995; Simon Rosser et al., 2008), age, education, gender, transmission route (Bouillon et al., 2007), marital status (Akani & Erhabor, 2006) were correlated with HIV disclosure in previous studies.

Individuals who concealed their HIV status from members within and outside family may limit their access to information about available services resulting to limited access to care (Waddell, & Messeri, 2006). Previous studies also suggested that HIV disclosure was an essential part of access to HIV prevention and treatment programs in resources limited settings, as well as other forms of care such as nongovernmental organization (NGO) support, social grants and economic supports (Medley, et al., 2004; Norman, Chopra, & Kadiyala, 2007). Therefore, HIV disclosure may play a very important part in HIV prevention and care efforts, but there were little studies conducted in China addressing the issues related to HIV disclosure (Li et al., 2007; Li et al., 2008; Liu et al., 2006). Moreover, there were no studies formally examining the relationship between HIV disclosure and access to care in China.

This study was conducted in a rural area of China where the epidemic was driven by blood plasma donations dating back to the 1990s (Ji, Detels, Wu, & Yin, 2006; Wu Rou, & Detels, 2001). There are two other major HIV/AIDS epidemics, which are driven by, respectively, men sex with men (MSM) and risky heterosexual behaviors in urban areas, and injecting drug use along the border regions of Yunnan and Xinjiang (He & Detels, 2005). The aim of this paper was to find out the reasons and predictors of HIV disclosure, and to assess whether the level of HIV disclosure affected PLH's access to care.

Subjects and methods

This study used the baseline data from a pilot study of a family intervention trial in China. PLHs were confirmed of AIDS diagnosis or HIV+ status and aged 18 years or above. Once the PLHs had been screened and had agreed to participate in the study, written informed consent was obtained. The refusal rate was approximately 4%. 88 PLHs were included in this study. Following informed consent, face-to-face interviews were conducted either at a family's home or at other preferred places such as village clinic. Each interview took about 45–60 minutes. All PLH participants were paid 50 Yuan ($8) for each assessment. The study was approved by the Institutional Review Boards of University of California at Los Angeles, the Medical Institution Review Board of Anhui Province Center for Disease Prevention and Control, and the Medical Institution Review Board of Anhui Medical University.

Participant demographic information as age, gender, education level, marital status and annual individual income were collected and used in this study. We also included the following HIV-related information: individuals whom PLH disclosed their HIV status first to other than health workers and the reasons, plan on disclosing HIV serostatus to children, the level of HIV status known to spouse/sex partners and members within community, ART and the length of time since HIV diagnosis.

Measures

HIV disclosure was measured by asking the level of HIV status known to spouse/sex partners and members within community: (1) spouse or sexual partner/s; (2) friends; (3) Relatives; (4) neighbors; (5) village clinic/township hospital doctor; (6) village leaders; (7) people in their village. This measurement of HIV disclosure included both the intended disclosure (i.e., PLH disclosed to others willingly) and the unintended disclosure (others disclosed PLH's status against their will). Responses to each statement ranged from 0 (none) to 2 (all of them). By adding the seven items, we constructed a 14-point continuous variable to measure level of disclosure. The items were similar to ones used in a study conducted in Thailand (Lee et al., 2010).

Access to care was assessed by eight items: (1) I have regular visits to my doctor or medical providers; (2) If I get sick, I know where to go to get treatment; (3) If I need more information about my illness, I know where to get them; (4) I know when to go for my check up regularly when I am not sick; (5) I know how to protect myself from getting sick; (6) I can talk freely to my doctor and other medical providers about my illness; (7) I use herbal or traditional medicine in order to stay healthy; (8) I take vitamins or supplement regularly in order to stay healthy. Responses to each statement ranged from 0 (no) to 1 (yes). By adding the eight items, we constructed an 8-point continuous variable.

Statistical analyses

All statistical analyses were performed using the SAS 9.2 statistical software package (SAS Institute Inc., Cary, NC, USA). First, descriptive statistics was used to describe the demographics and HIV-related variables. Second, predictors of level of HIV disclosure to partners and members within community were examined by multiple linear regression analyses. Last, multiple linear regression analysis was performed to examine relationship between HIV disclosure and access to care after adjusting for socio-demographic variables, time since HIV diagnosis and ART. Parameters coefficients (β) and 95% confidence intervals (CIs) were calculated and reported.

