

# Mental Health Problems of Female Spouses of Men Living With HIV in Sichuan, China: A Qualitative Study

Wangnan Cao, PhD • Hai Ming Wong, PhD\* • Phoenix Kit-han Mo, PhD, CPsychol • Shengzhi Sun, PhD • Yanhong Jessika Hu, PhD

## Abstract

HIV disclosure to spouses can promote HIV prevention and facilitate support from those spouses; it can also cause mental health challenges for the spouses. We conducted a qualitative study of the mental health status and potential contributing factors of mental health challenges of spouses of men living with HIV in Sichuan, China. We interviewed 31 spouses whose husbands were living with HIV. Qualitative data were analyzed using content and thematic analyses. We found that mental health challenges were common among the spouses; leading challenges were themed as hopelessness, depression, and anxiety. Greater HIV knowledge, close relationship with husband, and psychological support may protect spouses from mental health challenges, whereas HIV-related stigma, heavy caregiving burden, and an unsupportive environment might be detrimental to mental health. Spouses of men living with HIV need mental health services, which should take into account a wide spectrum of contributors at individual, couple, and social levels.

**Key words:** caregiving, depression, family member of people living with HIV, qualitative study, social support

**H**IV infection continues to be a major global public health issue in the era of effective antiretroviral therapy (ART). It has been estimated that approximately 36.9 million people were living with HIV (PLWH) at the end of 2017, and 59% of adult PLWH were receiving lifelong ART (World Health Organization, 2018). With the rapid scale-up of ART, the mortality of PLWH continues to decrease, and the number of aging PLWH ( $\geq 50$  years old) is continuing to increase (Costagliola, 2014). HIV is a major public health problem in China, and an estimated 850,000 PLWH were living in China in 2018 (National Health Commission of the People's Republic of China, 2018). The overall rate of ART coverage for PLWH was estimated to be 80%, and 90% of treated PLWH had achieved viral suppression (National

Health Commission of the People's Republic of China, 2018). With an increased ART coverage, the mortality of Chinese PLWH decreased from 39.3 per 100 person-years in 2002 to 14.2 per 100 person-years in 2009 (Zhang et al., 2011). HIV infection is no longer a life-threatening acute disease but a chronic disease, which requires lifelong treatment and management of multiple co-morbidities, including support for mental health (Deeks, Lewin, & Havlir, 2013).

The majority of countries have followed the World Health Organization's (2018) policy to treat all adults and adolescents living with HIV because early ART initiation reduces the risk of serious clinical conditions, the development of AIDS, and death (Temprano ANRS 12136 Study Group, 2015). The life expectancy of successfully treated PLWH in some countries is now comparable to that of the general population (May et al., 2014), but some cohort studies showed a continuing gap in mortality and life expectancy between PLWH and uninfected individuals in key populations (e.g., injecting drug users; Mills et al., 2011). Therefore, HIV care requires improving and broadening skills for health care workers (i.e., more expertise in the management of co-morbidities) and reshaping the system to provide chronic care (i.e., support millions of patients in a sustainable, efficient, and affordable manner, including providing mental health care; Deeks et al., 2013).

Health services for PLWH in China are mainly offered by hospitals and the Centre for Disease Control and

Sponsorships or competing interests that may be relevant to content are disclosed at the end of this article.

Wangnan Cao, PhD, is a Postdoctoral Fellow, Public Health and Healthy Aging Research Group, Faculty of Dentistry, University of Hong Kong, Hong Kong Special Administrative Region, China. Hai Ming Wong, PhD, is a Clinical Associate Professor, Department of Paediatric Dentistry, Faculty of Dentistry, University of Hong Kong, Hong Kong Special Administrative Region, China. Phoenix Kit-han Mo, PhD, CPsychol, is an Assistant Professor, Division of Behavioral Health and Health Promotion, JC School of Public Health and Primary Care, The Chinese University of Hong Kong, Hong Kong Special Administrative Region, China. Shengzhi Sun, PhD, is a Postdoctoral Research Associate, Department of Epidemiology, School of Public Health, Brown University, Providence, Rhode Island, USA. Yanhong Jessika Hu, PhD, is a Postdoctoral Fellow, Division of Community Medicine and Public Health Practice, School of Public Health, University of Hong Kong, Hong Kong Special Administrative Region, China.

\*Corresponding author: Hai Ming Wong, e-mail: wonghmg@hku.hk

Copyright © 2019 Association of Nurses in AIDS Care

<http://dx.doi.org/10.1097/JNC.000000000000104>

Prevention (CDC). Since June 2016, ART has been recommended for all PLWH regardless of their CD4<sup>+</sup> T-cell level. The government provides ART, services for opportunistic infections, and care/support for vulnerable populations. However, there is a shortage of HIV health care workers due to the rising number of PLWH, and available health care workers lack training to provide professional psychological services. HIV stigma and discrimination are still common in China (Burki, 2011), which prevents PLWH from receiving timely treatment and adhering to ART. Because of the limited development of nongovernmental organizations (NGO) and civil society and a lack of professional social workers in China, PLWH and their family members often have insufficient social support and community connection (Wang et al., 2014).

