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## Quality of life in HIV-infected Chinese women and their family caregivers: an intervention study

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### ABSTRACT

China is experiencing a rapid increase in the number of HIV-infected women. In this study, we describe the development and preliminary evaluation of an intervention tailored for Chinese HIV-infected women and caregivers to improve their self- and family management, with goals of enhancing their physical quality of life (QOL) and decreasing their depressive symptomatology. Forty-one HIV-infected women and their caregivers were recruited from two premier Chinese hospitals from July 2014 through March 2016. Participants were randomized to either the control or intervention arm for the Self- and Family Management Intervention (SAFMI). Each study dyad in the intervention arm received three counseling sessions with a nurse interventionist. At baseline, immediate post-intervention (month 1) and follow-up (month 3), the participants were assessed by a self-reported survey. Generalized Hierarchical Linear Modeling was used to evaluate the efficacy of the intervention. Chinese HIV-infected women in the intervention arm had significantly higher probability of higher physical QOL at month 1 and lower probability of clinically meaningful depressive symptomatology at month 3 compared with women in the control arm. In contrast, the effects of the intervention were less salient for caregivers. This study represents one of the first in China to include family caregivers in HIV management. Feasibility and acceptability were high, in that family members were willing to join the study, learn about HIV, and practice new skills to support the HIV-infected women in their lives. A larger trial is needed to fully evaluate this intervention which shows promising preliminary effects in promoting physical QOL and decreasing depressive symptomatology among Chinese HIV-infected women.

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### KEYWORDS

HIV; China; self- and family management; QOL; depression; women

## Introduction

An estimated 780,000 people are infected with HIV in China (Reuters, 2012). Of these, 180,000 are women between 16 and 45 years of age (WHO, UNAIDS, & UNICEF, 2010), and the gap between the rate of HIV infection in men compared with women is narrowing (Post, 2012). Women living with HIV/AIDS in particular, struggle to manage a variety of daily tasks required to cope with the disease (Jones et al., 2010). Behavioral interventions, such as self- and family management, may be effective in assisting the HIV-infected to better manage their HIV/AIDS. While self-management is defined as the process that an individual uses in conscious attempts to gain control of his or her disease (Richard & Shea, 2011), family management is defined as the role(s) that designated family member(s)

undertake in order to meet the care needs of a patient (Grey, Knafl, & McCorkle, 2006). Self-management has been found to be effective in improving health outcomes, reducing mortality and disability, and improving quality of life (QOL) among patients with other health conditions (Richard & Shea, 2011).

A critical component of self-management is seeking social support, a behavior strongly influenced by the Chinese cultural context. A recent study has shown that HIV-infected Chinese women tend to disclose their status within a short period of time after diagnosis, especially to their spouse or partner (Mao et al., 2018). In addition, in China, HIV-infected females demonstrate higher internalized stigma than males (Li, Lin, & Ji, 2017), perhaps reflecting that within a male-dominated society, women have less power than their male

counterparts who are also infected with HIV. Indeed, married women who work outside of their hometown had lower levels of social support (Ma et al., 2015). In addition, relationships with spouses, family average income, number of children, education, engagement with healthcare have been shown to influence the ability of HIV-infected Chinese individuals to obtain social support (Lin, Li, Ji, & Jie, 2015).

There have been numerous attempts to address self-management among individuals with HIV, but most have been group-based interventions conducted in the United States before the antiretroviral therapy (ART) era (Kelly et al., 1993). Recent attempts have focused on coping strategies or risk reduction among gay men (Chesney, Chambers, Taylor, Johnson, & Folkman, 2003), older adults with HIV (Heckman et al., 2006), and women with a history of sexual trauma (Sikkema et al., 2007). However none of them exclusively focused on women living with HIV/AIDS, let alone HIV-infected women in China.

