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Mental Health And Social Support Among Hiv-Positive Injection Drug Users And Their Caregivers In China

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Mental health and social support among HIV-positive injection drug users and their caregivers in China

Running head: Mental health, caregiving, and HIV

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ABSTRACT

The burden of HIV/AIDS in China is due to injection drug use. Non-clinical caregivers provide much of the care for HIV patients but are often not included in HIV care or research. The objective of this study is to examine the relationships between the caregiver context and mental health of HIV-positive injection drug users and their caregivers. We interviewed 100 patient and caregiver dyads using quantitative methods. A conceptual model was developed and used as a framework for multivariate linear regression modeling. The strongest predictor of patient mental health was social support, which was largely determined by the caregiver's stigma towards HIV/AIDS. Patient disability was the strongest predictor of caregiver mental health. The interrelated nature of caregiver and patient mental health supports the inclusion of caregiver health into the patient's HIV/AIDS treatment to maximize the support they provide as well as improve health for both members of the patient-caregiver dyad.

Keywords: HIV/AIDS, caregiver, China, mental health, social support, injection drug use

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INTRODUCTION

Caregiver mental health

Fulfilling the role of caregiver for someone with a chronic health condition can be taxing on the caregiver's health, particularly his or her mental health. Patients often depend on their non-clinical caregivers for financial, physical and emotional support, causing an increase in responsibilities for the caregiver¹. Caregiver mental health has long been ignored; however, negative health outcomes associated with providing care have become evident and therefore necessitate further attention².

Poor caregiver mental health may influence both the adequacy of care provided to the patient and the caregivers' risk of disease³. If the proposed relationships between patient and caregiver mental health exist, then it is increasingly important to make efforts to improve caregiver mental health such that they are capable of providing quality care to the patient without experiencing negative health outcomes as a result. This relationship is particularly important in countries such as China, which has high burden of disease and a weak mental health care structure.

Mental health and HIV in China

Approximately 173 million Chinese currently have a mental illness and less than 10% ever receive professional psychiatric care⁴. Culturally, mental health has not been formally recognized in China, though progress has been made by China's health ministry aligning its guidelines in accordance with international standards⁵. Few studies have explored the prevalence of poor mental health in China. Even fewer have looked at mental health among caregivers and patients suffering from a chronic illness. HIV/AIDS is particularly relevant to

mental health issues of patients and caregivers given its magnitude of symptoms, treatment needs, and community stigma.

The HIV/AIDS epidemic in southwest China is unique given its proximity to the Golden Triangle, the largest drug trade and trafficking point in the world until 2002⁶. Zhang et al. (2002) found the prevalence of HIV-1 to be over 70% among drug users in parts of Yunnan Province bordering Vietnam and Laos⁷. In 2005, injection drug users made up 44% of the estimated HIV/AIDS cases throughout China and are considered by the Ministry of Health to be the highest risk group nationally⁸. HIV-positive injection drug users are particularly vulnerable and highly stigmatized in China⁹⁻¹¹. Additionally, it has been shown that physicians who care for HIV patients felt stigmatized by other clinicians¹², which may explain why 30% of physicians in Yunnan Province refuse to provide care to HIV-positive patients¹³. These circumstances have transferred much of the responsibility of care to non-clinical caregivers.

Studies have shown associations between poor patient mental health and the progression of HIV/AIDS^{14,15}. The relationship between patient mental health, social support and caregiver mental health among HIV-positive injection drug users in China has not been investigated to date. Some studies have examined mental health and quality of life among caregivers for patients with other chronic illnesses in China. Results from these studies have shown that caregiver wellbeing is associated with factors relating to the patient's illness, the physical health of the caregiver, the relationship between the patient and caregiver, and various socioeconomic characteristics^{16,17}. These findings underline the importance of examining specific clinical and psychosocial elements of the caregiver context when exploring the relationship between caregiver mental health, social support and patient mental health.

Many components of the caregiver context directly contribute to the burden experienced by the caregiver. Caregiver burden is commonly described as being predictive of caregiver health outcomes^{16,18}. The perceived level of burden attributable to caregiving can be influenced by the caregiver's sense of self-efficacy, which is defined as the caregiver's confidence in their ability to provide adequate support to the patient^{19,20}. Objective caregiving difficulties include aspects of the patient's illness that necessitate additional care. There is a substantial amount of comorbid physical disability that is often associated with HIV/AIDS^{21,22}. Disease-specific indicators, such as length since diagnosis and CD4 count, as well as the patient's disability can be used to measure disease severity. In addition, psychosocial caregiving difficulties, such as stigma, can influence the wellbeing of caregivers and patients. Stigma towards HIV and injection drug use in China is extensive, and when in combination, the resulting stigma may increase multiplicatively. A qualitative study conducted in Yunnan Province discovered that community-level stigma towards drug abuse and HIV is a consequence of cultural and religious norms²³. Given China's strong emphasis on the family unit, these social consequences may also have a particularly strong impact on the caregiver. Furthermore, if the caregiver also has stigma towards HIV and drug use, this may influence their willingness to provide support to the patient.