Results

A total of 88 PLHs were recruited in this study. The age range was 30–60 with a mean of 41±6.8 years. Of whom, 60% were male and 40% were female. Most of them (91%) were married or living as married, the other 9% were separated/windowed/divorced. The main occupation for PLHs was farming (52%), 26% were part-time farmers, 15% were full-time stay-at-home houseperson. 15% of respondents had no schooling, 57% had 1–5 years of schooling, and 28% had more than 6 years. The median total annual individual income reported by the participants was RMB 2500 Yuan (US$ 366).

Table 1 outlines the characteristics of HIV disclosure among PLHs. When asked for people disclosed first other than health worker, more than half (61%) reported spouse/partner, 12% reported parents, 7% reported brother or sister, 6% reported son or daughter, 2% reported other family member, 1% reported friend. Only 3% said they have not disclosed to others. In some cases, instead of the service provider, it is the family member’s responsibility to inform PLH, the remaining 7% of them said family and friends informed them first. When asked for main reason of selecting this person to disclose first: 31% reported trust, 28% reported needing help, 26% reported close relationship, 9% reported being a relative. Other reasons included: 4% reported arrangement of things after his/her death, 1% reported protecting him/her from infection, 1% reported being infected from him/her. Also, almost half of them (54%) have already disclosed their HIV status to children, 9% had the plan on disclosing to children, and 37% didn’t have the plan on disclosing to children.

Table 2 presents the level of HIV status known to others including their spouse/partners and members within community. The levels of HIV status known to all types of members were higher. Over 95% of respondents reported that their partners knew their HIV serostatus, followed by their village leaders, village clinic/township hospital doctor, and neighbors, the level of HIV status known to friends reported by PLH were the lowest one.

Results from multiple linear regression of HIV disclosure with socio-demographics, time since HIV diagnosis and ART are summarized in Table 3. When looking at the P values and confidence intervals for coefficients of parameters in Model 1, we found only P values for annual individual income and time since HIV diagnosis were close to significance level of $\alpha = 0.05$ and the values in the confidence intervals are almost in one direction, negative or positive, respectively. The respondents with higher annual individual income reported a lower level of HIV status known to others ($\beta = -0.23$; 95%CI: −0.45, 0.00; $p = 0.0505$). The longer time since HIV diagnosis was related to a higher level of HIV status known to others in the study ($\beta = 0.32$; 95%CI: −0.03, 0.66; $p = 0.0717$). Considering 77% of the subjects in this study were currently on ART, the relatively higher associations between annual individual income and time since HIV diagnosis and level of disclosure were likely due to the relation between disclosure and being on ART. Therefore, we added antiretroviral treatment to the model (Model 2). Only use of ART was found to be significantly associated with the level of HIV disclosure ($\beta = 2.76$; 95%CI: 0.77, 4.74; $p = 0.0073$). Respondents who were currently on ART had a higher level of HIV status known to others than who were not. Also, people who were married or living as married reported a higher level of HIV status known to others ($\beta = 3.12$; 95%CI: −0.06, 6.31; $p = 0.0546$), which was borderline significant at $\alpha = 0.05$.

Relationship between HIV disclosure and self-reported access to care after adjusting for socio-demographics, time since HIV diagnosis and ART are illustrated in Table 3. Those respondents who reported a higher level of disclosure were related to a higher level of access to care ($\beta = 0.07$; 95%CI: 0.01, 0.13; $p = 0.0282$). Moreover, those who were currently on ART reported a higher level of access to care ($\beta = 0.59$; 95%CI: 0.08, 1.10; $p = 0.0233$). In addition, we found that education was positively associated with access to care (β =0.36; 95%CI: 0.04, 0.68; p =0.0278).

Discussion

In our sample, we found that 7% of participants were informed by their family members of their HIV positive status, which was consistent with findings from previous studies in China (Li et al., 2007; Li et al., 2008). As there are no reinforced policies for HIV status notification in China, health professionals sometimes make the decision for the test result notification based on their own judgment about the best method. One possibility was that family members were informed first of HIV status or PLH were informed while a family member was present (Li et al., 2007; Li et al., 2008). Findings suggest that there may be a need for further investigation of the impact of different types of HIV status notification on PLH and their family members in China.