For HIV-infected women in patriarchal cultures where women have lower social status (Huang et al., 2015), managing HIV/AIDS can be even more challenging, as they often must take the role of primary caregiver fulfilling the responsibility of caretaking both in nuclear and extended families. The culturally specific concerns for Chinese women living with HIV often surround family relationships and duties, including HIV stigma and serostatus disclosure, medication access, medication adherence, and continuation of fulfillment of family obligations, such as household chores (Jones et al., 2010). Therefore, to improve the effectiveness of the care delivered to Chinese HIV-infected women, it is critical to include in the care these contextual factors, in particular family relationships (Eller et al., 2010). A recent study has shown, with effective family intervention provided to HIV-infected individuals, both care burden and depressive symptoms were decreased in family caregivers and the HIV-infected individuals in China (Li et al., 2017). Empowering HIV-affected families appears to be an effective method to reduce mental distress and enhance family support.

In the present study, we describe the development and preliminary evaluation of a theory-informed self- and family management intervention (SAFMI) for promoting physical QOL and decreasing depressive symptomatology among Chinese HIV-infected women. In China, nurses have traditionally been the first line of assisting and educating HIV-infected women to perform self-management. By working with the women's family members, nurses can incorporate the individual's needs into a program of family support.

## Methods

### Participants

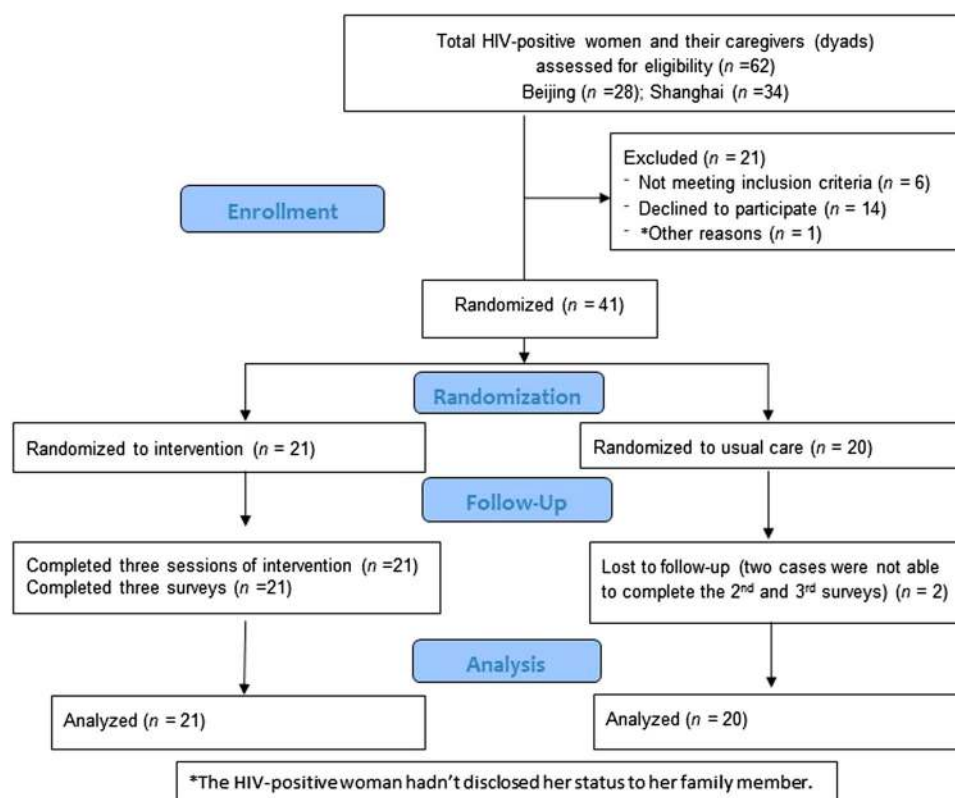
Forty-one HIV-infected women were recruited from Beijing Ditan Hospital and Shanghai Public Health Clinic Center (SPHCC) from July 2014 through March 2016. The inclusion criteria were (a) over 18 years of age, (b) confirmed HIV seropositive, (c) had disclosed their HIV status to at least one family member, (d) were able to bring a family member of their choice who had been told about their HIV status to attend three intervention sessions and (e) able to read and write Chinese. Cognitively impaired or actively psychotic individuals were excluded. Referrals came from the healthcare providers at Ditan Hospital or SPHCC. See Figure 1 for the recruitment flow chart.

