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Original Article

Investigation of perceived stigma among people living with human immunodeficiency virus/ acquired immune deficiency syndrome in Henan Province, China

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ABSTRACT

Purpose: To investigate the level of and factors influencing perceived stigma and discrimination among people living with human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (PLWHA) in Henan Province.
Methods: In total, 161 PLWHA from Zhengzhou and Zhenping were investigated using the Berger HIV stigma scale.
Results: The mean Berger stigma scale score was 105.70 ± 15.20, indicating a middle stigma level. Among the four subscales of the Berger stigma scale, the disclosure concerns score was highest, while the negative self-image score was lowest. Multivariate analyses showed that factors influencing perceived HIV stigma included the level of education and route of infection.
Conclusion: The level of perceived HIV stigma and discrimination among PLWHA in Henan Province is moderate and was affected by the level of education and route of infection. Special intervention should be established to address this problem.

1. Introduction

Since the first case of acquired immune deficiency syndrome (AIDS) was identified in 1981, the spread of human immunodeficiency virus (HIV)/AIDS has been accompanied by stigma [1]. HIV stigma remains a substantial challenge faced by every nation. Studies have consistently documented that HIV-related stigma negatively impacts disease disclosure, delays access to health care, interferes with adherence to antiretroviral therapy, and inhibits the use of preventative services for people at risk of HIV [2–4]. HIV stigma can be characterised as

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both public and perceived [5]. Public HIV stigma, or external stigma, refers to the cognitive, affective, and behavioural negative reaction toward people living with HIV/AIDS (PLWHA) [6]. Perceived HIV stigma, also termed self-stigma or internal stigma, refers to the PLWHA's perceptions of societal attitudes toward the PLWHA, the PLWHA's awareness of actual or potential social rejection, a negative change in the PLWHA's social identity based on his or her HIV status, and adoption of society's negative views into the PLWHA's own self-concept, including self-blame and shame [7].

Perceived HIV stigma has a stronger negative impact on the overall well-being of the PLWHA than does public HIV stigma [8]. Various negative effects of perceived stigma on the PLWHA have been established, including a high level of depression, reluctance to disclose their HIV status to others with resultant social isolation and disruptions in normal social relationships, decreased access to and retention of care, and poorer adherence to antiretroviral therapy [9].

Notably, HIV stigma is a cultural construct, and its experiences vary among individuals across countries and communities. Therefore, HIV stigma must be understood in a specific context. The aim of the present study was to provide a baseline for perceived stigma among Chinese PLWHA and help health care professionals to develop culturally sensitive practices to address this problem. This study emphasised identification of other variables that may be related to perceived HIV stigma, such as sex, age, treatment, and disclosure of HIV status.

2. Material and methods

2.1. Subjects

We conducted a quantitative survey of 161 HIV-positive individuals selected from two health clinics in Henan Province from January to August 2013. One health clinic was Zhenping CDC in Henan Province ($n = 81$), and the other was the Hospital for Infectious Diseases in Zhengzhou ($n = 80$). These two research sites were chosen because they contain independent departments for HIV therapy and consulting, which facilitated convenient recruiting of potential participants.

2.2. Surveys

A member of the clinic staff introduced the study to the patients, and interested individuals met with an interviewer to determine their study eligibility. The patients were required to be HIV-positive and have basic literacy skills to be eligible for the study. All patients were known to be HIV-positive according to a previous diagnosis. This study was approved by the Research Ethics Board of Peking Union Medical College, Beijing, China.

2.3. Measures

2.3.1. Demographic and background information

The patients' demographic and background information included age, sex, place of residence (rural or urban), highest level of education, marital status, employment condition, and items related to HIV status including presumed route of transmission, time since diagnosis, treatment conditions, family awareness of serostatus, CD4+ cell count, and current health status. The current CD4+ cell count was reported by the patient if he or she had undergone testing. One item from the quality of life scale of the 36-Item Short Form Health Survey measured the patient's self-rated health status at the time of the investigation; this item was "How are you feeling about your health at present?" The allowed responses fell into five categories ranging from extremely well to extremely poor.

2.3.2. Perceived HIV stigma

The subjects' perceived HIV stigma was assessed using the Berger HIV stigma scale [7]. This 40-item instrument was developed in 2001 to measure the stigma perceived by PLWHA in the United States. There is no validated Chinese version of the scale, but several studies have used the scale among Chinese populations. Therefore, we revised the scale and translated it into Chinese for use in the present study. All participants were asked to respond to each item in terms of whether they "strong disagree," "disagree," "agree," or "strong agree." Possible scores ranged from 40 to 160, with a larger score indicating a higher degree of perceived HIV stigma.

Berger et al. [7] identified four factors in their original sample of HIV-positive individuals: personalised stigma, disclosure concerns, negative self-image, and concern with public attitudes toward PLWHA. Personalised stigma (Factor 1) identifies the negative consequences of other people's knowledge that an individual has HIV, such as experiences with or fear of rejection. Disclosure concerns (Factor 2) includes items related to controlling information related to one's HIV-positive status. Negative self-image (Factor 3) refers to concerns about feeling unclean or being inferior to others because of an HIV-positive status. Finally, concern with public attitudes about PLWHA (Factor 4) focuses on perceptions about what "most people" think about a person with HIV or what individuals with HIV can expect from others when their HIV-positive status is discovered. The HIV stigma scale exhibited quite good reliability in the present sample (Cronbach's alpha, 0.94.)

2.4. Data analysis

Descriptive statistics were obtained for all study variables. Bivariate and multivariate stepwise linear regression was conducted to identify the predicting variables using the Statistical Package for the Social Sciences, version 18.0 (SPSS, Inc., Chicago, IL, USA). Assumptions of normality and constant standard deviations were tested, and the data met the assumptions. Variables were included in the multivariate model if the bivariate test resulted in a p value of ≤ 0.10, indicating a potential association with stigma. For the regression analyses, age and time since HIV diagnosis were treated as continuous variables, and the CD4+ count was dichotomised as <350 and >350 $\mu L/mm^3$.

3. Results

3.1. Demographics

In total, 161 PLWHA were investigated in this survey, including 89 male patients (55.3%) and 72 female patients