PLH in our sample were more likely to disclose their HIV status first to their spouse/partners, followed by parents and then other family members. Only one subject in our sample disclosed first to his/her friend. Our findings differ from other studies reporting HIV infected non-MSM individuals were more likely to disclose their HIV status to their partners and friends than immediate family members (Petrak et al., 2001; Simoni et al., 1995). In China, family members usually serve as the main sources of emotional support. Compared with other family members, spouse/partner appears to be the most reliable confidant. In our study, we found that trust, needing a help, and close relationship were the three main reasons of selecting this person to disclose first. These findings are consistent with the view that desire for support and feelings of obligation were two primary motivations for disclosure HIV status to family members (Huber, 1996; Simoni et al., 1995).

Compared with available data among other populations, the prevalence of disclosure in our sample was higher within families as well as outside families (Lee et al., 2010). For example, a study in Thailand found that disclosure within family was 72.5% and disclosure outside of family was only 2.5% (Lee et al., 2010). The majority of people living with HIV/AIDS in our sample had disclosed their HIV serostatus to their spouse/sex partner and over half of them had disclosed their HIV status to family members, friends and communities. This was very special phenomenon in the rural area of China. The majority of PLH in our sample were infected through commercial blood donation in the early 1990s. Many of them have developed AIDS symptoms, which possibly precipitated their disclosure. Moreover, majority of them had very low annual individual income, thus they were more likely to rely on others' economic support, which possibly influenced their decision of HIV disclosure. In addition, people infected with HIV through commercial blood donations were thought to be 'innocent' victims while commercial sex workers and their clients, injecting drug users and men who have sex with men who acquired HIV infection were perceived as 'guilty' (Chan, Yang, Li, Stoové, & Reidpath, 2009; Yang & Zhang, 2004). This difference could significantly affect the type of stigma and therefore their willingness to disclose.

Previous studies have described that the length of time since HIV diagnosis might influence decisions regarding HIV disclosure (Mansergh, Marks, & Simoni, 1995; Simon Rosser et al., 2008). However, our findings indicated that after accounting for use of ART, the length of time since HIV diagnosis was not a significant factor for HIV disclosure. This suggests that the length of time since HIV diagnosis may possibly be a confounder and does not necessarily have a direct effect on HIV disclosure. But we should note that our measurement of HIV disclosure included both the intended and the unintended disclosures. It is possible that the length of time since HIV diagnosis only affected the PLH's decision to disclose their HIV status to others, that was, intended disclosure (Mansergh, Marks, & Simoni, 1995).

A significantly higher level of HIV disclosure was found among PLHs who were currently on ART than who were not. There were two possible explanations for this. First, the increased risk of disclosure among people who received antiretroviral treatment reflects the difficulty of keeping their HIV serostatus as a secret when taking medications and observable side effects occur (Klitzman et al., 2004). Second, disclosure was an entry criterion for many treatment programs in resource limited settings (Norman, Chopra, & Kadiyala, 2007). However, in post-HAART era, the relationship between HIV disclosure and antiretroviral treatment may be more complex. Some other studies found there was no correlation between being on antiretroviral treatment and HIV disclosure, which was explained by patients no longer felt sick and therefore there was no reason to disclose (Skogmar et al., 2006).

Being on ART and having access to care are very closely-related concepts; however, having access to care is a more general concept, as it includes not only access to ART but also other health resources and care. Our findings indicated that PLH being treated with ART reported a significantly higher level of access to care. Therefore, the association between HIV disclosure and access to care could be explained by its direct relationship to ART. But we found that even when accounting for the length of HIV diagnosis and ART, PLHs with higher level of disclosure to partners and members within community reported higher level of access to care in our sample. This suggests that HIV disclosure may have a direct relation to access to care except through its relation to ART. We can explain this relationship in two perspectives. First, access to care in resource-limited countries depends on the disclosure of HIV serostatus, thereby access to care was important in making decisions of HIV disclosure. Second, HIV disclosure was the catalyst for access to a lot of important and essential health resources and cares to maintain health (Norman, Chopra, & Kadiyala, 2007). Therefore, the causal direction between HIV disclosure and access to care may be not limited to a single direction. It was possible that access to care precipitated the disclosure, but disclosure also increased access to care.

