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In Sickness and in Health: A Qualitative Study of How Chinese Women with HIV Navigate Stigma and Negotiate Disclosure within their Marriages/Partnerships

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Abstract

In China, there are currently an estimated 180,000 women between 16 and 45 years of age living with HIV. However, we know very little about their lived experiences. Given the spread of the AIDS epidemic in China and the burden it exerts on quality of life, there is an urgent need to understand how HIV affects Chinese women, particularly in the context of their marriages. How do they negotiate the extreme stigma of their illness in making decisions about disclosure and social support, especially in the context of their family life? We recruited 26 Chinese women with HIV in Beijing and Shanghai for in-depth interviews employing a phenomenological approach. We examined the process and outcomes of disclosure within the course of the women's search for social support. Women in HIV-discordant relationships often experienced a termination of their marriage after disclosure, yet others exhibited remarkably resilience, finding new strength through the challenge of their illness. Findings underscore the need for accessible and culturally acceptable interventions for Chinese women with HIV who face considerable stigma in their search for support.

HIV/AIDS is a significant health issue in China. Indeed, the country faces an HIV/AIDS crisis in which increasing numbers of HIV-positive individuals will need care (Gill, Huang, & Lu, 2007; Ji, Li, Lin, & Sun, 2007). Among those living with HIV/AIDS are an estimated 180,000 women between the ages of 16 and 45 years (UNAIDS/WHO, 2009). Most HIV-positive Chinese women receive their HIV diagnosis while in a relationship; indeed, a majority of them were likely infected by their husband or steady partner (UNAIDS/WHO, 2009).

Diseases, including HIV, can dramatically alter personal relationships (Lewis, 2004). In women who have been diagnosed with breast cancer, for example, studies have shown that spouses suffer elevated levels of distress as well, and problems in marital communication have been documented in both cross-sectional and longitudinal studies (Fletcher, Lewis, & Haberman, 2009). However, research specifically focused on the impact of the HIV diagnosis on marital relationships has been limited (Bradley, Remien, & Dolezal, 2008; Gilson, et al., 2010), and little research has been devoted to the phenomenon of divorce or abandonment following a women's HIV diagnosis.

In China, most women are married by 30 years of age, with an average age at first marriage of 23.49 years (All-China Women's Federation, 2007). When a married woman in China receives an HIV diagnosis, she is immediately faced with decisions around when and to whom to disclose. In our earlier work, we noted that the physician providing the diagnosis often disclose it to the woman's family members as well, without obtaining permission from her (Chen, et al., 2007). When they are given a choice, many HIV-positive women initially choose not to disclose their status to anyone, including their husbands (Chen, et al., 2007; Li, 2004). This is because disclosure often involves risk, particularly when the information revealed is potentially embarrassing, negative, or emotionally intense (Levy, et al., 1999). A decision to disclose HIV status involves a cognitive appraisal of potential negative consequences that is based on several considerations, including the individual's knowledge of HIV and perceived social attitudes toward HIV/AIDS and/or people with HIV (Omarzu, 2000). The decision to disclose one's HIV status often depends on the nature and resilience of one's social relationships. Fear and stigma related to the loss of these relationships are thus a predominant theme for those in this predicament (Bairan, et al., 2007).

Decisions around disclosure take place within a context of acute HIV-related stigma in China (Cao, Sullivan, Xu, & Wu, 2006; Zhou, 2007). In the collectivistic culture of Chinese society, the cultural imperative of familial responsibility over individual rights ensures that having an HIV-positive family member in the home will result in the stigmatization of the whole family (Li, Lin, Wu, Lord, & Wu, 2008; Sabin, et al., 2008; Stein & Li, 2008). Therefore, affected families tend to conceal the fact that they are suffering from a disease and may avoid or postpone seeking medical services in order to protect their family members from stigma associated with the disorder (Li, et al., 2007), similar to Mexican families (Mason, Marks, Simoni, Ruiz, & Richardson, 1995). Research specifically focused on how stigma affects Chinese HIV-positive women and their significant relationships is scant.

The specific aims of this paper were to describe how Chinese women living with HIV negotiate the extreme stigma of their illness in making decisions about disclosure, especially in the context of their marriages and families. We also aimed to examine the impact of these decisions on the quality of women's personal relationships and their ability to secure the social support so crucial to their continued quality of life.

Methods

Procedures

Ethical review boards in each of the researchers' home institutions, which included the University of Washington, Shanghai Public Health Clinic Center (SPHCC) and Ditan Hospital, approved the study. From December of 2009 through March of 2010, two in-depth interviews were conducted with each of 19 Chinese HIV-positive women selected in Shanghai. We combined these data with those of seven women interviewed for a related project in Beijing from July 2005 to March 2006 (Chen, et al., 2009; Chen, et al., 2010; Chen, et al., 2007; Starks, et al., 2008). Participants were approached through contacts at the SPHCC outpatient clinic and Beijing's Ditan Hospital. Snowball sampling methods (Marshall, 1996) were used to identify and enroll a sample of women who were HIV-positive, at least 18 years of age, and were willing to share their personal stories with the researchers. Women who were interested in the study met with the researchers, who then explained the study, answered questions, and obtained written consent.