Given the insufficient services and support from the health care system, care and support from family members have become even more important to PLWH as they benefit from longer survival (Schnall, Hirshfield, Liu, Siegel, & Gradilla, 2018). Female spouses of PLWH have been expected to perform a variety of tasks as primary caregivers to help their husbands adhere to ART and sustain a healthy life. Researchers have found that PLWH who have spousal support have better outcomes, including increased ART adherence and lower rates of depression and anxiety symptoms than those without this support (Amiya, Poudel, Poudel-Tandukar, Pandey, & Jimba, 2014; Poudel, Buchanan, Amiya, & Poudel-Tandukar, 2015). However, family members of PLWH may themselves face a significant level of mental health challenges (Casale, 2015; Skeen, Tomlinson, Macedo, Croome, & Sherr, 2014) because of caregiving burdens and HIV stigma.

We identified two main knowledge gaps in the literature regarding the mental health challenges of spouses of PLWH. First, studies that investigated caregiving burdens focused primarily on parent–children dyads (Kikuchi et al., 2017; Lentoer, 2017), and very few examined spouses as caregivers for PLWH. We were only able to identify one Chinese study (Hsieh, Li, Lin, Luo, & Ji, 2017) that reported on the caregiving burden of spouses of PLWH, but that study limited its investigation of potential correlates of caregiver burden to the caregiver's background characteristics (e.g., age, education, family size, income) that were difficult to address through service and support. Second, mental health challenges due to associated stigma experienced by spouses of PLWH are largely unknown because these spouses were rarely included in stigma-reduction research targeted to PLWH.

An updated understanding of the mental health status of spouses of PLWH is needed in the era of extended

PLWH survival and increasing caregiving burden associated with aging. We sought to gain a Chinese perspective given additional stigma and psychosocial challenges in the Chinese context. Accordingly, we aimed to understand mental health challenges encountered by these spouses and to explore a wide range of potential contributors of mental health problems for spouses of PLWH in China using a qualitative method. Findings of our study may inform psychological service planning and provision.

## Methods

### Study Population

This is a qualitative study using key informant in-depth interviews conducted in 2017, and our study population was female spouses of men living with HIV. A two-step approach was used to recruit participants by collaborating with two local organizations (an NGO and a CDC) serving PLWH in Sichuan, China. We first called and screened men living with HIV and then invited their female spouses to the interview. The screening criteria for the men included confirmed HIV diagnosis, married, and having disclosed their HIV status to their spouses. When the men met all these screening criteria, we briefed them about the study purposes and procedures. After obtaining written informed consent from these men, we approached their female spouses about participating in an interview. The inclusion criteria for the female spouses were age 18 years or older, being aware of their husbands' HIV status, and granting permission to audiorecord the interview. When the female spouses met the inclusion criteria, we briefed them about the study purposes and procedures and obtained their written informed consent.

### Data Collection

In-depth, face-to-face, semistructured, and audiorecorded interviews were conducted with eligible spouses by an interviewer with a PhD in Public Health. The interviewer had extensive experience conducting qualitative studies. All interviews were conducted in a private room, without the presence of the participants' husbands.

The interview guide was developed by a panel consisting of an experienced researcher who had expertise in HIV-related studies, a qualitative scientist who had experience conducting in-depth interviews, and a leader from the collaborating organization who had expertise in service provision for PLWH. The interview guide was conceptualized based on the Disclosure Processes Model

(Chaudoir & Fisher, 2010), a framework to examine when and why HIV status disclosure might be beneficial. The Disclosure Processes Model specifies the various consequences of HIV disclosure including those occurring at the individual, dyadic, and social contextual levels (Chaudoir & Fisher, 2010). The main open question in the interview guide was *Please describe how the various consequences of HIV disclosure (individual, dyadic, and social contextual) have affected your mental health status*. The interview guide also included questions about main mental health challenges and three self-rated items, including mental health status, overall quality of the relationship with her spouse, and overall satisfaction with the service and support she had received. Participant responses included *very good, good, neutral, bad, and very bad*. The guide was pilot tested with one eligible woman and finalized after discussion with the panel.

Participants received CNY100 (\$15 USD) cash as an incentive to compensate for their time. Interviews were conducted in the local language (Mandarin) and took about 35 min to complete. We stopped recruiting participants when saturation of information was reached.