The factors making up the caregiver context influence the health of both members of the caregiving dyad, the patient and the caregiver. There have yet to be any studies that examine the nature of dyadic caregiving relationships to the extent that the context of caregiving may influence the mental health of the caregiver and caregiver health may influence the health of the patient. To further investigate these relationships, this study aims to:

1. Examine the influence of the caregiver context (stigma, caregiver efficacy, caregiver burden, severity of disease) on the *mental health of the caregiver*.

2. Examine the influence of caregiver mental health and the caregiver context on the *level of social support the patient receives*.
3. Examine the influence of caregiver mental health, social support, and the caregiver context on the *mental health of the patient*.

METHODS

Participants

A clinical sample of HIV-positive current or former injection drug users was recruited to participate in this cross-sectional study from an HIV/AIDS treatment and drug rehabilitation clinic in Kunming, Yunnan Province, China between May and August 2011. Patients attending the clinic were approached by members of the clinic staff and were asked if they would like to be interviewed for the study. All eligible participants who were approached agreed to participate (100% participation rate). One individual was ineligible given the inclusion criteria. Inclusion criteria specified that the participants must be 18 years or older, must have their HIV-positive serostatus confirmed by clinic staff, must be a current or former injection drug user and must have a non-clinical caregiver to whom they've previously disclosed their HIV-positive serostatus. Each participant was then asked to recruit the caregiver whom they consider to be their primary source of support outside of the clinical setting. If the caregiver wasn't present at the time of recruitment, the patient was given an appointment date to return to the clinic with the caregiver and complete the interview. All patients who were given appointments returned with their caregiver and completed the interviews.

Data Collection

Patients and caregivers were interviewed individually in a private room at the clinic. All participants reviewed and signed a translated informed consent. Participants were paid 50 RMB (approximately 7.5 USD) for their participation. All interview documents were stripped of identifiers. An alphanumeric coding system was used to pair the caregivers and patients into dyads.

Measures

Cross-culturally validated interview questionnaires were employed to measure the constructs of interest. Each of these scales were translated and back-translated by a Chinese translator who is certified through the China Personnel Ministry's Aptitude Test for Translators and Interpreters (CATTI). This translator also served as the interpreter for the interviews in this study. Multiple professionals reviewed the translations.

Mental Health

Mental health was measured using the Hospital Anxiety and Depression Scale (HADS)²⁴. The HADS consists of fourteen questions; seven questions measuring depression and seven measuring anxiety. Responses are recorded on a likert scale ranging from zero to three. Higher scores indicated more depression and anxiety. The HADS has been used for assessing mental health in Chinese populations and has proven to be valid and reliable^{25,26}. The HADS was completed by both patient and caregiver and showed good internal consistency (Cronbach alpha=.86 For patients and .76 for caregivers)

Social Support

Social support of the patient was measured using an adapted version of the 14-item Social Support Questionnaire²⁷. One question was added to assess financial support. Items were measured on a three point likert scale measuring available support from “never”, “some of the time” to “all of the time” as reported by the patient. The Social Support Questionnaire was validated in a sample of Chinese females²⁸. Results showed good internal consistency (Cronbach alpha=.76).

Caregiver Context Variables

Clinical indicators such as CD4 count and length since diagnosis were reported by the patient. To measure patient disability, both the Physical Self Maintenance Activities of Daily Living Scale (ADL) and the Lawton and Brody Instrumental Activities of Daily Living Scale (IADL) were used²⁹. These scales measure the patient’s independence, as reported by the caregiver, by evaluating their ability to accomplish tasks such as dress themselves, complete household chores, cook and manage finances. The ADLs and IADLs have often been used to measure functioning in Chinese populations and they have both been validated and proven to be reliable measures^{30,31}. Higher scores represent more disability. This scale was completed by the caregiver. Results showed good internal consistency (Cronbach alpha=.82).

The psychosocial variables of the caregiver context were measured using previously validated scales. *Patient stigma* was assessed with four items adapted from the Personal Stigma Scale³² that assessed the participants’ perception of community level stigma towards HIV. Results showed good internal consistency (Cronbach alpha=.73). To measure *caregiver stigma*, the full 17-item Personal Stigma Scale was used which was developed to measure the caregiver’s

stigma specifically towards HIV³². Items were measured on a three point likert scale ranging from “disagree” to “agree”. Results showed good internal consistency (Cronbach alpha=.85).

Caregiver self-efficacy was measured using an adaptation of the Caregiver-Efficacy Questionnaire. Fourteen items evaluated the confidence of caregivers to perform different tasks related to caregiving. Responses ranged from “not confident” to “confident” with higher scores representing more caregiver self-efficacy. This scale was completed only by the caregiver.

Results showed good internal consistency (Cronbach alpha=.88). *Caregiver burden* was assessed with the 14-item Caregiver Burden Assessment scale that describes ways that caregiving may disrupt one's life including less privacy, less time and more stress³³. Responses ranged from “less than before” to “more than before” with higher scores representing more caregiver burden. This scale was completed only by the caregiver. Results showed good internal consistency (Cronbach alpha=.82).