### Procedures

Ethics review boards at institutions involved approved study procedures. Study staff at each site described the trial 62 HIV-positive women who recently visited the clinics 41 of them were recruited and provided written consent to participate. Fourteen of the potential study participants declined to participate, citing the following reasons: hesitation with opening up again due to their previously negative experiences with disclosure ( $n = 5$ ), family caregivers did not have time to participate in three sessions ( $n = 2$ ), spouses did not want them to participate ( $n = 3$ ), they lived in other provinces ( $n = 3$ ), and one woman was going through a divorce ( $n = 1$ ).

At the baseline appointment, participants were randomized to either the control or intervention arm using a computer-randomized number in recruitment sequence. Each study dyad in the intervention arm had three counseling sessions (60–90 minutes each) with a nurse interventionist over 4 weeks. Session times were coordinated with patients' clinic visits to reduce participant burden. Participants assigned to the control arm received no further intervention beyond the usual care at the clinic and all participants continued to receive medical care as usual. To ensure the retention of study participants, they were sent a text message reminder two days before and a phone call one day before their intervention appointment.

For this project, the US study team trained two Chinese teams separately at Ditan Hospital and SPHCC. Trainings were conducted over one intensive week, and included interventionists roleplaying delivering the intervention while integrating feedback until the trainer determined sufficient fidelity to the study protocol was achieved.



**Figure 1.** Study flow.

Interventionists were supervised at least weekly via online video and instant text messaging with selected sessions observed online by study investigators to ensure fidelity to the protocol. The interventionists also completed a content checklist and a progress note after each session, which were reviewed by investigators immediately following completion.

At baseline (pre-randomization), immediate post-intervention (month 1) and follow-up (month 3), the dyads were given an approximately 1-hour long ACASI assessment survey to complete at their own pace. Participants in both arms were reimbursed 150 RMB (~\$25) for completing each study session, a fee typical for research participation at the site and one that was not perceived as coercive. For control participants, each study session involved only the assessment survey, whereas intervention participants completed the assessment and a counseling session.

### **Self- and family management intervention**

SAFMI was designed and adapted conceptually using Gray's self- and family management theoretical framework (Grey et al., 2006). Our intervention components drew from Inouye and colleagues' (2011) model for self-management and were adapted for a Chinese cultural context based on qualitative interviews with HIV-

infected parents, community advisory board members, and HIV care providers (Chen, Lee, et al., 2013; Wang et al., 2016).

SAFMI consisted of five elements: biofeedback for relaxation; family support; anxiety, stress, and depression management; cognitive-behavioral management skills; and psycho-education. The primary desired outcome for intervention participants was to improve their physical QOL and decrease depressive symptomatology.

The intervention involved three sessions. In Session 1, HIV-infected women shared their diagnosis and disclosure stories. The interventionist then assessed strengths and challenges in the dyad's relationship. The interventionist assisted the dyad to prioritize their current issues, engaging both members in a discussion of the facilitators and barriers of self and family management. Based on the assessment of self-management functioning, the interventionist provided anxiety, stress, and depression management skills and discussed biofeedback relaxation techniques. Dyads were asked to practice spending time together and having intentional conversations about self- and family management as a homework assignment.

In Session 2, the interventionist provided psycho-education to assist the dyad to reprioritize their concerns based on the results of the homework assignment. The interventionist helped the dyad consolidate their goals for intervention, discuss pros and cons of alternative

goals, and plan strategies for achieving goals including practice and role-play of possible steps and required behavioral skills for handling possible reactions from other people. For homework, dyads were encouraged to carry out their plans for the immediate future.

In Session 3, nurses reviewed progress in dyads' goals, and troubleshooted reported barriers to carrying out plans. Before wrapping-up the intervention, the interventionist also invited dyads to express further concerns and helped them revise goals and plans for the future.

### Outcome measures

Three waves of surveys were collected at baseline, month 1 and month 3 to assess the preliminary efficacy of the intervention.

### Demographics

Data on participants' ethnicity, age, gender, marital/partner status, income, education level, residency, CD4 count, viral load, and employment status were collected.