### Data Analysis

Interviews were conducted and transcribed in Mandarin. All transcripts were read several times, and meaningful units were coded throughout the transcripts. We first conducted a content analysis to understand the mental health problems of the participants. Content analysis is a systematic and objective way to describe and quantify phenomena (Vaismoradi, Turunen, & Bondas, 2013). We then conducted a thematic analysis to explore factors that might influence mental health challenges among the participants. Thematic analysis is a method for identifying, analyzing, and reporting patterns within data (Braun & Clarke, 2006). Two native Mandarin researchers reviewed the transcripts and extracted codes independently, disagreements were resolved by discussion, and the final agreement was made by the panel. All extracted codes and themes were finalized in Mandarin and then translated into English. Based on participant responses to the self-rated items, we did a descriptive analysis to report the overall status of the participants.

### Trustworthiness

First, the data were transcribed verbatim, which reflected a detailed level of information. All transcripts were double checked against the recordings for accuracy. They were also translated and backtranslated to ensure

linguistic equivalence. During data analyses, all data were given equal attention in the coding process. All identified themes were checked against each other and also with the text. To ensure that the identified themes reflected participant experiences, the results were discussed by the authors and checked with the participants; corrections were made when needed. To improve the transferability of the findings, participants were recruited through two organizations, one CDC and one NGO, who served participants with differing characteristics. Both organizations offered routine medical and counseling services to local residents living with HIV. Furthermore, investigator triangulation was applied to improve confirmability.

### Ethical Considerations

This study was approved by the Chinese Clinical Trial Registry (ChiECRCT-20170104). Anonymity, confidentiality, valid consent, and the right to withdraw from the study were emphasized to each participant. During participant recruitment, interviews, and data analysis, individual participant names were unknown to everyone, including field workers, interviewers, and authors preparing this manuscript. Consent forms signed by participants were stored separately from interview records. We audiorecorded the interview, and only the research team had access to these records. Contact details of the participants were destroyed as soon as the interviews were completed. Potential participants were reassured that a refusal to participate would not affect their right to services and that they could withdraw from the interview at any time. All participants were offered clinical and psychological consultation and referral services if required.

### Results

A total of 224 men living with HIV were screened until data saturation, of which 98 (43.8%) had disclosed their HIV status to their spouses and 41 (41.8%) agreed to invite their spouses to participate. All 41 of these spouses were contacted by the research team, and 31 (75.6%) agreed and completed the interview between August and November 2017.

Characteristics of the participants are presented in Table 1. The median age of the participants was 43 years, ranging from 26 to 62 years. About half (55%) of the participants had been married for more than 3 years. More than one-third (39%) of the spouses were also living with HIV, and all of these spouses were on ART. All participants living with HIV reported they had acquired HIV by sexual transmission from their husbands.

**Table 1. Participant Characteristics (N = 31)**

Variables	N	%
Age (in years)		
26–30	7	22.6
31–45	12	38.7
46–62	12	38.7
HIV status		
Living with HIV infection	12	38.7
Uninfected	19	61.3
Length of marriage		
<1 year	5	16.1
1–3 years	9	29.0
>3 years	17	54.8
Participant awareness of husband's HIV status		
Before marriage	2	6.5
After marriage	29	93.5
Period since disclosure by husband		
<1 year	5	16.1
1–3 years	15	48.4
>3 years	11	35.5
Overall mental health status		
Good/very good	2	6.5
Neutral	9	29.0
Bad/very bad	20	64.5
Overall quality of the relationship with the husband		
Good/very good	3	9.7
Neutral	15	48.4
Bad/very bad	13	41.9
Overall satisfaction with service and support		
Good/very good	5	16.1
Neutral	11	35.5
Bad/very bad	15	48.4

About half (48%) of the spouses had been aware of their husbands' HIV status for 1–3 years, one-third had been aware for more than 3 years, and the remaining 16% had known for less than a year. Two participants

had learned of their husbands' HIV status before marriage; one of these women then discovered she was also living with HIV, whereas the other tested negative. The remaining 29 participants (94%) had learned of their husbands' HIV status after marriage; 11 participants were then diagnosed with HIV and the remaining 18 participants were uninfected. It was impossible to determine whether the husbands were infected before or after marriage. The majority of the participants reported decreased satisfaction with the relationship after disclosure. The quality of the relationship varied across participants but was rated as *good/very good* by fewer than 10%. The overall satisfaction with the service and support was rated as either *neutral* (35%) or *bad/very bad* (48%; Table 1).

### **Mental Health Challenges**

During the interview, the majority of the participants self-reported at least one mental health challenge, including hopelessness (74%), depression (61%), anxiety (39%), suicidal ideation (23%), insomnia (19%), and sadness (13%). The overall self-assessed mental health status was poor but had improved, in general, when compared to the moment of disclosure.

### **Potential Contributors to Mental Health Challenges**

Participants reported contributors at different levels that potentially affected their mental health status, including individual-, couple-, and social-level contributors.

