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Emotional social support and access to care among older people living with HIV in rural China

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Objectives: Globally, the number of older people living with HIV (PLH) is growing. Additionally, older PLH are facing particular challenges related to accessing health care. The objective of this study is to investigate the older PLH's access to care and its relationship to emotional and tangible social support.

Methods: A cross-sectional study was conducted among 225 PLH who were 50 years of age or older in Anhui, China. A computer-assisted personal interview was used to collect the participants' demographic characteristics, perceived health status, and access to care. The following two dimensions of social support were measured: emotional support and tangible support. The association between emotional/tangible support and access to care was calculated using Pearson's/point-biserial correlations and with multiple linear regression.

Results: Higher tangible support was reported by the participants who were married or living with a partner, those who had higher annual income levels, and those with better perceived health status. Emotional support was correlated with higher education, higher income, and better perceived health status. Multiple regression analyses showed that access to care was significantly associated with emotional support ($\beta=0.2807$, $p<0.0001$) but not with tangible support ($\beta=-0.0183$, $p=0.7922$).

Conclusions: The study findings point to the importance of providing emotional support for older PLH. It is suggested that emotional support should be provided for older PLH in addition to tangible assistance, in order to engage them in treatment and care. Copyright © 2015 John Wiley & Sons, Ltd.

Key words: HIV; older; access to care; social support

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Introduction

In recent years, the prevalence of human immunodeficiency virus (HIV) among the older population has become an emerging public health issue. According to the latest data by the Joint United Nations Programme on HIV/AIDS, there were 3.6 million people aged 50 years and older living with HIV by the end of 2013 (United Nations Programme on HIV/AIDS, 2014). In high-income countries, the older population (50 years of age and above) accounted for 33% of all people living with HIV (PLH) (United Nations Programme on HIV/AIDS, 2014). The prevalence of HIV in older

populations is also increasing within low-income and middle-income countries, including China (Zhang *et al.*, 2013). In China, adults aged 50 years and above represented 20.6% of all reported cases of HIV/AIDS in 2011 (Ministry of Health, People's Republic of China, 2011). The high prevalence of the HIV epidemic within the older population in China is due to the availability of highly active antiretroviral therapies (ARTs) that have prolonged the lives of PLH (Liu *et al.*, 2012; Xie and Wu, 2013; Zhang *et al.*, 2013). Moreover, the HIV infection rates may be attributed to the often overlooked risk-taking behaviors among the older population (United Nations Programme on HIV/AIDS, 2014).

Providing treatment and care for the older population raises a set of challenges. Given their age group, older PLH are at a high risk of developing age-related diseases such as cardiovascular disease, cancer, and cognitive impairment (Slavin *et al.*, 2011). Thus, the older population infected with HIV may need additional treatment and may require care for multiple comorbidities (Negin *et al.*, 2012; Cahill and Valadez, 2013). Existing literature has documented that older patients are more likely to experience delayed access to health care (Lanoy *et al.*, 2007; Mojumdar *et al.*, 2010). This delay in health care may be due to age-related declines in physical and cognitive functionings that hinder the older people from seeking health care and health-related information (Fritsch, 2005; Cahill and Valadez, 2013). In addition to the prevailing discrimination and rejection toward PLH, older PLH are facing amplified stigma correlated with comorbidity, disability, and cognitive and functional decline (Emlet, 2006; Dobbs *et al.*, 2008). The “double stigma” of HIV infection and ageism further discourages older PLH from accessing treatment and care (Sherr *et al.*, 2009; Chambers *et al.*, 2014). Given these challenges, efforts to address the healthcare needs of older PLH have been inadequate.

Literature suggests that a relationship exists between social support and the patients' access to care (Alfonso *et al.*, 2006; McCoy *et al.*, 2009). Social support is believed to be one of the most consistent predictors of successful ART (Catz *et al.*, 2000; Knowlton *et al.*, 2007). Perceived social support has also been evidenced to improve coping strategies and care-seeking behaviors (Tate *et al.*, 2006). However, previous studies have found that older adults are more likely to live alone than their younger counterparts (Emlet *et al.*, 2009) and are also more vulnerable to loneliness and social isolation (Wang and Zhao, 2012; Dury, 2014). In line with this, older PLH are less likely to be linked to care (Groves *et al.*, 2010; Roger *et al.*, 2013; Cao *et al.*, 2014).