### Veterans Short Form (VSF)-12

QOL was assessed using the physical domain of the VSF-12 examining the dyad's physical conditions and whether they could participate in activities as they wished. This 12-item health survey has been used in Chinese populations with sufficient validity and reliability (Chen, Wantland, et al., 2013). We dichotomized scores using the median split method (higher than 50% vs. lower than 50% physical stability) due to an outlier, as our sample size was small and would be highly sensitive to outliers (DeCoster, Iselin, & Gallucci, 2009).

### Center for Epidemiologic Studies Depression Scale (CES-D)

The CES-D has been widely utilized for screening severe depressive symptomatology for further clinical attention. We summed up CES-D items and dichotomized scores using the clinically meaningful cutoff point of 16, because we aimed to align our results with decision flows in regular clinical practice and model probabilities for Chinese HIV-infected women to screen positive for clinically meaningful depressive symptomatology.

### Data analysis

Univariate statistics were used to investigate distributions of key characteristics of the study sample. Bivariate statistics were used to investigate quality of randomization. The Generalized Hierarchical Linear Model was used to model the changes in the outcomes by intervention status and participant types while

appropriately handling the nested structure arising from longitudinal dyadic data. Because both outcomes were binary variables following binomial distributions, we used logit link and set the covariance structure as "unstructured". We further used the cluster-robust estimator to compute standard errors as the sample came from two study sites. A three-way interaction term among time (baseline, month 1 and month 3), intervention status (Treatment as usual (TAU) and Intervention arms), and participant type (women and caregivers) was entered into the model to not only simultaneously estimate the treatment effects for both HIV-infected women and their caregivers, but also capture the average treatment effects with intent-to-treat. In this way, the estimated treatment effects were net off their baseline values. We also included study site and education to further adjust the estimations. Finally, we calculated the model-adjusted probabilities of the outcomes by intervention status and participant type across time, and used Wald tests to conduct post-hoc cross-sectional comparisons between two intervention arms.

## Findings

### Intervention outcomes

As seen in Table 1, descriptive analyses of the outcome indicators were similar between women and their caregivers at baseline (non-significant at  $p \geq .10$ ), suggesting that these two arms were randomly assigned. The combined study group participants' average age was 42 years and caregivers' average age was 41 years, with no significant difference between groups. For caregivers, 78% ( $n = 32$ ) were male, most were married (68%;  $n = 28$ ), about half (51%;  $n = 21$ ) were the women's partners. More than half (54%;  $n = 22$ ) of the caregivers were also HIV-infected individuals. Almost all of them had been diagnosed with HIV over five years ago. Most of the participants and HIV-infected family caregivers were on ART, with a mean CD4 count from 385 to 527 cells/mm<sup>3</sup>.

As shown in Table 2, the treatment effects reached a .05 significance level for HIV-infected women at one time-point for both outcomes. Specifically, women who received the intervention had odds of higher physical QOL at month 1 (adjusted OR = 7.43,  $SE = 2.83$ ,  $p < 0.01$ ) and lower odds of clinically meaningful depressive symptomatology the scores at month 3 (adjusted OR = 0.20,  $SE = 0.07$ ,  $p < .01$ ) as compared with women in the TAU group after controlling for their respective baseline values. These estimated coefficients were considered to have moderate to large effect sizes (Chen, Cohen, & Chen, 2010). Cross-sectionally, compared with women in TAU group, women receiving the intervention also