**Personal knowledge of HIV.** A higher level of knowledge and understanding of HIV-related prevention and treatment seemed to benefit the mental health status of participants. In particular, participants revealed that information (e.g., PLWH can have a normal life expectancy with good adherence to ART, consistent condom use can effectively prevent HIV transmission among serodiscordant couples, undetectable virus in the blood equals untransmittable, and parents living with HIV can have an HIV-free baby) helped them maintain a positive attitude. “I just knew a few days ago that we could have an AIDS-free baby. I was so happy on that day. I would not have been so upset if I had known it earlier” (28-year-old, living with HIV, 2 years since disclosure).

**Close spousal relationship.** Having a close relationship with their husbands seemed to promote the mental health status of the participants. Participants reported that intimacy, information sharing, and support from husbands helped them sustain a positive mental status. Couples who were both living with HIV

were more likely to have a closer relationship, partly due to open discussion of HIV-related issues, shared experiences in disease management, and no worries related to HIV stigma. “He (the husband) recently has shared more information with me and spent more time with the family, which makes me feel relieved and happy” (34-year-old, uninfected, 2 years since disclosure). “We usually go to see the doctors together, and we are also free to discuss disease-related concerns, which you may not share with others. I am happy that someone is here with me” (40-year-old, living with HIV, 8 years since disclosure).

**Sufficient psychological support.** Psychological support from health workers and peers emerged as another essential facilitator of positive mental health for participants. First, the majority of participants living with HIV considered health workers as the primary resource for psychological support, and those health workers included physicians who prescribed medicine and CDC officers who provided counseling and follow-up services. However, some participants complained about the quality of the counseling services. Second, some participants considered peers, such as other PLWH and other spouses whose husbands were living with HIV, as an essential resource for psychological support. Two types of psychological support offered by peers were frequently mentioned and especially helpful for mental health, including functioning as a role model in real life and providing communication platforms for PLWH and their family members. Participants who had no opportunities to engage with peers seemed to report more mental challenges. “The CDC officer is very nice, and she answers my text messages even at night. She can always make me feel better” (34-year-old, living with HIV, 1 year since disclosure). “She (a peer living with HIV) is a role model to me. Her existence keeps me fighting with the disease, as she makes me believe that PLWH can also have a healthy and decent life” (34-year-old, living with HIV, 3 years since disclosure). “She (a peer living with HIV) always tells me that everything will be fine, and I am not alone. I might have been in a psychiatric hospital without her” (40-year-old, living with HIV, less than 1 year since disclosure).

Sometimes the doctor does not understand my real problems, they simply told me I should not worry, but it did not help at all. They offered me the contact information of another doctor who is an expert for this kind of problem (persistent sadness), but I do not want to see more doctors, it (HIV) is not a thing I am proud of. (45-year-old, living with HIV, 5 years since disclosure)

**HIV-related stigma.** Low acceptance of HIV status had a negative impact on the mental health status of the participants. First, low acceptance of their HIV status

was reflected by a high level of stigma attached to the disease; participants reported self-stigma as PLWH and also associated stigma as a family member of a PLWH. Second, low acceptance of HIV status was reflected by adverse emotional reactions, including anger and self-blame, which jeopardized mental health. Third, some participants reported intensive struggles keeping the HIV diagnosis from their children and parents, which was stressful. “The disease is a shame that I have to carry on during my entire life. There is no hope at all” (45-year-old, living with HIV, 5 years since disclosure). “I am not sure if I should tell our son about this (HIV). What can I do if my son does not accept it? But he needs to know sooner or later. I am so worried about his reactions” (52-year-old, living with HIV, 8 years since disclosure).

**Heavy caregiving/self-care burden.** Heavy caregiving burden increased participant vulnerability to mental health challenges. Participants frequently reported moderate to severe levels of caregiving burdens in terms of worrying about their husbands’ futures and suffering a constrained social life because of their husbands’ HIV status. However, they reported no or low levels of caregiving burdens in finding time for their own interests as a result of the time and money needed to take care of their husbands. Sources of caregiving burdens varied according to the participant’s own HIV status. Participants living with HIV were more likely to report worries related to the disease (i.e., life expectancy, backup plan when medicine loses effectiveness), whereas uninfected participants were more likely to report burdens/inconveniences in daily life (i.e., no spicy food allowed at home, all family members needed to go to bed before 9 p.m.). “I have to cut off my connections with my friends; otherwise, they will find it (the husband’s HIV status) out” (35-year-old, uninfected, 3 years since disclosure). “I do not want to understand his disease, and he should take care of himself. Sometimes I have to change our menus when his stomach is upset, and this is inconvenient and annoying” (52-year-old, uninfected, 4 years since disclosure).