Social support is a multidimensional construct which can be subdivided into tangible support and emotional support. In theory, tangible support refers to the provision of financial assistance, material goods, or services (Sherbourne and Stewart, 1991; Heaney and Israel, 2008; McCoy *et al.*, 2009). Emotional support is envisioned as support in the form of conveying empathy, acceptance, respect, and trust (Sherbourne and Stewart, 1991; Heaney and Israel, 2008; McCoy *et al.*, 2009). Previous research has generally focused more on social support as a single entity. Services for older patients are often aimed at providing tangible support, such as providing assistance with activities

of daily living (Hand *et al.*, 2013). Very few studies have delved into the roles of different subtypes of social support and their distinct effects on access to care. This research aims to extend the current literature through an investigation of the concept of multifaceted social support in relation to older PLH.

Study participants

The study used the baseline data from a randomized controlled intervention trial targeting PLH and their family members in Anhui province, China. A substantial proportion of PLH in Anhui provinces were infected through contaminated commercial plasma/blood donation in the last century and are currently entering old age (Ji *et al.*, 2006; Zhang *et al.*, 2013). The randomized controlled trial recruited a total of 522 PLH. In the current study, only the subsample of PLH who were 50 years and above at baseline were included ($N = 225$; 43.1%).

Procedure

Data were collected between the months of October 2011 and March 2013. To recruit participants, informational flyers were mounted in the local clinics where the PLH usually receive routine check-ups and care. The health workers informed the potential participants about the study verbally and using informational flyers. The project recruiters explained the study purpose, procedure, risks, benefits, and voluntary participation to the potential study participants during the recruitment process. Each participant was assured of confidentiality and their right to withdraw from the study at any time without penalty. Before starting the data collection, informed consent was obtained from the participants. The study was reviewed and approved by the Institutional Review Boards of the University of California, Los Angeles and the Anhui Provincial Center for Disease Control and Prevention.

The participants completed a survey using the computer-assisted personal interview method. Trained interviewers read the questions to the participants and directly entered their responses into a computer database. Each survey lasted for 45–60 min and took place in a private room based on the participants' preference, such as an office behind a closed door in a clinic, a local school classroom, or the home of the participant. The participants received 50 yuan (US \$8.3) for time spent in the assessment.

Measures

Access to care was measured using an eight-item scale developed by Li *et al.* (2010). The scale was previously validated among the Chinese PLH population (Ding *et al.*, 2011). The scale measures if the participants (1) pay regular visits to medical providers, (2) know where to get treatment if they were sick, (3) have access to disease-related information, (4) go for regular check-ups when they were not sick, (5) know how to protect themselves from being sick, (6) eat right to get proper nutrition, (7) exercise to stay healthy, and (8) can talk freely with their medical providers about their illnesses. Responses to each item ranged from 1 (totally untrue) to 4 (totally true). By summing the eight items, a continuous variable was constructed within which a higher score indicates better access to care ($\alpha = 0.84$).

Social support was assessed using the Medical Outcomes Study (MOS) social support survey (Sherbourne and Stewart, 1991). Psychometric properties of the MOS social support survey have been tested among Chinese population, and good reliability and validity were demonstrated (Shyu *et al.*, 2006). Two subscales, emotional support and tangible support, were adopted based on the study interests. The *emotional support* subscale contains eight items that measure how often is each of the following kinds of support are available to the participants. The eight items documented are if they have (1) someone they can count on to listen to when they need to talk, (2) someone to give information to help them understand a situation, (3) someone to give them good advice about a crisis, (4) someone to confide in or talk to about themselves or their problems, (5) someone whose advice they really want, (6) someone to share their most private worries and fears with, (7) someone to turn to for suggestions about how to deal with a personal problem, and (8) someone who understands their problems ($\alpha = 0.86$). The *tangible support* subscale consists of four items that evaluate if there is someone to provide actual and tangible help to the participant when necessary. The tangible support subscale is as follows: (1) how often if someone was available to help the participants if they were confined to bed, (2) how often if someone was available to take them to the doctor if they needed it, (3) how often if someone was available to prepare meals they were unable to do it themselves, and (4) how often if someone was available to help with daily chores if they were sick ($\alpha = 0.88$). Each subscale includes five-point item ratings that range from "1" (none of the time) to "5" (all of the time). The overall emotional support score

and tangible support score were calculated by summing all items on each subscale. A higher score indicates better emotional/tangible support.