Demographic and Medical Covariates

Demographic covariates were collected from the patient and the caregiver. The information collected included age, sex, ethnicity, education, birthplace, time living at current residence, marital status, income, employment and frequency of interaction between the caregiver and the patient. Medical covariates were collected to include family history of mental illness and personal history of mental illness. Family and personal history of mental illness excluded history of substance abuse because all of the patients were required to have a history of drug abuse given the inclusion criteria. Family history of substance abuse was collected as a separate item on the demographic questionnaire.

Data Analysis

The variation of the demographic and medical covariates between the caregiver and the patient were statistically evaluated using a paired t-test for continuous variables, a McNemar test for 2-level categorical variables and a Cochran's Q test for categorical variables with more than two levels. For continuous variables, the means and standard deviations were calculated and compared using a paired t-test. For categorical variables the proportion of the sample represented by each category were described for both the caregiver and the patient.

To examine the correlations between each of the independent and dependent variables, we conducted bivariate correlations. We used multivariate linear regression to statistically evaluate the three aims of this study. Mental health and social support were used as the dependent variables. The factors comprising the caregiver context were each considered independent variables for the outcomes of interest. To test the hypothesis that caregivers' poor mental health status may adversely affect their ability to provide adequate support, which in turn, may adversely affect patient's mental health status, multivariable analysis of each subsequent outcome also included the prior outcomes) as covariates.

The adjusted models tested for the possible covariates of age, sex, income, employment, family and personal history of mental illness (other than substance abuse) and frequency of interaction between caregiver and patient. All covariates that were significant at $p < .10$ for a particular outcome were included in the adjusted analysis for that outcome. Bivariate correlations between all independent and dependent variables were calculated to assess multicollinearity between the variables of interest. All data were analyzed using SAS statistical software (version 9.2). We conducted Sobel tests based on the three aims to determine if any of

the predictors of social support and caregiver mental health have an indirect effect on patient mental health.

RESULTS

Descriptive Statistics

One hundred patients and their caregivers (N=100 couples; 200 individuals) participated in the study. The majority of patients were male (60.4%) whereas the majority of caregivers were female (63.5%). The average age of patients and caregivers was 41.1 (SD=4.9) and 41.4 (SD=11.2) years respectively. Most patients reported not having injected drugs within the past year (66.7%) and some reported injecting drugs daily (16.7%). Four patients reported never using injection drugs and having been infected with HIV through sexual transmission (n=3) or through a contaminated blood transfusion (n=1). These four participants were not included in analyses because they were no longer classified as a current or former injection drug users, resulting in a final sample size of 96 couples.

To evaluate the influence of the dyadic relationship role, we compared demographic and medical covariates of caregivers (n=96) to patients (n=96) (Table 1). There were no significant differences by relationship role in mean age, ethnicity, time living at current residence, education, employment status, marital status, reported relationship to the other member of the dyad, reported frequency of interaction with other member of the dyad, family history of substance abuse, and family or personal history of mental illness (excluding substance abuse). There were significant differences with respect to sex such that patients were more likely to be male (60.4%) and caregivers were more likely to be female (63.5%) ($\chi^2=7.67$; $p=0.008$). The

mean daily income of the caregiver (31.0 ± 29.2 RMB) was significantly greater than the patient (18.1 ± 19.3 RMB) ($t=-3.67$; $p<0.001$).

Table 2 presents the bivariate correlations between the caregiver context variables, caregiver mental health, patient mental health and social support. Results showed the worse the patient's mental health the less their perceived social support ($r=-0.32$; $p=0.001$), the higher their perceived stigma ($r=0.21$; $p=0.04$), the worse the caregiver's mental health ($r=0.23$; $p=0.03$) and the lower their CD4 count ($r=-0.22$, $p=0.04$). Furthermore, the patient's perceived social support was associated with higher caregiver self-efficacy ($r=0.23$; $p=0.03$). Results showed that the worse the caregiver's mental health, the higher the caregiver burden ($r=0.27$, $p=0.007$) and caregiver stigma ($r=0.20$; $p=0.046$). Additionally, caregiver burden was correlated with more total patient disability ($r=0.29$; $p=0.004$). Lastly, more caregiver stigma was related to less caregiver self-efficacy (-0.33 , $p=0.001$), and a lower CD4 count ($r=-0.21$; $p=0.04$).

Linear Regression Analysis

Multivariate linear regression analyses were conducted to determine the relationships between the caregiver context, caregiver mental health, social support and patient mental health. All raw and standardized parameter estimates are described in Table 3. The first model included caregiver mental health as the dependent variables and CD4 count, length since diagnosis, patient disability, patient stigma, caregiver stigma, caregiver self-efficacy and caregiver burden for the independent variables along with demographic and medical covariates to control for confounding. The first model was significant ($F=3.24$; $p<0.001$), predicting 47.5% of the variance in caregiver mental health. Results showed several aspects of the caregiver context that predicted caregiver mental health. Higher patient CD4 count was associated with worse

caregiver mental health ($\beta=0.22$, $p=0.045$). Patient disability was associated with worse caregiver mental health ($\beta=0.83$, $p=0.022$). Lastly, increased caregiver burden was associated with worse caregiver mental health ($\beta=0.404$, $p<0.001$).