In addition to caregiving burdens for their husbands, participants living with HIV had self-care burdens, which affected their mental health status. Caregiving offered by their husbands might help alleviate mental health challenges. “It is very troublesome to take the pills every day” (38-year-old, living with HIV, 3 years since disclosure). “My husband takes care of me when I have an upset stomach or insomnia symptoms, which really makes me feel so relieved” (45-year-old, living with HIV, 6 years since disclosure).

**Unsupportive environment.** Insufficient support worsened the mental health status of the participants. In particular, participants frequently reported lacking confidence in the health care system and receiving limited support from significant others (i.e., close friends), and these factors affected their mental health. “I am not satisfied with the doctor. The long waiting time at the hospital makes me very uncomfortable and increases the risk to be recognized by someone we know” (35-year-old, uninfected, 3 years since disclosure). “None of my friends know it (my HIV). There is no one I can talk to when I feel depressed or lonely, which makes me feel devastated” (35-year-old, living with HIV, 2 years since disclosure).

I am not sure whether the doctor provides me the best medicine, the side effects are so common. I heard that drugs exported from overseas countries would be better, but they are expensive and the government does not pay for them. The disease costs me a lot, as I have to pay for some expensive laboratory tests. This poor health care system makes me worried and annoyed. (52-year-old, living with HIV, 8 years since disclosure)

## Discussion

Our qualitative study showed that spouses of PLWH in Sichuan, China had various mental health challenges, especially hopelessness, depression, anxiety, and suicidal ideation. Self-assessed mental health was poor in general for these women, and poor health was affected by individual-, couple-, and social-level contributors.

Mental health challenges were prevalent in our participants, which was consistent with caregivers of PLWH in other countries. All caregivers in one Vietnamese survey expressed fear, anxiety, and frustration (Lundberg, Doan, Dinh, Oach, & Le, 2016). One-third of our participants were living with HIV, and these mental health challenges made them more vulnerable. Mental problems have been shown to reduce motivation to seek health care, impair adherence to treatment, lead to alcohol abuse or dependence, and increase mortality (Mayston, Kinyanda, Chishinga, Prince, & Patel, 2012). Of the two-thirds of participants who were uninfected, mental problems affected their quality of life and reduced the capacity to care for their husbands. Despite these adverse outcomes, mental health services were scarce and poor in quality for PLWH and their caregivers in China (Liu et al., 2011). There is, in particular, a shortage of skilled mental health workers, with a disproportionate concentration of mental health resources in large cities and uncovered psychological service charges in health insurance (Liu et al., 2011).

We found that HIV-related knowledge and stigma toward HIV affected the mental health status of spouses of men living with HIV regardless of their own HIV status. Most studies have reported these mental health effects only in PLWH themselves (Kalichman et al., 2008). Our study extended the impact to spouses of men living with HIV as well. Our findings complement a study reporting that improved HIV-related knowledge and reduced HIV-related stigma can benefit the mental health of both PLWH and their caregivers (French, Greeff, & Watson, 2014), and evidence has shown that intervention can improve mental health of PLWH and their families, which has significant and measurable outcomes (Jiwatram-Negrón & El-Bassel, 2014). Policymakers can view investment in psychosocial support as a way to improve clinical outcomes and reduce health expenditures for managing the consequences of non-adherence and treatment failure.

We found that a close spousal relationship and particularly marital intimacy could benefit the mental health of our participants. Similarly, caregivers of people with dementia (Robinson, Bottorff, Pesut, Oliffe, & Tomlinson, 2014) reported lower levels of depression when they experienced higher levels of marital intimacy. However, it might be challenging for HIV serodiscordant couples (two-thirds of our sample) to develop marital intimacy if they do not have sufficient HIV knowledge and worry about transmission. In couples with mixed HIV status, various sources of conflict and stress have been reported in the literature, including concerns about HIV transmission, the vulnerable health status of the partner living with HIV, and continuing uncertainty regarding longevity (Shelby & Beckerman, 2012). These conflicts and stress have been shown to affect a couple's ability to maintain intimacy (Shelby & Beckerman, 2012). Therefore, it is challenging but essential to identify ways that mental health care providers can intervene with couples in these circumstances to facilitate the development of an intimate spousal relationship.

Researchers have attributed distress, depression, and suicidal ideation to a heavy caregiver burden (Lee, Li, Jiraphongsa, & Rotheram-Borus, 2010; Mitchell & Knowlton, 2012), which was consistent with our findings. Despite the various forms and sources of caregiver burdens demonstrated by participants, a common threat was that the women in our study faced social isolation. Increasing constriction of social activities has been identified as a strong correlate of depression among caregivers (Wight, 2000). As revealed in our study, symptoms of depression seemed to stem from feelings of social isolation and decreasing social support that was incumbent with social constriction. However, the

heterogeneity of forms and sources of caregiver burdens should be noted as well. For example, participants reported high caregiving burdens worrying about a husband's future but low burdens finding time for their own interests because most of their husbands were still healthy and did not require much time from the spouses to take care of them. To better serve the caregivers of PLWH, further studies should explore which caregiver burdens are more related to mental health stress and what types of supports are needed to lower these burdens.