In addition to the aforementioned measures, the participants' *background characteristics* including age, gender, education, marital status, and family income were collected. Participants' *perceived health status* was measured using a health perception subscale from the MOS HIV Health Survey (Ichikawa and Natpratan, 2004). The MOS HIV Health Survey is one of the most widely used quality of life instruments for PLH, and its Chinese version has been previously validated among Chinese PLH (Lau *et al.*, 2006). The health perception subscale has four items. The participants were asked to evaluate in general if (1) they were somewhat ill, (2) they are as healthy as anybody they know, (3) their health is excellent, and (4) they had been feeling bad lately. Each item ranged from 1 (definitely true) to 5 (definitely false). After reversing some of the items, we summed all responses from the four items and generated a perceived health score, within which higher scores indicate better perceived health status ($\alpha = 0.81$).

Statistical analysis

We first performed a descriptive analysis of the participants' demographic characteristics, emotional and tangible social support, health perceptions, and access to care scores. Secondly, Pearson's correlations (r) were calculated to investigate the relationships between continuous variables, including age, years of education, perceived emotional and tangible support, health perceptions, and access to care scores. The univariate correlations between binary variables (female gender and being married/living with partner) and continuous variables were calculated using point-biserial correlation. Thirdly, a multiple linear regression was performed with the access to care score while controlling for the simultaneous effects of participants' demographics, perceived health status, and perceived tangible and emotional support. Standardized regression coefficients and their significant levels were reported. The statistical analyses were performed using the SAS 9.4 statistical software package (SAS Institute Inc., Cary, NC, USA).

Results

Among the 225 older PLH participants, 125 (56.9%) were women. The mean age was 57 years. About one-third ($N = 83$, 36.9%) fell into the category of

56–60 years of age at the time of the survey. Over half of the study population ($N=117$, 52%) were illiterate. The majority of the participants ($N=160$, 71.1%) were married or living with a partner. The average annual family income was 15 300 yuan (US \$2508). The participants' background characteristics and the summary statistics of social support, access to care, and perception of health are presented in Table 1.

Correlation coefficients of identified variables are reported in Table 2. Being woman ($r=-0.493$, $p<0.0001$) and of an older age (-0.195 , $p=0.0034$) were significantly associated with less education. Being married or living with a partner was significantly associated with tangible support ($r=0.159$, $p=0.0171$) but not with emotional support. Higher family income had a significant positive relationship with better perceived health status ($r=0.156$, $p=0.0197$), higher emotional support ($r=0.2118$, $p=0.0015$), tangible support ($r=0.188$, $p=0.0049$), and access to care ($r=-0.141$, $p=0.0349$). Perceived health status was

correlated with both emotional support ($r=0.174$, $p=0.0089$) and tangible support ($r=0.206$, $p=0.0019$). Emotional support and tangible support were correlated with each other ($r=0.291$, $p<0.0001$). The access to care score was strongly associated with emotional support ($r=0.269$, $p<0.0001$), but no significant association was found between the access to care score and tangible support ($r=0.052$, $p=0.4416$).

The results of the multiple regression analyses are presented in Table 3. Age became significantly associated with access to care ($\beta=0.136$, $p=0.049$) after controlling for the variables of gender, education, marital status, income, perceived health status, and emotional and tangible support. Those who perceived better health reported a lower level of access to care ($\beta=-0.168$, $p=0.0124$). A strong association remained between emotional support and access to care ($\beta=0.2807$, $p<0.0001$) in the model. The correlation between tangible support and access to care remained insignificant ($\beta=-0.0183$, $p=0.7922$) when other variables were controlled.