All interviews were conducted in Mandarin, audio-recorded, and transcribed into Mandarin verbatim. Select quotations were later chosen from the transcripts and translated into English for this report. Interviews took approximately 2 hours and were conducted in a private

setting. In Beijing, bilingual research staff as well as Chinese physicians and nurses conducted the interviews. A nursing faculty member and a social work doctoral student (both bilingual, bi-cultural Chinese Americans) conducted all interviews in Shanghai.

Interviewers used a checklist during interviews to inquire about the participants' perceptions of their relationships both before and after their HIV diagnosis, among other topics not covered in this report. Specific questions included the following: "Who knows about your diagnosis?", "What was their reaction to your disclosure?", and "How has your relationship with them been since they found out?" In order to corroborate the results among the participants, the researcher started each interview by saying, "Many women have experienced stigma and loss of support from their intimate partners. Do you agree with that statement? What has your experience been?"

Data Analysis

Content analysis was used to summarize the range of responses (Hsieh & Shannon, 2005). The first two authors reviewed transcripts independently and identified codes to represent concepts in the narratives related to the interview questions and additional topics raised by the participants. The investigators agreed on a coding scheme, the meaning associated with each of the codes, and general patterns observed in the data during the process. The Atlas.ti qualitative data analysis program (Scientific Software Development, 2005) was used to manage the data coding process and generate reports that included sections of the narrative assigned to codes for stigma and disclosure.

Results

Sample Characteristics

The 26 study participants' mean age was 39.9 years (SD = 9.5 years; range 25–59). Most were of Han ethnicity (92%) and lived in Shanghai (88%). Twenty-two participants (85%) had at least a high-school diploma. Reported methods of HIV transmission included blood products (n = 6), sexual contact (n = 17), intravenous drug use (n= 1) and unknown (n= 2). Blood products include accepting blood products from transfusions or products made from blood sold by donors. Among the 17 participants who had contracted HIV via sexual transmission, 8 of their spouses/partners were HIV-positive. Another 7 had contracted HIV via extra-marital affairs, and 2 had been raped during the external immigration process by a local immigration agent. At the time of their diagnoses, all participants were in a relationship, either married or with a steady partner. At the time of the study, 16 of them (62%) were in the relationships, which includes 11 of the participants were married, 3 were living with a partner, 1 was never married (and not living with a partner), 9 were divorced (2 of them were dating), and 2 were widowed. Among the married women, two were not living with their husbands. One of the two widowed women was seeing someone at the time of interview.

Stigma

Study participants described stigma so acute that they would trade years of their own life in exchange for reducing the shame brought by HIV. To these women, the misery brought by HIV stigma was more terrifying than the more immediate threat to life posed by a disease such as cancer. A 47-year-old woman who received her diagnosis 10 years ago vividly described her experience of HIV as not only a biological disease, but a moral one as well:

> If I could choose between cancer and this disease [HIV], I would choose cancer. Even if I could survive only for one month with cancer but another decade with this disease, I would definitely choose cancer, and would definitely choose to die within

> a month. I would never want to live with this disease for ten years. The shame brought by this disease is even beyond my words. It is like the "dirty disease," in Chinese and Shanghai dialects.

However, one exception was a 46-year-old woman who said she was glad that she had HIV and not cancer, because "at least with HIV I know I still have time to manage my life and plan my days as long as I take the medicine on time."

One response of some couples to the intense HIV stigma was to completely withdraw. One 32-year-old woman stated that after carefully weighing cost and benefits of several life-arrangement options, she and her husband made the decision for her to quit her job and stay at home. Her husband was afraid that her disease might be accidentally disclosed, leading to stigmatization by her friends and co-workers. She stated:

> I have no friends at all now. Because my husband always tells me "don't get too close to your colleagues and friends. If they come to visit you when you are in hospital, you would be in great trouble." So I haven't had a job for two years. And I don't have friends, and tell [my status] to no body. . . . My husband earns more than I do, so I just stay at home and have no job. As I got better recently, I feel bored staying at home.

Disclosure

Most of the study participants in a steady partnership had disclosed their HIV status to their partners (85%). However, there were four participants who had not disclosed to anyone in their social circle, but had disclosed to peers that they met in healthcare settings. In addition, some had disclosed to their siblings.

Reasons for disclosure centered mainly around wanted to protect their sexual partners. A 30-year-old professional woman shared her concern over her boy friend's health, and had pushed him hard to get tested.

> When my physician told me I might be infected, I told my boyfriend right away. If I was in trouble, he would be, too. I told him I was suspected to have HIV. He said, "How that could happen?" I said, "I don't know either. But there is a possibility. You should calm down and go test. I am waiting for the final report."…Then, during the day I got my diagnosis, I told him. He said, "Why? When did you get this? Before we get together?" I said, "It doesn't matter right now as I am already infected. Go and get your test, and do it as soon as possible."

In the face of the extreme stigma associated with HIV in Chinese society, the women displayed various strategies for disclosing their HIV status. First, they carefully considered the nature and quality of the relationships with individuals to whom they were considering disclosing. Usually, women disclosed only to their partners and selected family members. However, this does not necessarily mean that the closer a relationship was, the more willing a woman was to disclose her diagnosis.