**Table 1.** Background characteristics of the study sample by condition.

N	Participant			p	Caregiver			p
	Total 41	Intervention 20	Control 21		Total 41	Intervention 20	Control 21	
<i>Demographic background</i>								
Age, mean (SD)	41.88 (10.61)	40.55 (11.18)	43.14 (10.15)	.44	40.68 (14.22)	40.05 (14.22)	41.29 (14.58)	.78
Sex (%)				–				.77
Female	100	100	100		21.95	20	23.81	
Male	0	0	0		78.05	80	76.19	
Ethnicity (%)				.95				.52
Han	85.37	85	85.71		92.68	90	95.24	
Others	14.63	15	14.29		7.32	10	4.76	
Marital status (%)				.66				.41
Married	68.29	65	71.43		75.61	70	80.95	
Others	31.71	35	28.57		24.39	30	19.05	
Relationship with caregiver (%)				–				.44
Partner	–	–	–		51.22	45	57.14	
Non-partner	–	–	–		48.78	55	42.86	
Education (%)				.65				.05*
HS or lower	78.05	75	80.95		78.05	65	90.48	
More than HS	21.95	25	19.05		21.95	35	9.52	
Work (%)				.88				.09†
No	51.22	50	52.38		53.66	40	66.67	
Any	48.78	50	47.62		46.34	60	33.33	
Income (%)				.64				.90
Insufficient	48.78	45	52.38		39.02	40	38.1	
Sufficient	51.22	55	47.62		60.98	60	61.9	
Health insurance (%)				.66				.37
No coverage	36.59	40	33.33		31.71	25	38.1	
Any coverage	63.41	60	66.67		68.29	75	61.9	
Children (%)				.80				.37
No	26.83	25	28.57		31.71	25	38.1	
Any	73.17	75	71.43		68.29	75	61.9	
<i>Clinical factors</i>								
HIV status (%)				–				.65
Positive	100	100	100		53.66	50	57.14	
Negative	0	0	0		46.34	50	42.86	
HIV year, mean (SD)	6 (4.66)	5.16 (4.62)	6.76 (4.68)	.28	6.45 (4.74) <sup>a</sup>	6.3 (6.24) <sup>a</sup>	6.58 (3.32) <sup>a</sup>	.89
AIDS diagnosis (%)				.13				.08†
No	75.61	85	66.67		92.68 <sup>a</sup>	100 <sup>a</sup>	85.71 <sup>a</sup>	
Yes	21.95	10	33.33		7.3 <sup>a</sup>	0 <sup>a</sup>	14.29 <sup>a</sup>	
Unknown	2.44	5	0		0 <sup>a</sup>	0 <sup>a</sup>	0 <sup>a</sup>	
HIV medications (%)				.89				.19
Currently on	85	84.21	85.71		81.82 <sup>a</sup>	70 <sup>a</sup>	91.67 <sup>a</sup>	
Not currently on	15	15.79	14.29		18.18 <sup>a</sup>	30 <sup>a</sup>	8.33 <sup>a</sup>	
CD4, mean (SD)	449.74 (209.77)	432.72 (239.79)	464.33 (185.05)	.65	450 (256.05)	527.1 (303.36)	385.75 (199.89)	.20
Viral load (%)				.65				.13
Undetectable	55	47.37	61.9		53.85 <sup>a</sup>	35.71 <sup>a</sup>	75 <sup>a</sup>	
Detectable	17.5	21.05	14.29		11.54 <sup>a</sup>	14.29 <sup>a</sup>	8.33 <sup>a</sup>	
Unknown	27.5	31.58	23.81		34.62 <sup>a</sup>	50 <sup>a</sup>	16.67 <sup>a</sup>	

<sup>a</sup>Estimations were calculated among HIV+ caregivers; † $p \leq .01$ ; \* $p \leq .05$ .

had a higher probability of higher physical QOL at month 1 (65.6% vs. 37.4%,  $\chi^2_{(1)} = 10.6$ ,  $p < .01$ ) and lower probability of clinically meaningful depressive symptomatology at month 3 (32.2% vs. 52.1%,  $\chi^2_{(1)} = 6.51$ ,  $p = .01$ ).

In contrast, the treatment effects were less salient among caregivers. The interaction term did not reach a 0.05 significant level across time-points for both outcomes. However, in cross-sectional evaluations, caregivers in the intervention arm had a higher probability of higher physical QOL at month 1 (54.4% vs. 41.5%,  $\chi^2_{(1)} = 59.6$ ,  $p < .01$ ) and lower probability of clinically meaningful depressive symptomatology at month 3 (9.9% vs. 24.7%,  $\chi^2_{(1)} = 19.52$ ,  $p < .01$ ).

Figures 2 and 3 present the differences between the study arms on probabilities of higher physical QOL and clinically meaningful CES-D scores respectively over the study period.