Table 1 Descriptive analysis of demographics, health status, support, and access to care

| Parameter | |
|----------------------------------|------------------|
| Female | |
| Number (%) | 128 (56.9) |
| Age | |
| Mean \pm SD | 57.0 \pm 5.2 |
| Median (min-max) | 57.0 (50.0–73.0) |
| Number (%) | |
| 50–55 years | 90 (40.0) |
| 56–60 years | 83 (36.9) |
| 61–65 years | 41 (18.2) |
| 66 years and above | 11 (4.9) |
| Years of education | |
| Mean \pm SD | 2.5 \pm 3.3 |
| Median (min-max) | 0 (0–11) |
| Number (%) | |
| 0 year | 117 (52.0) |
| 1–6 years | 71 (31.6) |
| 7 years and above | 37 (16.4) |
| Married or living with partner | |
| Number (%) | 160 (71.1) |
| Yearly family income (1000 yuan) | |
| Mean \pm SD | 15.3 \pm 12.3 |
| Median (min-max) | 10.0 (0–65.0) |
| Perceived health status | |
| Mean \pm SD | 9.3 \pm 3.2 |
| Median (min-max) | 9.0 (5.0–19.0) |
| Emotional support | |
| Mean \pm SD | 16.6 \pm 5.7 |
| Median (min-max) | 16.0 (8.0–32.0) |
| Tangible support | |
| Mean \pm SD | 13.3 \pm 3.5 |
| Median (min-max) | 13.0 (4.0–20.0) |
| Access to care | |
| Mean \pm SD | 26.4 \pm 4.0 |
| Median (min-max) | 26.0 (16.0–32.0) |

SD, standard deviation.

Discussion

The study identified the importance of emotional social support and its correlation with access to care among older PLH. Although practical assistance and daily care for older PLH is thought to be necessary, the study found no association between tangible support and the older PLH's access to care. This finding is contradictory to the expectations, as tangible support was reported to reduce nonpsychological burdens and improve ease of access and utilization of services among people with dementia (Han *et al.*, 2014). The contradictoriness between our findings and that of Han's study may be attributed to the differences in health status and health needs of the study population (e.g., people with dementia *versus* people with HIV/AIDS). However, the finding does not imply that practical assistance and care for older PLH are unnecessary. The null finding may be due to the high levels of tangible support already available to the study population (average tangible score = 13 out of 20), which may mask the true effect of access to care.

In contrast, emotional support was found to be strongly correlated with access to care among the older PLH. The result is supported by previous researchers, who reported that emotional support was related to greater positive affect and satisfaction with life among older people (Friedman and King, 1994). This beneficial effect of emotional support for older PLH is due to the fact that emotional support may create a sense of

Table 2 Correlation coefficients (top line) and *p*-values (bottom line) among demographics, health status, support, and access to care

| | Age | Years of education | Married or living with partner | Family income | Perceived health status | Emotional support | Tangible support | Access to care |
|--------------------------------|-------------------|--------------------|--------------------------------|-------------------|-------------------------|-------------------|-------------------|-------------------|
| Women | -0.0666 0.3024 | -0.4929 <0.0001 | -0.0400 0.5502 | -0.0089 0.8950 | 0.0155 0.8172 | 0.0173 0.7966 | 0.0453 0.4990 | 0.0096 0.8864 |
| Age | | -0.1945 0.0034 | -0.1538 0.0210 | -0.0093 0.8905 | 0.0451 0.5013 | -0.0533 0.4267 | -0.0660 0.3247 | 0.0981 0.1425 |
| Years of education | | | 0.0512 0.4444 | -0.0093 0.9776 | 0.0444 0.5076 | 0.1349 0.0433 | 0.0352 0.5992 | -0.0121 0.8570 |
| Married or living with partner | | | | 0.0054 0.9364 | 0.0405 0.5456 | 0.0522 0.4356 | 0.1588 0.0171 | 0.0648 0.3331 |
| Yearly family income | | | | | 0.1560 0.0197 | 0.2118 0.0015 | 0.1877 0.0049 | 0.1414 0.0349 |
| Perceived health status | | | | | | 0.1740 0.0089 | 0.2058 0.0019 | -0.0926 0.1663 |
| Emotional support | | | | | | | 0.2913 <0.0001 | 0.2687 <0.0001 |
| Tangible support | | | | | | | | 0.0516 0.4416 |