The second model included patient's perceived social support as the dependent variable and the same independent variables as the first model with the addition of caregiver mental health. The model for social support was also significant ($F=2.98$; $p<0.001$) predicting 47.1% of the variance in social support. Given this model, caregiver stigma was most strongly predictive of perceived patient social support such that increased levels of caregiver stigma was associated with decreased levels of social support ($\beta=-0.26$; $p=0.047$). Patient disability was associated with more social support ($\beta=0.24$; $p=0.029$). Lastly, increased caregiver burden was associated with less social support provided to the patient ($\beta=-0.23$, $p=0.047$).

The third model included patient mental health as the dependent variable and the same independent variables as the second model with the addition of patient's perceived social support. The model for patient mental health was also significant ($F=2.07$; $p=0.013$) predicting 39.7% of the variance in patient mental health. Increased social support was most strongly predictive of better patient mental health ($\beta=-0.37$; $p=0.007$). Increased levels of patient stigma were associated with worse patient mental health ($\beta=0.22$; $p=0.047$). Additionally, patient disability was associated with worse patient mental health ($\beta=0.24$; $p=0.045$). We assessed for the possible indirect effects between patient disability, caregiver stigma, caregiver burden and patient mental health as mediated by social support. Results showed that there were marginally significant indirect effects between patient disability (Sobel= -1.75, $p=0.081$), caregiver stigma (Sobel=1.71, $p=0.088$), and caregiver burden (Sobel=1.64, $p=0.10$) and patient mental health as mediated by social support.

DISCUSSION

Consistent with results, our conceptual model based on previous research investigating the relationship between caregiver and patient health, this study provides evidence that elements of the caregiver context are predictors of mental health and social support in this sample of HIV-positive injection drug users and their caregiver^{12,16-18,22}. Our results showed that aspects of the caregiver context were associated with the functioning and wellbeing of both HIV patients and caregivers in China. This suggests that prevention and care programs that incorporate caregivers may be beneficial to the overall quality of lives of families affected by HIV.

The prevalence of poor mental health of the patients in this sample was similar to other studies assessing depression and anxiety among HIV-positive patients in China³⁴, but higher than the prevalence of these mental disorders reported from studies of HIV-patients conducted in other countries³⁵. The prevalence of anxiety and depression among caregivers in this sample was also higher than the prevalence depression among caregivers in previous studies³⁶. Given the clinical cutoffs for depression and anxiety validated by the Hospital Anxiety and Depression Scale, 71.9% of patients and 55.2% of caregivers in this study met the criteria for depression. Similarly, 67.7% of patients and 61.5% of caregivers met the criteria for anxiety. These findings suggest that the prevalence of poor mental health among HIV-patients and caregivers may be higher in China compared to other contexts given the sociocultural norms.

The strongest relationship between the three outcomes of interest was found to be between social support and patient mental health such that greater amounts of social support were predictive of better patient mental health. These findings are supported by previous empirical research and psychological models such as the buffering hypothesis and the direct

effects hypothesis which state that adequate support during a chronic illness can lessen the negative mental health consequences of the disease³⁷. This echoes the importance of ensuring HIV patients in China have adequate support systems to help them cope with their illness and navigate the complexity of living with their disease.

One of the fundamental principles of Chinese culture and Confucianism is filial piety. Filial piety not only states that individuals should support their family above all else, but one should also make decisions outside the home that will uphold the family name³⁸. Given the current social attitudes towards substance abuse and HIV/AIDS, the patients in this sample may be perceived by their family as defacing the family name. It is important to maximize supportive familial relationships given that the majority of caregivers for the patients in this sample were part of the patient's family, predominantly female members of the family. This sense of familial obligation also has implications for the caregiver. The gender roles in China are such that women tend to have more family responsibilities than men. This is consistent with our findings that women were primarily the caregivers for patients with HIV/AIDS. Research on gender roles in China has found that the mental health status of females is closely tied to work and family-related obligations which may further increase due to the extra physical and psychological responsibilities associated with caring for someone with HIV/AIDS³⁹. Understanding the socially established family structure is imperative when evaluating its relationship to the social support that is provided within the family unit. Hansell et al. (1998) showed that social support boosting interventions targeting seronegative caregivers are successful at improving the levels of social support the caregiver provides to HIV-positive family members⁴⁰. An intervention such as this has potential benefits for patients and caregivers in China if adapted in a culturally-appropriate manner.

Social support, being the strongest predictor of patient mental health, was largely determined by the caregiver's stigma towards HIV in this study. Research has shown that stigma can influence HIV patient's behavior and well being⁴¹, however no studies that we are aware of have shown that the HIV stigma of the caregiver might influence how the caregiver behaves toward the patient and the level of support the patient receives. Our results suggest that stigma can be present even when HIV directly affects a caregiver's loved one. This finding is important in suggesting that care and prevention programs should incorporate stigma reduction methods as a way of naturally increasing levels of support within caregiver-patient dyads. Programs and interventions aimed at reducing HIV-related stigma have shown to be successful. A stigma reduction intervention in Yunnan Province utilizing small group participatory activities found that health service providers who completed the intervention had significantly lower levels of stigma and a better understanding of HIV/AIDS compared to the control group⁴². Caregivers may benefit from such interventions given the similarities in the nature of care provision required by health care providers and caregivers as well as their concerns and fears regarding transmission.

