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Perceived stigma, medical social support and quality of life among people living with HIV/AIDS in Hunan, China

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ABSTRACT

Purpose: The present study aimed at examining the relationships among perceived stigma, social support, and quality of life (QOL) in people living with HIV (PLWH).
Methods: We recruited 190 participants meeting the inclusion criteria from two HIV clinics in Hunan, China. HIV-related Stigma Scale, the Chinese Version of the Medical Outcomes Study — Social Support Survey (MOS-SSS-C), and the Medical Outcomes Study-HIV (MOS-HIV) were used to measure the perceived stigma, social support and QOL in PLWH.
Results: The mean scores of the perceived stigma, social support, and QOL were 104.32, 53.63, and 61.97 respectively, which were in moderate range. Stepwise multivariate regression analysis showed ($R^2 = .49$, $p < .01$) a low score of internalized stigma and family stigma, a high score of tangible support for non-drug use and antiretroviral treatment, and high CD4 count predicted better QOL.
Conclusion: Perceived stigma and social support are correlated with the QOL in PLWH. Interventions designed to decrease perceived stigma and strengthen social support from family are necessary to improve the QOL in PLWH.

1. Introduction

AIDS is the leading cause of death in China when compared with other infectious diseases and has drawn much attention. The China AIDS Response Progress Report of 2012 estimated 780,000 people living with HIV/AIDS (PLWH) in China at the end of 2011, with a prevalence rate of 0.058% in the general population (Ministry of Health of China, 2012). Highly active antiretroviral therapy (HAART) is the standard treatment for HIV infection in the world and has decreased mortality and morbidity among PLWH (Kushnir & Lewis, 2011). By the end of 2011, almost 155,000 PLWH received HAART in China, with adults increasing from 67.2% in 2011 to 76.1% (Ministry of Health of China, 2012). Currently, counseling and monitoring services sponsored by the government are being expanded in most provinces in China to control the spread of HIV/AIDS. HIV infection has become a chronic and manageable disease as diabetes and high blood pressure (Oguntibeju, 2012).

In China, several studies reported that the QOL of PLWH worsened when people's HIV status was notified, especially for those infected through sexual contact (Sun, Li, Zhao, & Lu, 2012; Sun, Wu, Qu, Lu, & Wang, 2013). Meng et al. (2008) reported poor QOL of PLWH measured with short form SF-36. Another study showed that the mean score of overall QOL in Hubei was 25.8 by WHOQOL-BREF instrument (Chinese version) (Mkangara et al., 2009). HIV positive individuals reported poor QOL in groups such as the widowed or separated women, people with lower levels of education and the needy. A report found out that in Thailand PLWH had a moderate QOL (Munsawaengsub, Khair, & Nanthamongkolchai, 2012). But in Nepal, the QOL of PLWH was low with a mean score of 4 measured by the World Health Organization Quality of Life Questionnaire, and psychological domain was also the lowest (Giri et al., 2013).

In the era of HAART, a majority of patients are now on the life prolonging treatment globally. HAART has improved the QOL of PLWH by reducing the morbidity and mortality that were previously associated with AIDS, but the adverse reactions such as fatigue, anemia and digestive tract disorders are to blame for the low QOL of some patients (Adane, Desta, Bezabih, Gashaye, & Kassa, 2012; Mandorfer et al., 2013). In China, many patients have been diagnosed at advanced stages of the disease with severe symptoms, lower CD4 count and higher viral load, which mean that they have to deal with problems such as chronic clinical symptoms, heavy economic burden for health care, and loss of labor due to illness, and eventually poor QOL (He et al., 2012).

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HIV-related discrimination and stigma impact negatively on the QOL of PLWH (Fuster-Ruizdeapodaca, Molero, Holgado, & Mayordomo, 2014; Herrmann et al., 2013). HIV/AIDS is highly stigmatized in China with PLWH trying to cope with daily discrimination, in despite of the introduction of "Four Free, One Care" policy and increased knowledge and understanding of HIV/AIDS. For the public, AIDS is associated with "horror", "drug abuse", "metamorphosis", and "sexual promiscuity (Goffman, 1963). "Sex" has always been an obscure topic in China and the public considered PLWH as sexual perverts who suffer for sexual immorality and deserve no mercy. Public discrimination makes them feel guilty, afraid of normal interaction with friends, lose social support, and denied job opportunities. Moreover, perceived stigma and discrimination may prevent PLWH from disclosing their status and treatment, causing nonadherent therapy, low self-esteem and poor QOL (Charles et al., 2012; Li et al., 2011). PLWH are beset with various psychological problems, such as depression (Charles et al., 2012), anger (Archibald, 2010), despair and hatred, which all negatively affect their QOL directly or indirectly.

Social support has a significant effect on the QOL of PLWH. Previous studies reported that social support was correlated with the QOL (Bajunirwe et al., 2009; Gielen, McDonnell, Wu, O'Campo, & Faden, 2001; Yadav, 2010). People with good social support reported better mental health and QOL. In Colombia, satisfaction with family support was significantly associated with patients' QOL (Cardona-Arias, Pelaez-Vanegas, Lopez-Saldarriaga, Duque-Molina, & Leal-Alvarez, 2011). Social support provides psychological boost for PLWH which in turn ensures a good mental state, a necessity for good health.