Table 3 Multiple linear regressions with access to care score

| | Standardized β | <i>p</i> -value |
|--------------------------------|----------------------|-----------------|
| Women | 0.0112 | 0.8819 |
| Age | 0.1361 | 0.0449 |
| Years of education | -0.0123 | 0.8730 |
| Married or living with partner | 0.0825 | 0.2105 |
| Yearly family income/1000 yuan | 0.1124 | 0.0923 |
| Perceived health status | -0.1678 | 0.0124 |
| Emotional support | 0.2807 | <0.0001 |
| Tangible support | -0.0183 | 0.7922 |

acceptance and appreciation, which are crucial to help patients sustain their therapeutic efforts and achieve treatment success (Alfonso *et al.*, 2006; Reblin *et al.*, 2014). The significant relationship between emotional support and access to care suggests that, when delivering care for older PLH, aside from providing concrete assistance, expressing sympathy, care, and respect for older PLH would potentially have a more profound impact.

The Chinese cultural context is important in interpretation of the findings. In China, family provides the most critical source of tangible support, including financial support, daily assistance, and care for a sick patient (Fredriksen-Goldsen *et al.*, 2011; Li and Wang, 2012). However, emotional support provided by family is often insufficient, because it is believed in Chinese culture that emotions must be contained and controlled (Tsai and Levenson, 1997). Patients tend to keep their physical and psychological issues to themselves in order to avoid upsetting their family

members and also to maintain harmony within the family (Liu *et al.*, 2012). Explicit and open emotional communication is often discouraged, as family members are assumed to know others' feelings without direct inquiry (Lam *et al.*, 2012). Given that the study identified the importance of emotional support for older PLH, it is suggested that the role of the older patient's family members should be altered to enhance emotional support. Open discussions concerning the family members' thoughts, fears, and emotions are encouraged which is beyond offering basic assistance with the patients' daily chores and with monetary support for treatment.

Emotional support provided by the patient's social network, including their trusted friends and peers, is irreplaceable, especially after bereavement and/or children leaving home. Arora and colleagues (2007) pointed out that support from friends, although less available than support from family members, is more desired by patients with HIV (Arora *et al.*, 2007). Developing peer-based programs to incorporate friends and peers of the older patients to provide emotional support is warranted. Emotional support may also be available from the healthcare provider (Arora *et al.*, 2007). Effective communication and a relationship built on trust between healthcare providers and patients may foster a number of health and wellbeing benefits for the patients, including an enhanced mood and self-efficacy to manage physical symptoms (Forsythe *et al.*, 2014). Development and implementation of specific intervention programs that educate healthcare providers and enhance their skills

related to providing emotional support to older PLH (e.g., active listening, empathic expression and/or empowering statements) may promote access to care (Slomka *et al.*, 2013).

This study presents limitations: the study was conducted largely among a cohort infected through commercial plasma donation. PLH who were infected through other transmission routes (e.g., injecting drug use and sexual behaviors) were underrepresented, which may reduce the generalizability of the results to the general PLH population. In addition, this study was conducted in an area where free ART and HIV-related treatment and care were highly available, so the level of access to care and the relationship between social support and access to care may be different in other areas. A final limitation of this study lies in the cross-sectional design that does not allow causal inferences to be made between social support and access to care.

In conclusion, the study draws attention to emotional support and its relationship with older PLH's access to care. A combination approach involving multiple parties, such as families, social networks, and healthcare providers, is suggested to provide emotional support and to empower older PLH to achieve better access to care.

Conflict of interest

All authors have no conflict declared.

Key points

- A cross-sectional survey was conducted with older PLH to determine the availability of emotional and tangible social support and the relationship with the participants' perception of access to care.
- It was found that access to care was significantly associated with emotional social support, but not tangible social support.
- The findings suggest that providing emotional support is important to enhance access to care for older PLH.

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