While there are several similarities between these results and previous research, there are also some inconsistencies that may be explained by the study sample and cultural context. Caregiver self-efficacy has often been cited in the literature as relating to the level of caregiver burden^{19,20}. Dunkin et al. (2011) conducted a review of the caregiver literature and found that self-efficacy was an important mediator for the caregiver's experience of their burden related to the provision of care to an elderly patient with dementia¹⁹. The majority of the research evaluating the influence of caregiver self-efficacy examines this relationship with respect to caregivers of elderly patients with a form of cognitive impairment^{20,43,44}. There are inherent

differences in caring for patients with diseases naturally associated with the aging process and caring for patients with a highly stigmatized disease such as HIV/AIDS, especially within the cultural context. This difference may explain the existence of this inconsistency between the hypotheses and results related to the lack of predictive power of self-efficacy in understanding mental health and social support.

Furthermore, objective indicators of disease severity such as length since diagnosis and CD4 count were not as predictive of mental health and social support as were the psychosocial elements of the caregiver context. This suggests that mental health and social support may be more strongly determined by social factors and experiential aspects of the disease process rather than objective clinical measures. Patient disability, another measure of disease severity was described from the caregiver's perspective based on a validated scale and was found to be predictive of mental health and social support. This measure described the level of disease severity as it related to daily functioning and independence as opposed to clinical indicators of disease severity.

Limitations

Several limitations are necessary to consider when interpreting these results. Given that this study is cross-sectional in nature, it is impossible to conclude that the relationships between the caregiver context, mental health and social support are causal. In order to make this determination, longitudinal studies will need to be conducted. Given the sequential nature of the conceptual model developed a priori in this study, we have some confidence in the direction of these relationships (see Figure 1). Additionally, all of the data was collected from a single study site in Kunming, China. This limits the generalizability of the findings considering there may be

differences in patient and caregiver characteristics between those attending clinics in Kunming, Yunnan Province and caregiving dyads in other cities and provinces in China. Additional data from other regions in China must be collected before extrapolating these results to further locations. It is also important to consider cultural validity with respect to the conversion of the study content from English to Chinese, both linguistically and culturally. The measurement tools were selected because most have been previously used in Chinese populations and all of the measures demonstrated adequate reliability in this sample. However given cultural differences, some of the intended connotations may have been slightly distorted in the translation process. Despite these concerns, we are confident that cultural differences didn't significantly distort the data because of the thoroughness in translator training, the translation and back translation process, and the certification of the interpreter employed for this study.

Implications

This study provides evidence supporting the incorporation of caregivers into programs aimed at improving the physical and mental health of HIV-positive injection drug users. Considering that non-clinical caregivers, primarily family members, provide much of the care for these patients⁴⁵, it is important to maximize their ability to provide adequate care while maintaining the quality of their personal health throughout the caregiving process. This has implications for both preventive and clinical practice. Preventive measures can be taken to improve the social support a patient receives once they are diagnosed with HIV by developing, implementing and scaling up programs that incorporate stigma reduction efforts. By doing this, the stigma perceived by the patient may also decrease, which can additionally benefit their mental health. As has been shown in previous studies, poor mental health contributes to a substantial amount of burden^{46,47}

and by improving patient mental health, we may be able to improve their level of daily functioning by decreasing overall disability. Clinically, physicians and other care providers can integrate psychoeducational programs that have proven to be effective for caregivers in reducing their burden⁴⁸ such that they can have better mental health. In conclusion, it is imperative that health care providers understand the interconnectedness of caregiver and patient health. Clinical providers must increase their attentiveness to the caregiver and understand that by doing so, they are ultimately contributing to the improvement of both patient and caregiver mental health.