## Discussion

In this study, we described the development and preliminary testing of a culturally tailored self- and family management intervention for Chinese HIV-infected women. SAFMI has demonstrated preliminary efficacy in improving physical QOL of study participants, in particular for women living with HIV. This implies that these Chinese HIV-infected women may experience

**Table 2.** Evaluation of preliminary efficacy of the intervention using bivariate analysis and generalized hierarchical linear models.

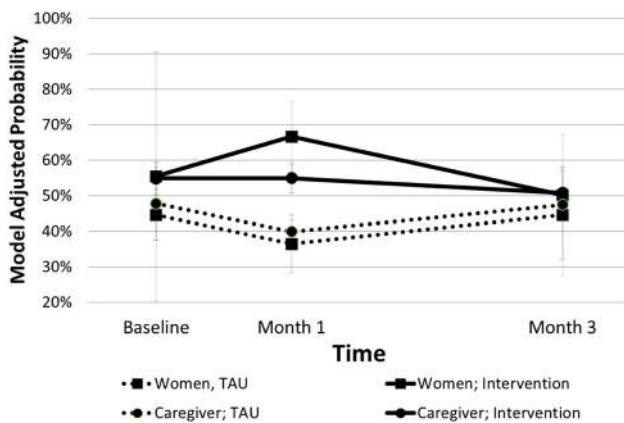
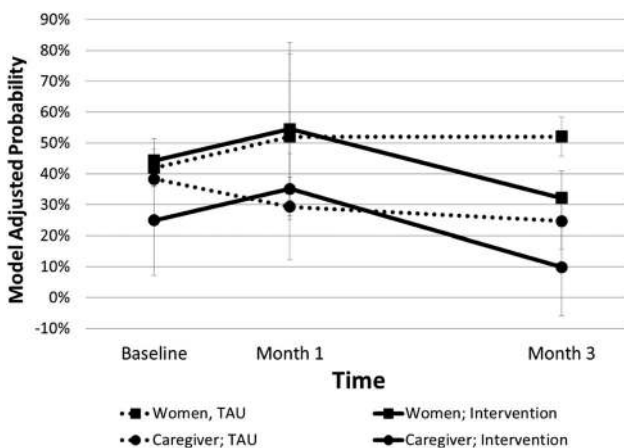
	Bivariate analysis results		GHLM adjusted results					
	TAU	Intervention	TAU <sup>a</sup>		Intervention <sup>a</sup>		Treatment effects <sup>b</sup>	
	%	%	%	(SE)	%	(SE)	OR	(SE)
HIV-Infected women								
<i>Physical QOL</i>								
Baseline	47.6	55.0	45.0	(2.6)	55.0	(16.5)	–	–
Month 1	38.1	65.0	37.4	(5.7)	65.6**	(7.4)	7.42**	(2.83)
Month 3	47.6	52.6	45.1	(6.6)	50.0	(0.5)	0.54	(0.31)
<i>CES-D</i>								
Baseline	42.9	45.0	42.0	(3.1)	44.3	(3.6)	–	–
Month 1	52.4	55.0	52.1	(14.0)	54.5	(14.4)	0.99	(1.44)
Month 3	52.4	31.6	52.1	(3.2)	32.2**	(4.5)	0.20**	(0.07)
Family caregivers								
<i>Physical QOL</i>								
Baseline	47.6	55.0	48.3	(3.6)	54.3	(1.2)	–	–
Month 1	42.9	55.0	41.5	(4.0)	54.4**	(1.0)	1.85	(0.76)
Month 3	47.6	50.0	48.0	(9.4)	50.9	(3.4)	0.73	(0.88)
<i>CES-D</i>								
Baseline	38.1	25.0	38.4	(1.3)	24.9	(9.1)	–	–
Month 1	28.6	35.0	29.4	(8.8)	35.1	(1.9)	5.11	(8.21)
Month 3	23.8	11.1	24.7	(4.7)	9.9**	(8.0)	0.54	(1.00)

TAU, Treat as usual; QOL, Quality of life; CES-D, Center for Epidemiologic Studies Depression.

<sup>a</sup>The estimated proportions for TAU and Intervention arm derived from marginalization of the fitted GHLM model. The significance tests for the ad-hoc comparisons are Wald-tests.

<sup>b</sup>The treatment-effects were the interaction term between intervention status and time.

