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# Disclosing Parental HIV Status to Children in China: Lessons Learned Through an Intervention Study

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*For HIV-infected parents, deciding whether and how to disclose their illness to their children is a major stressor. In China, due to significant HIV stigma, disclosure distress is acute. Our objective was to understand HIV-infected parents' concerns regarding disclosure of their HIV status to their children. HIV-infected parents (N = 10) were recruited to attend a three-session nursing intervention. In our post hoc analysis, progress notes from each session were analyzed for themes to illuminate parental decision-making processes. By the end of the intervention, all parents had considered the importance of HIV disclosure and stated that they felt somewhat prepared to disclose. Primary themes included (a) severe stigma experienced by fathers who were sexually active with men, (b) need for both parents to agree on plans for disclosure, and (c) parents' fears about the consequences of disclosure. Parents living with HIV can benefit from nurse-delivered interventions during parental HIV disclosure decision-making.*

**Key words:** children, China, disclosure, HIV, intervention, nursing, parent

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Globally, there are more than 33 million people living with HIV (PLWH), with an estimated 780,000 infections in China (World Health Organization, Joint United Nations Programme on HIV/AIDS, & United Nations International Children's Emergency Fund, 2010). For Chinese PLWH, social stigma is a critical concern (Ministry of Health People's Republic of China Joint United Nations Programme on HIV/AIDS World Health Organization, 2015). The Chinese government is committed to curbing the spread of HIV, as it has recognized the serious health, economic, and security challenges the epidemic poses (Li et al., 2011). In 2004, a State Council HIV/AIDS Working Committee was assembled as part of the government's ongoing effort to address the epidemic. Based on recommendations from this council, national legislation was passed to establish HIV treatment and testing centers throughout China and to provide widespread free antiretroviral therapy (ART) and care for children affected by HIV (Ministry of Health People's Republic of China Joint United Nations Programme on HIV/AIDS World Health Organization, 2006). There is currently a window of opportunity for clinicians to intervene with psychosocial support in conjunction with the Chinese government's ongoing efforts. Increasing numbers of individuals are seeking testing and initiating ART at local infectious disease clinics; this population is both accessible to researchers and amenable to behavioral intervention.

Of the individuals seeking testing and initiating ART, many are fathers who are married to women but who also identify as men who have sex with men (MSM; Guo, Li, & Stanton, 2011). Same-sex sexual behaviors have a compounding effect on the stigma related to HIV and complicate the issue of parental HIV disclosure in traditionally close-knit Chinese families (Yang et al., 2015). A primary concern for HIV-infected parents all over the world is the issue of making a decision about whether to, when to, and how to disclose their HIV status to their children (Simoni et al., 2015). In China in particular, parents face many culturally specific barriers to disclosure, and these include a child's maturity, mental burden of the diagnosis, stigma, and isolation (Kyaddondo, Wanyenze, Kinsman, & Hardon, 2013; Yang et al., 2015). In addition, HIV-infected parents

are concerned about critical moments in their children's life stages (e.g., preparing for college entrance exams, finding a life partner, having a baby), and often desire to wait for the best time to disclose their serostatus.

## Background

Globally, HIV-infected parents face similar difficulties when they consider whether to disclose their status to their children. For example, in Uganda, HIV-infected parents are afraid of discrimination from the community, and experience shame and guilt related to unprotected intercourse and loss of societal privileges (Kyaddondo et al., 2013). However, without disclosure, they also lose access to the health care system, societal resources, and potential treatment because they did not express their need for HIV care (Kyaddondo et al., 2013). In the United States, HIV-infected mothers not only worry about their children's situations but also about their own conditions. These women are stressed about the role of mother, which is especially true for women who have a weaker attachment with their children (Murphy, Marelich, Armistead, Herbeck, & Payne, 2010). In addition, HIV-infected mothers also tend to be faced with low socioeconomic status, high perceived stigma, and high-risk behavior. In particular, mothers with younger children worry about the developmental maturity of their children and whether the children can keep the secret inside the family if disclosure were to occur (Murphy et al., 2010). The majority of HIV-infected parents in the United States (around 60%) have not revealed their serostatus to their children (Murphy et al., 2010). The only study to report rates in China indicated that 77% of Chinese parents had not revealed their serostatus to their children (Zhou, Zhang, Li, & Kaljee, 2013).

In fact, the majority of disclosure studies on HIV-infected parents have been conducted in the United States, with little specific information about either mothers or fathers in low-resource settings (Qiao, Li, & Stanton, 2013). The limited research that has been done on parental disclosure in China has indicated that the majority of HIV-infected parents were reluctant

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