Figure 1: Conceptual Model of Specific Aims

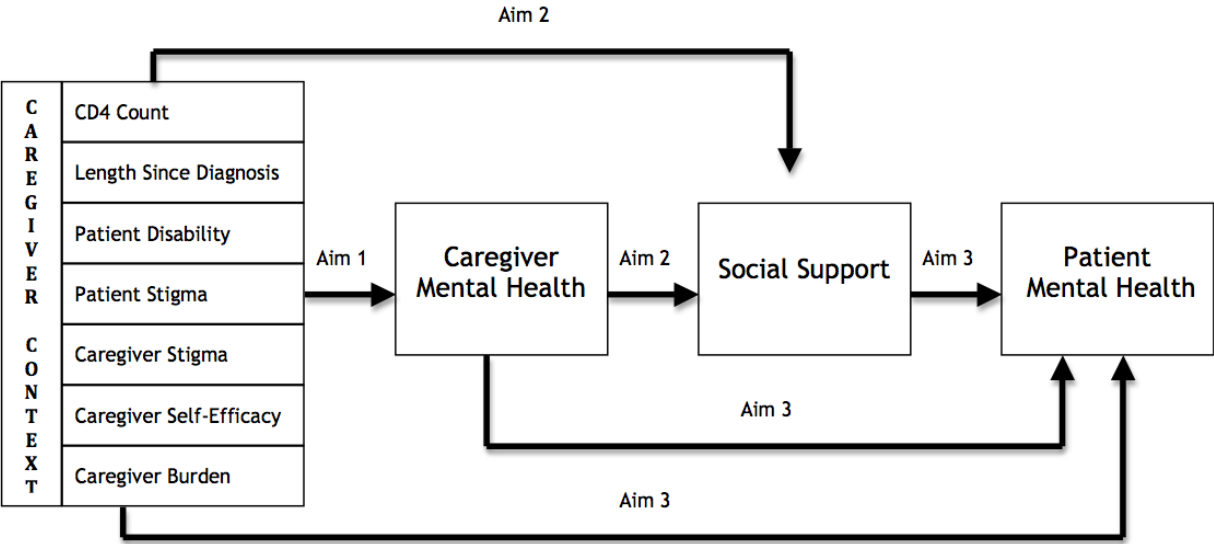


Table 1: Characteristics of the Sample (N=96 Patient-Caregiver Dyads)

| Characteristic | Patients (n=96) | Caregivers (n=96) | Test Statistic* |
|---|--------------------|----------------------|---------------------------|
| Age | 41.1 ± 4.9 | 41.4 ± 11.2 | t=-0.30 p=0.762 |
| Male Sex | 58 (60.4) | 35 (36.4) | $\chi^2=7.67$ p=0.0008 |
| Han ethnicity | 85 (88.5) | 82 (85.4) | $\chi^2=0.692$ p=0.581 |
| Lived at current residence more than 1 year | 11 (11.6) | 11 (11.6) | $\chi^2=1.00$ p=1.000 |
| High school education or greater | 28 (29.2) | 37 (38.5) | $\chi^2=2.19$ p=0.188 |
| Employed | 27 (28.1) | 37 (38.5) | $\chi^2=2.27$ p=0.174 |
| Average Income (RMB) | 18.1 ± 19.3 | 31.0 ± 29.2 | t=-3.67 p<1.001 |
| Married or in a relationship | 64 (66.7) | 68 (70.8) | $\chi^2=0.89$ p=0.481 |
| Patient-caregiver dyad married or in a relationship together | 50 (52.1) | 50 (52.1) | $\chi^2=1.00$ p=1.00 |
| Daily interaction between patient and caregiver | 79 (82.3) | 80 (83.3) | $\chi^2=0.09$ p=0.763 |
| Family history of substance abuse | 66 (68.8) | 70 (72.9) | $\chi^2=0.62$ p=0.557 |
| Family history of mental illness (other than substance abuse) | 5 (5.2) | 2 (2.1) | $\chi^2=1.80$ p=0.375 |
| Personal history of mental illness (other than substance abuse) | 10 (10.4) | 6 (6.3) | $\chi^2=1.00$ p=0.455 |
| Hospital Anxiety and Depression Scale | | | |
| Mean ± SD | 14.82±8.99 | 11.86±7.01 | t=2.88 p=0.005 |
| Poor mental health | 60 (62.5) | 46 (47.9) | $\chi^2=4.67$ p=0.044 |

*p-value for paired t-test (continuous variables), McNemar's χ^2 (dichotomous categorical variables), or Cochran's Q test (categorical variables with ≥ 3 levels).

** Numbers may not sum to total due to missing data and percentages may not sum to 100% due to rounding.

Table 3: Multivariate Linear Regression Analysis

| | OUTCOMES: | | | | | | | | | | | | | | |
|--------------------------------|--------------------------------|-----------|----------|----------------|----------|-----------------------|----------|----------------|----------|-----------|------------------------------|----------------|--|--|--|
| | Caregiver Mental Health | | | | | Social Support | | | | | Patient Mental Health | | | | |
| | B | SE | β | p-value | B | SE | β | p-value | B | SE | β | p-value | | | |
| Intercept | -8.423 | 9.863 | 0 | 0.396 | 12.724 | 6.973 | 0 | 0.073 | 34.723 | 14.338 | 0 | 0.0182 | | | |
| CD4 Count | 0.008 | 0.004 | 0.220 | 0.045 | -0.004 | 0.003 | -0.147 | 0.194 | -0.009 | 0.006 | -0.183 | 0.139 | | | |
| Length Since Diagnosis | -0.001 | 0.001 | -0.146 | 0.1187 | -0.000 | 0.000 | -0.113 | 0.237 | -0.002 | 0.001 | -0.177 | 0.090 | | | |
| Patient Disability | 0.034 | 0.160 | 0.834 | 0.022 | 0.251 | 0.112 | 0.236 | 0.029 | 0.478 | 0.234 | 0.241 | 0.045 | | | |
| Patient Stigma | 0.361 | 0.311 | 0.116 | 0.251 | 0.222 | 0.221 | 0.103 | 0.318 | 0.903 | 0.447 | 0.224 | 0.047 | | | |
| Caregiver Stigma | 0.164 | 0.122 | 0.154 | 0.186 | -0.188 | 0.087 | -0.256 | 0.035 | -0.099 | 0.181 | -0.072 | 0.586 | | | |
| Caregiver Self-Efficacy | 0.157 | 0.210 | 0.089 | 0.459 | -0.040 | 0.149 | -0.032 | 0.791 | -0.226 | 0.298 | -0.099 | 0.451 | | | |
| Caregiver Burden | 0.906 | 0.222 | 0.404 | <0.001 | -0.352 | 0.174 | -0.225 | 0.047 | -0.067 | 0.361 | -0.023 | 0.853 | | | |
| Caregiver Mental Health | N/A | N/A | N/A | N/A | 0.007 | 0.085 | 0.011 | 0.931 | 0.103 | 0.171 | 0.080 | 0.548 | | | |
| Social Support | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | -0.683 | 0.245 | -0.366 | 0.007 | | | |