Studies have also suggested that caregivers living with and without HIV may require different support systems, as the effect of HIV infection, compromised physical health, and stigma associated with HIV in caregivers may result in different outcomes. Although the evidence has been inconclusive, studies found that caregivers living with HIV had a higher risk of stress and depression than uninfected caregivers (Dyer, Stein, Rice, & Rotheram-Borus, 2012; Lee, Li, Jiraphongsa, & Rotheram-Borus, 2010). For caregivers living with HIV, poor health, role captivity, and greater financial worry predicted higher levels of depression. Multiservice agencies are needed to provide direct support for both the physical and financial needs of these caregivers. However, for seronegative caregivers, providing assistance with daily living was identified as a predictor of greater depression (Land, Hudson, & Stiefel, 2003). Assistance activity adds a dimension of dependence to a relationship and may produce feelings of losing control for both a caregiver and her spouse. Moreover, due to the lack of "common interest," seronegative caregivers may be less likely to empathize with the PLWH, and assistance activities may be more likely to be considered as burdens. Our participants confirmed this by claiming that it was the patient's responsibility to take care of himself and it was troublesome to adjust diets to meet the needs of the husbands. Therefore, seronegative caregivers may be in need of both assistance in caregiving and mental health counseling.

Participants reported that supports from health workers and peers complemented each other and were both helpful in maintaining mental health status. Health workers provided the spouses with HIV-related services, such as testing, medications, and counseling on safe sex. These supports, more instrumental and informational, improved participant skills and confidence in coping with HIV, which was good for mental health (Crepaz et al., 2008). Peer educators offered consolation and functioned as role models. These supports, more emotional and appraisal (provision of information for self-evaluation), have been shown to reduce HIV-associated

stigma and raise hope to live positively with HIV, which was good for mental health as well (Venable, Carey, Blair, & Littlewood, 2006). Overall, support from health workers and peers were equally important, and all forms of support were linked to better mental health outcomes.

To the best of our knowledge, this is one of the few studies conducted to understand the mental health status and its potential contributors in female spouses of men living with HIV in China. The findings of a high rate of mental health challenges provide evidence for the urgent need for health care providers to be trained in mental health service delivery and support. A better understanding of potential contributors to mental health challenges can inform the design and implementation of a support and mitigation program.

It is, however, important to note the limitations of our study. First, the study sample only contained 31 participants recruited from two agencies, so these results may not be representative of all spouses of PLWH living in China or elsewhere. Second, self-reporting bias may exist. Participants might underreport their mental health challenges due to stigma toward people with mental issues. Finally, we only interviewed women whose husbands consented to their participation. It is likely that spouses of men who refused their participation were living under substantially more challenging circumstances and were in even greater need of support. Of subjects screened for participation, only 43.8% had disclosed to their spouses, and of that group, only 41% allowed their spouses to be interviewed.

## Conclusion

We found that mental health challenges were common in female spouses of men living with HIV in Sichuan, China. Greater HIV-related knowledge, a close relationship with the husband, and psychological support from health workers and peers were beneficial to participants' mental health, whereas HIV-related stigma, heavy caregiving burden, and unsupportive environments were associated with impaired mental health. Overall, spouses of PLWH were in need of professional mental health services, and mental health promotion programs would be most helpful if addressing a wide range of contributors at individual, couple, and social levels.

## Disclosures

The authors report no real or perceived vested interests related to this article that could be construed as a conflict of interest.

### Key Considerations

- Mental health challenges, especially hopelessness, depression, and anxiety, are problems for female spouses of men living with HIV in China.
- Spouses of men living with HIV need professional mental health services.
- HIV knowledge, close relationship with the husband, and psychological support can help spouses of men living with HIV.
- HIV-related stigma, heavy caregiving burden, and an unsupportive environment are challenges for spouses of men living with HIV.
- Mental health programs should address a wide range of contributors to mental health problems at individual, couple, and social levels.