There were several limitations to this study. First, we conducted data analyses based on cross-sectional data; therefore, causal interpretations of the results cannot be established. We cannot make inferences on whether higher level of HIV disclosure contributed to better access to care. Second, our study relied entirely on self-report to assess HIV-status disclosure to partners and members within community. Given the social demands placed on PLH to disclose their HIV status, our findings may overestimate the level of disclosure among PLHs. Third, we were unable to fully distinguish between the intended and the unintended disclosures. Different types of HIV disclosure might have different predictors and relationships to access to care. As Wong *et al.* (2009) noted that it was very difficult to make the distinction, especially in the small, tightly knitted rural communities where strong social ties facilitate the flow of social information, such that when individuals disclose their HIV status, an entire community may know of the individual’s status. Moreover, the number of individuals not enrolled in ART in the sample was quite low, 20 out of 88, leading to low reliability of the measurements; therefore, the magnitude of the association between HIV disclosure and access to care may be overestimated. In addition, it was helpful to note that our study population was predominantly of farmers and being infected through commercial blood donation; therefore, we were unable to detect an association that actually exists between socioeconomics and disclosure due to lack of variability within our study sample.

Despite these limitations, our study findings have important implications for future research and practice. We found that the level of HIV disclosure to spouse/sex partners and members within the community was positively associated with access to care. HIV disclosure is important in access to HIV treatment and other health services and care, however, the disclosure process is complex and has both benefits and risks to PLHs. In order to improve

PLHs' access to health services and care, future intervention programs should consider both the potential benefits and risks associated with HIV disclosure (intentional and unintentional), and assist PLHs to prepare for HIV disclosure and reduce potential negative impacts that come with it. Further research is needed to determine the causal direction between HIV disclosure and access to care, and also whether similar findings can be found among other populations of PLHs, such as commercial sex workers, injecting drug users and men sex with men.

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Table 1

HIV disclosure among PLHs (N=88)

	N	%
People you disclosed first other than health worker		
Spouse/Partner	54	61
Parents	11	13
Brother or sister	6	7
Son or daughter	5	6
Other family member	2	2
Friend	1	1
Family and friends informed me	6	7
None	3	3
Main reason of selecting this person to disclose first		
Trust	25	31
Need help	22	28
Close relationship	21	26
Being a relative	7	9
Other reason	5	6
Have plan on disclosing to children		
Yes	8	9
No	31	36
Already disclosed	46	54

Table 2

Level of HIV status known to partners and members within community

	Total	None of them (%)	Some of them (%)	All of them (%)
Friends	85	19 (22)	33 (39)	33 (39)
Relatives	88	8 (9)	33 (38)	47 (53)
Neighbors	88	13 (15)	18 (20)	57 (65)
Village clinic/Township hospital doctor	88	4 (5)	28 (32)	56 (64)
Village leaders	88	10 (11)	14 (16)	64 (73)
People in your village	87	15 (17)	29 (33)	43 (49)
Sexual partner/s or Spouse	87	2 (2)	4 (5)	81 (93)

Table 3

Multiple linear regressions of HIV disclosure and access to care with demographic, time since diagnosis and ART

Independent Variables	HIV disclosure				Access to care	
	Model 1		Model 2			
	β (95%CI)	P value	β (95%CI)	P value	β (95%CI)	P value
Age (Years)	0.07 (−0.20, 0.06)	0.2845	−0.07 (−0.19, 0.05)	0.2388	−0.00 (−0.03, 0.03)	0.8076
Gender (male)	0.96 (−0.95, 2.86)	0.3204	0.64 (−1.20, 2.49)	0.4889	0.07 (−0.27, 0.64)	0.7598
Married or living as married	2.04 (−1.25, 5.33)	0.2193	3.12 (−0.06, 6.31)	0.0546	−0.16 (−0.96, 0.64)	0.6883
Education (Years)	−0.34 (−1.73, 1.05)	0.6228	−0.26 (−1.58, 1.06)	0.6889	0.36 (0.04, 0.68)	0.0278
Annual individual income (1000 Yuan)	−0.23 (−0.45, 0.00)	0.0505	−0.00 (−0.28, 0.28)	0.9994	0.02 (−0.05, 0.09)	0.5308
Time since HIV diagnosis (Years)	0.32 (−0.03, 0.66)	0.0717	0.21 (−0.12, 0.54)	0.2165	0.07 (−0.01,0.16)	0.0735
ART			2.76 (0.77, 4.74)	0.0073	0.59 (0.08, 1.10)	0.0233
HIV disclosure					0.07 (0.01, 0.13)	0.0282

CI, confidence interval