\* $p < .05$ ; \*\* $p < .01$ .

**Figure 2.** Model-adjusted probabilities of higher physical QOL by intervention condition and participant role.**Figure 3.** Model-adjusted probabilities of clinically significant CES-D scores by intervention condition and participant role.

greater functioning in their daily lives and higher capacity to fulfill their social roles. However, the intervention effects appeared to decrease three months later, when their physical QOL was similar to those in the control group. This may be because during the intervention sessions, their caregivers were encouraged to provide family management, including offering assistance for simple household chores and providing help in taking care of children while the HIV-infected women sought quiet time or visited doctors about their ailments. However, as the intervention only lasted for one month, behavioral changes in caregivers may not have become new established routines yet, and after termination of the study, the additional assistance from these caregivers may have become unavailable again.

Among our sample, we observed that about 40% of the Chinese HIV-infected women live with clinically meaningful depressive symptomatology. We found that during the first month, women in both study arms increased in their probability of reporting clinically meaningful depressive symptomatology compared to baseline. This may be due to a previously observed phenomenon that many Asian women tend to keep their mental discomfort to themselves and rarely talk about the issues with their family members (Wang et al., 2016; Zhou & Hearst, 2016), thus the intervention may be one of their first opportunities to openly discuss their psychological difficulties. However, after the intervention, the probability of clinically meaningful depressive symptomatology decreased for women in the intervention arm while it remained consistent for the



women in the TAU group. This may be due to the nurse interventionists discussing coping strategies and positive thinking with participants and offering possible solutions to the problem of how to cope with daily tasks.

In contrast, the intervention did not have as salient effects for caregivers as for the HIV-infected women, in particular regarding improving their physical QOL. This may be due to the fact that the intervention primarily focused on the women. Importantly however, this also implies that our intervention, despite the fact that we encouraged caregivers to share more caregiving tasks with the HIV-infected women, women's physical QOL did not improve at the expense of their caregivers' health.

In this study, we learned that HIV-infected women face a range of difficulties. For example, in male-dominated society, the final decision of whether to join a research study rested with their husbands for some of the potential study participants. Empowerment for women, especially HIV-infected women, may be a useful target for reinforcement. In addition, this was a pilot study, in which we only recruit 20 HIV-infected women and their family members from each site. Therefore, interventionists contacted the women who had recent visits to the clinics first. In addition, three sessions of the intervention appear to be acceptable for the HIV-infected women as the dyads tried their best to complete all three sessions.

### Limitations

There are several limitations to this study. First, as this study aimed to develop a culturally tailored intervention for dyads of Chinese HIV-infected women and their caregivers, the study was not designed to have a large sample size that offered sufficient power. Indeed, the GEE approach we utilized, despite being considered well-suited for the data structure arising from our dyadic, longitudinal study design, requires greater sample size to have sufficient power. Therefore, with the 41 study dyads, the results of the efficacy evaluation were conservative and preliminary in nature. However, as HIV-infected Chinese women belong to a very difficult-to-reach population, this study has demonstrated that it is feasible to culturally adapt a behavioral intervention to better serve this hidden and vulnerable subpopulation living with HIV. In addition, the nurse interventionists at study sites had varying amounts of experience in communication skills required for the success of behavioral interventions. There may have been some site-based differences reflected in the study data. Despite this, we found that nurses at both sites were interested in the on-site continuous education for counseling and were willing to assume the role of interventionist. Nurses in

China, with additional training and supervision, are well positioned to address the psychological needs of their HIV-infected patients. It may be promising for future studies to further test the efficacy and effectiveness of the intervention with larger samples.

### Conclusion

This study is one of the first in China to include family caregivers within HIV care. Family members were willing to join the intervention and learn about the disease and how to cope with it. Future intervention work should consider the possible advantages of involving current caregivers more systematically as part of self- and family management. If the results from future studies with greater sample sizes continue to support the intervention, future work on the best methods for dissemination will be justified. Those methods might include training nurses in infectious diseases to discuss self- and family management strategies or train-the-trainer models, as well as other computer-based programs, allowing the greatest possible access for HIV-infected women in need.

### Disclosure statement

No potential conflict of interest was reported by the authors.

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