### Acknowledgments

The authors acknowledge the 31 participants for their time spent in this study. They acknowledge Dr. Joseph Harwell for critically reviewing and editing the manuscript. Chinese Clinical Trial Registry (ChiECRCT-20170104)

### References

- Amiya, R. M., Poudel, K. C., Poudel-Tandukar, K., Pandey, B. D., & Jimba, M. J. P. (2014). Perceived family support, depression, and suicidal ideation among people living with HIV/AIDS: A cross-sectional study in the Kathmandu Valley, Nepal. *PLoS One*, *9*(3), e90959. doi:10.1371/journal.pone.0090959
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. doi:10.1191/1478088706qp0630a
- Burki, T. K. (2011). Discrimination against people with HIV persists in China. *Lancet*, *377*(9762), 286-287. doi:10.1016/S0140-6736(11)60079-2
- Casale, M. (2015). The importance of family and community support for the health of HIV-affected populations in Southern Africa: What do we know and where to from here? *British Journal of Health Psychology*, *20*(1), 21-35. doi:10.1111/bjhp.12127
- Chaudoir, S. R., & Fisher, J. D. (2010). The disclosure processes model: Understanding disclosure decision making and postdisclosure outcomes among people living with a concealable stigmatized identity. *Psychological Bulletin*, *136*(2), 236. doi:10.1037/a0018193
- Castagliola, D. (2014). Demographics of HIV and aging. *Current Opinion in HIV and AIDS*, *9*(4), 294-301. doi:10.1097/COH.0000000000000076
- Crepaz, N., Passin, W. F., Herbst, J. H., Rama, S. M., Malow, R. M., Purcell, D. W., & Wolitski, R. J. (2008). Meta-analysis of cognitive-behavioral interventions on HIV-positive persons' mental health and immune functioning. *Health Psychology*, *27*(1), 4. doi:10.1037/0278-6133.27.1.4
- Deeks, S. G., Lewin, S. R., & Havlir, D. V. (2013). The end of AIDS: HIV infection as a chronic disease. *Lancet*, *382*(9903), 1525-1533. doi:10.1016/S0140-6736(13)61809-7
- Dyer, T. P., Stein, J. A., Rice, E., & Rotheram-Borus, M. J. (2012). Predicting depression in mothers with and without HIV: The role of social support and family dynamics. *AIDS and Behavior*, *16*(8), 2198-2208. doi:10.1007/s10461-012-0149-6
- French, H., Greeff, M., & Watson, M. J. (2014). Experiences of people living with HIV and people living close to them of a comprehensive HIV stigma reduction community intervention in an urban and a rural setting. *Journal of Social Aspects of HIV/AIDS*, *11*(1), 105-115. doi:10.1080/17290376.2014.938104
- Hsieh, J., Li, L., Lin, C., Luo, S., & Ji, G. (2017). Spousal role and caregiver burden in HIV affected families in Anhui Province, China. *AIDS Care*, *29*(10), 1270-1274. doi:10.1080/09540121.2017.1300631
- Jiwatram-Negrón, T., & El-Bassel, N. (2014). Systematic review of couple-based HIV intervention and prevention studies: Advantages, gaps, and future directions. *AIDS and Behavior*, *18*(10), 1864-1887. doi:10.1007/s10461-014-0827-7
- Kalichman, S. C., Pope, H., White, D., Cherry, C., Amaral, C. M., Swetzes, C., Flanagan, J., & Kalichman, M. O. (2008). Association between health literacy and HIV treatment adherence: Further evidence from objectively measured medication adherence. *Journal of the International Association of Providers of AIDS Care*, *7*(6), 317-323. doi:10.1177/1545109708328130
- Kikuchi, K., Poudel, K. C., Rwibasira, J. M., Majyambere, A., Mutabazi, V., Nyonsenga, ... Jimba, M. (2017). Caring for perinatally HIV-infected children: Call for mental care for the children and the caregivers. *AIDS Care*, *29*(10), 1280-1286. doi:10.1080/09540121.2017.1307917
- Land, H., Hudson, S. M., & Stiefel, B. (2003). Stress and depression among HIV-positive and HIV-negative gay and bisexual AIDS caregivers. *AIDS and Behavior*, *7*(1), 41-53. doi:10.1023/A:1022509306761
- Lee, S. J., Li, L., Jiraphongsa, C., & Rotheram-Borus, M. J. (2010). Caregiver burden of family members of persons living with HIV in Thailand. *International Journal of Nursing Practice*, *16*(1), 57-63. doi:10.1111/j.1440-172X.2009.01812.x
- Lentoor, A. G. (2017). Psychosocial challenges associated with caregiving in the context of pediatric HIV in rural Eastern Cape. *Frontiers Public Health*, *5*, 127. doi:10.3389/fpubh.2017.00127
- Liu, J., Ma, H., He, Y. L., Xie, B., Xu, Y. F., Tang, H. Y., ... Yu, X. (2011). Mental health system in China: History, recent service reform and future challenges. *World Psychiatry*, *10*(3), 210-216. doi:10.1002/j.2051-5545.2011.tb00059.x
- Lundberg, P. C., Doan, T. T. K., Dinh, T. T. X., Oach, N. K., & Le, P. H. (2016). Caregiving to persons living with HIV/AIDS: Experiences of Vietnamese family members. *Journal of Clinical Nursing*, *25*(5-6), 788-798. doi:10.1111/jocn.13099
- May, M. T., Gompels, M., Delpech, V., Porter, K., Orkin, C., Kegg, S., ... Gilson, R. J. A. (2014). Impact on life expectancy of HIV-1 positive individuals of CD4+ cell count and viral load response to antiretroviral therapy. *AIDS*, *28*(8), 1193. doi:10.1097/QAD.0000000000000243
- Mayston, R., Kinyanda, E., Chishinga, N., Prince, M., & Patel, V. (2012). Mental disorder and the outcome of HIV/AIDS in low-income and middle-income countries: A systematic review. *AIDS*, *26*, S117-S135. doi:10.1097/QAD.0b013e32835bde0f
- Mills, E. J., Bakanda, C., Birungi, J., Chan, K., Ford, N., Cooper, C. L., ... Hogg, R. S. (2011). Life expectancy of persons receiving combination antiretroviral therapy in low-income countries: A cohort analysis from Uganda. *Annals of Internal Medicine*, *155*(4), 209-216. doi:10.7326/0003-4819-155-4-201108160-00358
- Mitchell, M. M., & Knowlton, A. (2012). Caregiver role overload and network support in a sample of predominantly low-income, African-American caregivers of persons living with HIV/AIDS: A structural equation modeling analysis. *AIDS and Behavior*, *16*(2), 278-287. doi:10.1007/s10461-011-9886-1
- National Health Commission of the People's Republic of China. (2018). *The press conference on China's work progress in HIV/AIDS*

