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Original Article

Facilitators of and barriers to HIV self-management: Perspectives of HIV-positive women in China☆

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ABSTRACT

Aims: The aim is to explore perceived facilitators of and barriers to HIV self-management for HIV-positive Chinese women.
Background: Little is known about self-management among HIV-positive Chinese women in China. Understanding the experiences of this population is needed to promote self-management.
Methods: 27 in-depth interviews were conducted in Beijing and Shanghai. Facilitators included families being supportive after disclosure, patients learning how to live with HIV, antiretroviral therapy (ART) adherence, and rediscovering the meaning of life. Several barriers were also identified, including lack of support, stigma, fatigue, and financial difficulty.
Results: HIV disclosure is essential to obtaining necessary support. Ironically, disclosing to family members who stigmatize the disease may invite unwelcome responses. Helping HIV-positive women to decrease self-stigma and develop an effective way to disclose, if they choose to, is important.
Conclusion: Future interventions should focus on disclosure strategies development and self-management to prevent isolation, enhance social support, and decrease self-stigma.

Currently, close to half of the 37 million adults living with HIV/AIDS worldwide are women, and many of them are in their reproductive years (UNAIDS, 2015). Of people with HIV, on average young women and adolescent girls with HIV are contracting it 5–7 years earlier than young men (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2012). HIV is thus influencing women's lives more deeply, as they are more susceptible to the disease at an age when they are experiencing rapid social development (Semprini, Hollander, Vucetich, & Gilling-Smith, 2008).

In China, heterosexual sex is currently the most common transmission route for HIV.[28] Many infected women belong to the high-risk category of commercial sex workers, but a significant number are housewives or career women who have been infected by their husbands (Zhang et al., 2007). In addition to being infected through sexual contact, women can contract HIV by selling blood (this happened frequently during the 1990s in China) and by sharing needles during injection drug use (IDU) (Zhang et al., 2008). At least one third of sexually active men who have sex with men in China are married, so a woman might be married to a high-risk partner without realizing the need to take precautions against HIV/AIDS (Tucker, Chen, & Peeling, 2010). China currently faces an HIV/AIDS crisis in which increasing numbers of HIV-positive individuals will need antiretroviral therapy and psychosocial support to cope with the diagnosis and ongoing treatment (Gill, Huang, & Lu, 2007; Ji, Li, Lin, & Sun, 2007).

In many societies women have lower social and economic status, while also assuming primary care of the family (Turmen, 2003). This is true for Chinese women, for example, who are still perceived to have a gender obligation that includes continuing the family line (by bearing children) and providing care to the extended family (Zhou, 2008). Although HIV infection does not change their identities as women, it does threaten their ability to continue functioning in their traditional gender-based roles (Turmen, 2003). Facing multiple social expectations and obligations, HIV-positive Chinese women may come to doubt their personal worth and feel that they have brought shame on themselves. Families living with a member who has a chronic illness (especially HIV) vacillate between hope and despair, between suffering and possibility.

Based on Gray's revised self- and family management theoretical framework, we updated the model to focus on HIV-positive population and develop a series of qualitative in-depth interviews, the results of which we analyzed to understand HIV-positive women's self-

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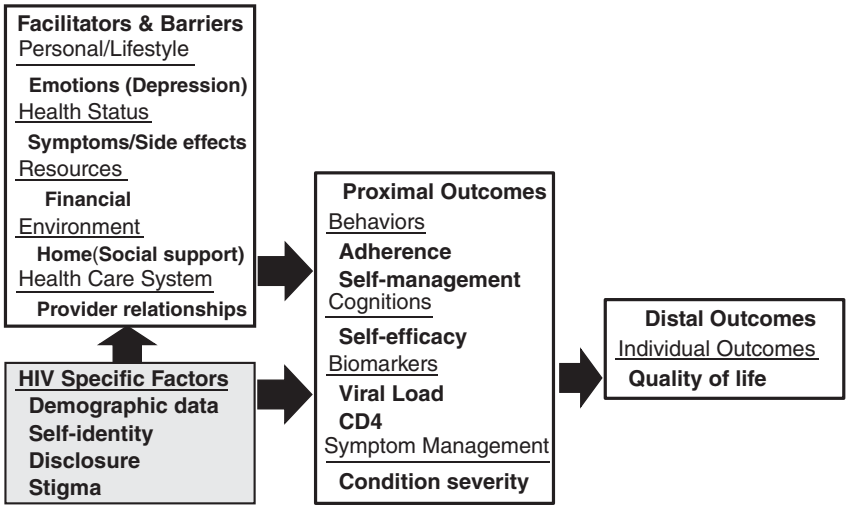