*All models adjusted for sex, income, employment status, family history of mental illness and frequency of interaction between the patient and the caregiver
 B: Unstandardized parameter estimate
 SE: Standard error of unstandardized parameter estimate
 β: Standardized parameter estimate

REFERENCES

1. Lim J-w, Zebrack B. Caring for family members with chronic physical illness: A critical review of caregiver literature. *Health and Quality of Life Outcomes*. November 20, 2011 2004;2(50).
2. Northouse LL, Mood D, Kershaw T, et al. Quality of life of women with recurrent breast cancer and their family members. *J Clin Oncol*. Oct 1 2002;20(19):4050-4064.
3. Haley WE, Roth DL, Howard G, Safford MM. Caregiving strain and estimated risk for stroke and coronary heart disease among spouse caregivers: differential effects by race and sex. *Stroke*. Feb 2010;41(2):331-336.
4. Phillips MR, Zhang J, Shi Q, et al. Prevalence, treatment, and associated disability of mental disorders in four provinces in China during 2001-05: an epidemiological survey. *Lancet*. Jun 13 2009;373(9680):2041-2053.
5. Cyranoski D. China tackles surge in mental illness. *Nature*. November 10, 2010 2010;468:145.
6. Kulsudjarit K. Drug problem in southeast and southwest Asia. *Ann N Y Acad Sci*. Oct 2004;1025:446-457.
7. Zhang C, Yang R, Xia X, et al. High prevalence of HIV-1 and hepatitis C virus coinfection among injection drug users in the southeastern region of Yunnan, China. *J Acquir Immune Defic Syndr*. Feb 1 2002;29(2):191-196.
8. MoH. *2005 Update on the HIV/AIDS Epidemic and Response in China*. Beijing: National Center for AIDS/STD Prevention and Control, China CDC;2006.
9. Chan KY, Yang Y, Zhang KL, Reidpath DD. Disentangling the stigma of HIV/AIDS from the stigmas of drugs use, commercial sex and commercial blood donation - a factorial survey of medical students in China. *BMC Public Health*. 2007;7:280.
10. Lieber E, Li L, Wu Z, Rotheram-Borus MJ, Guan J. HIV/STD stigmatization fears as health-seeking barriers in China. *AIDS Behav*. Sep 2006;10(5):463-471.
11. Grusky O, Liu H, Johnston M. HIV/AIDS in China: 1990-2001. *AIDS and Behavior*. December 2002 2002;6(4):381-393.
12. Li L, Lin C, Wu Z, et al. Stigmatization and shame: consequences of caring for HIV/AIDS patients in China. *AIDS Care*. Feb 2007;19(2):258-263.
13. USAID. *HIV/AIDS Health Profile*. Bangkok: USAID Regional Development Mission for Asia;2010.
14. Cook JA, Grey D, Burke J, et al. Depressive symptoms and AIDS-related mortality among a multisite cohort of HIV-positive women. *Am J Public Health*. Jul 2004;94(7):1133-1140.
15. Ickovics JR, Hamburger ME, Vlahov D, et al. Mortality, CD4 cell count decline, and depressive symptoms among HIV-seropositive women: longitudinal analysis from the HIV Epidemiology Research Study. *JAMA*. Mar 21 2001;285(11):1466-1474.
16. Lu L, Pan B, Sun W, Cheng L, Chi T, Wang L. Quality of life and related factors among cancer caregivers in China. *Psychiatry Clin Neurosci*. Oct 2010;64(5):505-513.