On the contrary, many women did not disclose to those with whom they had the closest relationships. In fact, two still had not disclosed to their husbands more than 10 years after being diagnosed. Because of HIV, one 56-year-old woman described how "I saw him 'stepping out' of the house to look for other women, but I could not say anything. Because I have HIV. . . . I couldn't say anything." She was willing to tolerate infidelity because of her shame around HIV. Her self-stigma prevented her from seeing herself as the kind of "complete" wife that would have been entitled to faithfulness on the part of her spouse.

Often, a diagnosis led to recriminations, discrimination, and dissolution of the marriage. In some cases, an HIV-negative husband would be the one who initiated discrimination against his HIV-positive wife. However, in other cases, the HIV-positive woman, concerned about not being able to bear healthy sons to carry on the family name, was the one who insisted on a divorce or separation. Sometimes, disclosure led to a deepening of the marital bond, which in turn resulted in the HIV-positive wife getting more help with medical care and counseling than she otherwise would have.

The most cited reason for non-disclosure was, again, to protect a loved one from being hurt by an HIV-positive diagnosis and associated stigma. The women in the study often felt the need to hide their diagnoses and their emotions while bearing the burden alone. Women who did disclose often were desperate for support. One 33-year-old woman who had been infected from needle sharing at a young age decided to disclose her diagnosis right after she was diagnosed. She called her sister from the CDC office:

> I knew that disclosing was a gamble. I was not sure what my sister would do, because I had let my family down before and they had rescued me once [when I was using drugs], but I really needed to know [whether they would still support me]. If they rejected me this time, I had already decided that I would move to a faraway place where no one could find me; I would restart my life somewhere else. I am glad that they accepted me right away. My sister said, “How come life is so hard on you? You really need to treat yourself better!”

Summary

Given the increasing effect of the AIDS epidemic in China, there is an urgent need to understand how the disease affects women’s close personal relationships, particularly in the area of how Chinese women with HIV/AIDS deal with issues of stigma and disclosure. Results of this study demonstrated that Chinese HIV-positive women struggled whether to disclose to their family members or keep the diagnosis to themselves in order to keep the intact families. In addition, stigma played an important role in the decision of disclosure in this population.

HIV is not only a physical disease but also a complex social issue with potentially devastating consequences for all kinds of social relationships. Within this context, multiple factors affect the decision to disclose (Chaudoir, Fisher, & Simoni, In Press). The stigma associated with HIV is an issue that married HIV-positive women must deal with on a daily basis. In this qualitative study of HIV-positive women in China, high stigma was shown to lead to extreme caution around disclosure, with some women opting not to inform their own husbands of their diagnosis.

Data from studies of other diseases suggest that the health status of marriage partners can have a strong effect on the marital relationship (Lewis, et al., 2006). However, there is extremely limited research devoted specifically to the effects of HIV infection on marital relationships, particularly regarding the experiences of discordant couples. Much of the existing HIV-related research focuses on discordant gay men (Bradley, et al., 2008; Remien, Wagner, Dolezal, & Carballo-Dieguez, 2003).

Since there is no “gay marriage” in China as such, there may be an assumption among researchers that HIV infection among men will not have implications for marriage. However, of the estimated 20 million homosexual males in China, about 80% are married (Li, 2009). Future studies are needed to understand in greater detail the specific challenges of the women these men marry.

There are several conclusions to be drawn from the results of this study. First, women have a range of reasons for disclosing or not disclosing their diagnosis. For some of them, protecting their loved ones was the main goal of disclosure. Others wanted to protect themselves, therefore they did not disclose to anyone. Second, many of the women in the study stated that they were not ready to disclose their status to their spouse (especially if the spouse was HIV-negative) and their child, out of fear that by doing so they might destroy the family. Last, many women felt that if they were to reveal their HIV-positive diagnosis, they could no longer have sexual relations, even if they had a steady partner and used a condom. In the future, it might be interesting to explore the correlation between level of knowledge about the disease and susceptibility to stigmatization.

There are several limitations in the current study. First, the study was conducted in the metropolitan areas in China, where women who might have more sexual liberty and different attitudes toward marriage; indeed several reported extra-marital affairs and others had divorced. Second, the sample included women who were recently diagnosed of HIV and, therefore, may not have had the occasion to disclose yet to many family members. Third, in this study, we did not interview the women's intimate partners, who might have had different perspectives on the relationship and the decision to disclose than did the women themselves. Finally, none of the women reported a husband who was gay, either because there were none, they were unaware of it, or they declined to share this information with us.

Interventions focusing on accessible, affordable, and culturally acceptable care should be designed for women struggling with decisions around disclosure of their HIV status. Future studies should focus on creating culturally appropriate interventions that encourage women to develop their own disclosure strategies. Interventions that focus on decreasing self-stigma, enhancing social support and lowering perceived stress should be designed for Chinese HIV-positive women. Such interventions may reduce stigma, enhance social support and strengthen women's personal relationships, ultimately providing them with better strategies for disclosure and long-term treatment.

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