Fig. 1. The self-management framework in HIV-positive Chinese women.

management strategies (Grey, Schulman-Green, Knafl, & Reynolds, 2015). As seen in Fig. 1, the framework highlights the facilitators of and barriers to the individual and family, as well as proximal and distal outcomes. We highlighted the HIV-related factors and added potential HIV-positive female specific issues (e.g., perceived stigma of HIV infection) as they will likely influence the participants' provider relationships and QOL. The identified factors were seen as affecting reasons for and against disclosure and are weighed in decisions about disclosure. (Without disclosure, the typical HIV-positive female will not get the support she needs.) As self-management improves, stigma and clinical symptoms decrease and disclosure decisions occur. Disclosure in turn initiates family support, which has a positive effect on family dynamics and self-efficacy skills.

HIV is now considered a chronic rather than terminal disease, and lifelong antiretroviral therapy (ART) is needed to manage it (Lau & Tsui, 2005; Sabin et al., 2010). For HIV-positive women, managing the disease is a major concern—particularly in cultures where women have little power to regulate their sexual availability to men and are thus at increased risk for exposure to HIV (Dickens, 2008). The concerns for Chinese women living with HIV include stigma, serostatus disclosure, medication access, medication adherence, and continuation of family obligations (Jones et al., 2010; Marion et al., 2009; Voss, Portillo, Holzemer, & Dodd, 2007). There is very limited research focusing on interventions for HIV-positive women in Chinese culture, particularly in the context of self-management. Therefore, in this paper, we focus on factors that either facilitate or hinder women's HIV-related self-management strategies.

1. Methods

1.1. Design

A qualitative design incorporating in-depth interviews was used for the study. Qualitative content analysis and a commercial software package (ATLAS.ti) were used to code and analyze the data.

1.2. Participants

Twenty-seven HIV-positive women were purposively sampled from two premier Chinese hospitals: Beijing's Ditan Hospital and Shanghai's Public Health Clinic Center (SPHCC) in China. We recruited Chinese women who were diagnosed with HIV by infectious disease physicians. The women were aged 18 years and above without significant cognitive problems and were receiving care at one of the two hospitals above, either inpatient or outpatient. To be eligible for the study, the women had to be willing to share their personal experiences with us.

1.3. Data collection

Potential participants were approached directly by clinic staff and their primary care providers, who informed them about the study; those who were interested were referred to study personnel. After study staff explained the nature, risks, and benefits of the study, those who agreed to participate provided written informed consent. In this qualitative study, participants could choose whether or not to have their interviews audio recorded; if they declined, detailed notes were taken. All participants received 150 RMB (~U.S. $20) as compensation for their participation in the single semi-structured in-depth interview.

1.4. Interview process

There were two phases of in-depth interviews. The first phase was conducted between July and September of 2005 in Beijing. The second phase was conducted from November 2009 to March 2010 in Shanghai. Each of the in-depth interviews took 60–90 minutes and was conducted in a private office at the hospital or in another place of the participant's choosing. Interviewers included research staff, physicians, and nurses at the hospital. All interviewers were Chinese speakers and interviews were conducted in Mandarin Chinese. All interviewers first completed a 2-day training course to familiarize themselves with the goals of the study and to learn standardized procedures for qualitative interviewing.

A total of 27 HIV-positive Chinese women were recruited and interviewed. After briefly introducing the study and doing a warm-up discussion, the interviewer posed questions in a conversational format. Interview guides included open-ended questions and various probes related to general experiences of HIV self-management and any facilitators and barriers the subject may have encountered. Interviewers used a checklist during the interviews to ensure that specific topics related to self-management were discussed as part of a general discussion on the women's experience with self-management. The self-management topics included: testing history, disclosure experience, social support, medication history, side effects, adherence to ART, facilitators of and barriers to adherence, and social support. To address these topics, we asked the HIV-positive Chinese women questions like the following: How did you take care yourself after you learned you had HIV? Are you currently taking any medicine for HIV? Any issue with taking HIV medicine? How many people have you told that you are HIV-positive? What happened after you told them? Can you tell me who your support person is and describe how your support person helps you with HIV-related care? All interviews except one were audio recorded, and all were transcribed into Chinese verbatim.