17. Li J, Lambert CE, Lambert VA. Predictors of family caregivers' burden and quality of life when providing care for a family member with schizophrenia in the People's Republic of China. *Nurs Health Sci.* Sep 2007;9(3):192-198.
18. Grunfeld E, Coyle D, Whelan T, et al. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *CMAJ.* Jun 8 2004;170(12):1795-1801.
19. Dunkin JJ, Anderson-Hanley C. Dementia caregiver burden: a review of the literature and guidelines for assessment and intervention. *Neurology.* Jul 1998;51(1 Suppl 1):S53-60; discussion S65-57.
20. Zeiss AM, Gallagher-Thompson D, Lovett S, Rose J, McKibbin C. Self-efficacy as a mediator of caregiver coping: development and testing of an assessment model. *Journal of Clinical Geropsychology.* 1999;5(3):221-230.
21. Hanass-Hancock J, Nixon SA. The fields of HIV and disability: past, present and future. *J Int AIDS Soc.* 2009;2(1):3.
22. Oursler KK, Goulet JL, Leaf DA, et al. Association of comorbidity with physical disability in older HIV-infected adults. *AIDS Patient Care STDS.* Nov 2006;20(11):782-791.
23. Deng R, Li J, Sringernyuang L, Zhang K. Drug abuse, HIV/AIDS and stigmatisation in a Dai community in Yunnan, China. *Social Science and Medicine.* 2007;64:1560-1571.
24. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand.* Jun 1983;67(6):361-370.
25. Leung CM, Ho S, Kan CS, Hung CH, Chen CN. Evaluation of the Chinese version of the Hospital Anxiety and Depression Scale. A cross-cultural perspective. *Int J Psychosom.* 1993;40(1-4):29-34.
26. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J Psychosom Res.* Feb 2002;52(2):69-77.
27. Sarason IG, Levine HM, Basham RB, Sarason BR. Assessing social support: The social support questionnaire. *Journal of Personality and Social Psychology.* 1983;44(1):127-139.
28. Wong ST, Nordstokke D, Gregorich S, Perez-Stable EJ. Measurement of social support across women from four ethnic groups: evidence of factorial invariance. *J Cross Cult Gerontol.* Mar 2010;25(1):45-58.
29. McDowell I. *Measuring Health: A Guide to Rating Scales and Questionnaires.* Oxford University Press; 2006.
30. Tang Z, Wang HX, Meng C, et al. The prevalence of functional disability in activities of daily living and instrumental activities of daily living among elderly Beijing Chinese. *Arch Gerontol Geriatr.* Sep-Oct 1999;29(2):115-125.
31. Tong Y-cA. *The validation of the Hong Kong Chinese version of the Lawton Instrumental Activities of Daily Living Scale for the institutionalized elderly persons.* Hong Kong: Rehabilitation Services, Hong Kong Polytechnic University; 1999.
32. Visser MJ, Kershaw T, Makin JD, Forsyth BW. Development of parallel scales to measure HIV-related stigma. *AIDS Behav.* Sep 2008;12(5):759-771.
33. NYSAAAA. Caregiver Burden Assessment. 2011; www.nysaaaa.org.
34. Jin H, Hampton Atkinson J, Yu X, et al. Depression and suicidality in HIV/AIDS in China. *J Affect Disord.* Aug 2006;94(1-3):269-275.

35. Chandra PS, Ravi V, Desai A, Subbakrishna DK. Anxiety and depression among HIV-infected heterosexuals--a report from India. *J Psychosom Res.* Nov 1998;45(5):401-409.
36. Gallagher D, Rose J, Rivera P, Lovett S, Thompson LW. Prevalence of depression in family caregivers. *Gerontologist.* Aug 1989;29(4):449-456.
37. Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. *Psychol Bull.* Sep 1985;98(2):310-357.
38. Shek DTL. Chinese Family Research: Puzzles, Progress, Paradigms, and Policy Implications. *Journal of Family Issues.* 2006;27:275-284.
39. Lai G. Work and family roles and psychological well-being in urban China. *J Health Soc Behav.* Mar 1995;36(1):11-37.
40. Hansell PS, Hughes CB, Caliandro G, et al. The effect of a social support boosting intervention on stress, coping, and social support in caregivers of children with HIV/AIDS. *Nurs Res.* Mar-Apr 1998;47(2):79-86.
41. Vanable PA, Carey MP, Blair DC, Littlewood RA. Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. *AIDS Behav.* Sep 2006;10(5):473-482.
42. Wu S, Li L, Wu Z, et al. A brief HIV stigma reduction intervention for service providers in China. *AIDS Patient Care STDS.* Jun 2008;22(6):513-520.
43. Huang HL, Shyu YI, Chen MC, Chen ST, Lin LC. A pilot study on a home-based caregiver training program for improving caregiver self-efficacy and decreasing the behavioral problems of elders with dementia in Taiwan. *Int J Geriatr Psychiatry.* Apr 2003;18(4):337-345.
44. Gilliam CM, Steffen AM. The relationship between caregiving self-efficacy and depressive symptoms in dementia family caregivers. *Aging & Mental Health.* 2006;10(2):79-86.
45. Li L, Wu S, Wu Z, Sun S, Cui H, Jia M. Understanding family support for people living with HIV/AIDS in Yunnan, China. *AIDS Behav.* Sep 2006;10(5):509-517.
46. Prince M, Patel V, Saxena S, et al. No health without mental health. *Lancet.* Sep 8 2007;370(9590):859-877.
47. Collins P. Grand challenges in global mental health. *Nature.* July 7, 2011 2011;475:27-30.
48. Ostwald SK, Hepburn KW, Caron W, Burns T, Mantell R. Reducing caregiver burden: a randomized psychoeducational intervention for caregivers of persons with dementia. *Gerontologist.* Jun 1999;39(3):299-309.