Previous studies have reported the relationships between stigma, social support, and QOL. But in China, researches on the QOL of PLWH mainly focus on exploring the relationship between different factors and finding the mediation effect (Li et al., 2011; Rao et al., 2012), while studies on relationships between the physical index, medical social support, stigma and QOL are rare. To recommend new interventions to improve QOL and help PLWH manage the chronic disease, we applied a cultural grounded stigma scale and certain physical indexes to explore the relationships among these factors.

2. Methodology

2.1. Participants and setting

We used a cross-sectional descriptive design in this study. Data were collected from July 2011 to September 2012. The study included 190 PLWH. Participants were PLWH who received medical care at the HIV clinics of 2 hospitals in Hunan: the Third Hospital of Hengyang and Changsha Hospital of Infectious Diseases. Participants were included if they met the following criteria: 1) age 18 years or older; 2) confirmed diagnosis of HIV/AIDS; 3) physically able to answer questions in the questionnaires and clearly convey their advice; 4) receiving treatment with care and support. Patients who had the following traits were excluded: 1) failed to understand the aim of the study and communicate with researchers; 2) failed to finish the study due to physical diseases; 3) enrolled in other similar studies. All participants signed informed consent before the study.

2.2. Measurements

2.2.1. General information questionnaire

The general information questionnaire provided demographic data such as participants' age, gender, residence (rural or urban), marital/partner status, average household income, education, and employment status. Other information about HIV/AIDS status is also included, such as the date of HIV diagnosis, CD4 cell count, mode of infection, and drug abuse.

2.2.2. HIV/AIDS-related stigma scale

HIV/AIDS-related stigma scale is a culturally sensitive Chinese scale developed by Li, G., and H. (2010), including 5 domains (disclosure concern, public rejection, family stigma, internalized stigma and health professional stigma) and 34 items in total. It is a 5-point Likert scale, of which each item is from *Strongly Disagree* to *Strongly Agree* scoring 1 to 5. The total score is 100 and high scores imply severe degree of perceived stigma and discrimination. Cronbach's alpha of the scale was 0.90, the content validity index was 0.88, and the evaluation results were acceptable (Li et al., 2010).

2.2.3. The Chinese version of the Medical Outcomes Study — Social Support Survey (MOS-SSS-C)

The MOS-SSS-C is a multidimensional measure of perceived social support developed for patients with chronic diseases (Yu, Lee, & Woo, 2004). It contains 19 items and each item is scored on a 5-point Likert scale format indicating how often a patient receives the needed support, with "1" representing none of the time and "5" all of the time. The 4 subscales consist of tangible support, affectionate support, positive social interactive support and emotional–informational support, and measure different domains of medical social support. The total score of MOS-SSS-C ranges from 0 to 100, in which the higher score indicates better perceived social support. The Cronbach's alpha of the scale was 0.98, with good validity and reliability (Li, 2012).

2.2.4. The Medical Outcomes Study-HIV (MOS-HIV)

The Chinese simplified version of MOS-HIV (Yang, Liu, Jia, & Xun, 2007) was used to measure the QOL of PLWH, containing 10 domains and 35 items, which is a valid measure used globally (Bajunirwe et al., 2009; Huang, Tian, Dai, & Ye, 2012; Ichikawa & Natpratan, 2004; Lau, Tsui, Patrick, Rita, & Molassiotis, 2006; Wu, Revicki, Jacobson, & Malitz, 1997). The score for each subscale was calculated by summing each score and transformed with a standard formula (Wu, 1996).The total score of the scale ranged from 0 to 100, in which high score predicted better QOL.

2.3. Ethical considerations

The study was approved by Institutional Review Committee in School of Nursing of Central South University. An informed consent was signed by every participant after we explained the purpose, procedure, risk, and benefit about the study to the participants, who were given codes instead of names on the questionnaires to ensure anonymity and confidentially. The participants were assured that their participation or non participation or withdrawal from the study would not affect the care they would receive from the clinic. Upon completing the questionnaire, a box of multivitamins (cost of 20–30 RMB) was provided to each participant as a gift for participating in the study.

2.4. Data analysis

Statistical Package for Social Sciences (SPSS) 16.0 was used to analyze the data. The participants' demographic information was reported with measures of central tendency and percentages. Scores of perceived stigma, social support, and QOL were presented as mean and standard deviation. Bivariate relationships between subscales of each variable and all domains of QOL were examined with Pearson coefficients. Stepwise logistic regression was used to analyze the relationships among the independent variables (perceived stigma, social support and demographic variables) and dependent variable (QOL).

3. Results

3.1. Sample

We recruited 190 participants (137 males and 53 females) in the study. The average age of the participants was 38.3 years (21–68 years, SD = 9.4 years). A total of 166 participants (87.4%) received antiretroviral therapy (ART), and 49 participants (26%) used drugs and the average drug use lasted 24.2 months (0–74 months, SD = 19.9). The average HIV diagnosis took 30.3 months (0–98 months, SD = 23.1). Other demographic information was presented in Table 1.