- prevention and treatment. Retrieved from <http://www.scio.gov.cn/xwfbh/gbwxwfbh/xwfbh/wsb/Document/1642083/1642083.htm>
- Poudel, K. C., Buchanan, D. R., Amiya, R. M., & Poudel-Tandukar, K. (2015). Perceived family support and antiretroviral adherence in HIV-positive individuals: Results from a community-based positive living with HIV study. *International Quarterly of Community Health Education*, 36(1), 71-91. doi:10.1177/0272684X15614220
- Robinson, C. A., Bottorff, J. L., Pesut, B., Oliffe, J. L., & Tomlinson, J. (2014). The male face of caregiving: A scoping review of men caring for a person with dementia. *American Journal of Men's Health*, 8(5), 409-426. doi:10.1177/1557988313519671
- Schnall, R., Hirshfield, S., Liu, J., Siegel, K., & Gradilla, M. (2018). Characteristics of persons living with HIV who have informal caregivers in the cART age of the epidemic. *The Journal of the Association of Nurses in AIDS Care: JANAC*, 29(2), 152-162. doi:10.1016/j.jana.2017.08.008
- Shelby, R. D., & Beckerman, N. L. (2012). *Couples of mixed HIV status: Clinical issues and interventions*. Abingdon, United Kingdom: Routledge.
- Skeen, S., Tomlinson, M., Macedo, A., Croome, N., & Sherr, L. (2014). Mental health of carers of children affected by HIV attending community-based programmes in South Africa and Malawi. *AIDS Care*, 26(Suppl 1), S11-S20. doi:10.1080/09540121.2014.906559
- Temprano ANRS 12136 Study Group. (2015). A trial of early antiretrovirals and isoniazid preventive therapy in Africa. *The New England Journal of Medicine*, 373(9), 808-822. doi:10.1056/NEJMoa1507198
- Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, 15(3), 398-405. doi:10.1111/nhs.12048
- Vanable, P. A., Carey, M. P., Blair, D. C., & Littlewood, R. A. (2006). Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. *AIDS and Behavior*, 10(5), 473-482. doi:10.1007/s10461-006-9099-1
- Wang, H., Zhang, C., Ruan, Y., Li, X., Fennie, K., & Williams, A. B. (2014). Depressive symptoms and social support among people living with HIV in Hunan, China. *The Journal of the Association of Nurses in AIDS Care: JANAC*, 25(6), 568-576. doi:10.1016/j.jana.2014.02.001
- Wight, R. G. (2000). Precursive depression among HIV infected AIDS caregivers over time. *Social Science & Medicine*, 51(5), 759-770. doi:10.1007/s10461-006-9099-1
- World Health Organization. (2018). *WHO HIV update: Global epidemic, progress in scale up and policy uptake*. Retrieved from <https://www.who.int/hiv/data/en/>
- Zhang, F., Dou, Z., Ma, Y., Zhang, Y., Zhao, Y., Zhao, D., ... Chen, R. Y. (2011). Effect of earlier initiation of antiretroviral treatment and increased treatment coverage on HIV-related mortality in China: A national observational cohort study. *The Lancet Infectious Diseases*, 11(7), 516-524. doi:10.1016/S1473-3099(11)70097-4