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# Unmet needs of symptom management and associated factors among the HIV-positive population in Shanghai, China: A cross-sectional study



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## ABSTRACT

**Background:** People living with HIV/AIDS (PLWHA) are a vulnerable group who experience multiple physiological and psychological symptoms. A better understanding of unmet symptom management needs will allow researchers to design interventions that are more reflective of deficits in care and more effective at improving patient care. Few studies have focused on unmet needs for symptom management in PLWHA particularly in China. Factors influencing Chinese PLWHA symptom management needs are rarely discussed.

**Aim:** The purpose of this study was to investigate the unmet needs for symptom management of PLWHA and how their symptom burden, HIV perceived stigma, and self-management capacity contributes to HIV-related self-management practices in Shanghai, China.

**Design:** Study participants were recruited from the outpatient and inpatient HIV/AIDS wards in an infectious hospital in Shanghai, China. Self-administered questionnaires were implemented and medical charts were reviewed.

**Results:** A total of 367 participants was recruited from April to September 2017. The results show that 53.1% (195 of 367) of participants presented at least one unmet symptom management need and that symptom burden, as well as perceived stigma, reduced self-management capacity, and no employment significantly affected unmet symptom management needs.

**Conclusion:** The findings indicate that there is room for improvement in symptom management for Chinese PLWHA. Culturally appropriate interventions focusing on improving symptom burden, decreasing HIV perceived stigma, and enhancing self-management capacity can enhance symptom management in this population.

## 1. Introduction

HIV is a significant health issue in China (Lo, 2018). According to the China CDC, the total number of people living with HIV/AIDS (PLWHA) was 849,602 as of September 2018 (China CDC, 2018). Current reports of the HIV epidemic in Shanghai, China estimate that approximately 29,463 people were infected with HIV at the end of November 2018 (Shanghai Municipal Health Commission, 2018). HIV-related expenses are costly from both an economic and human suffering standpoint (Liu et al., 2018).

## 2. Background

A symptom is defined as an objective perception of a physical,

psychological, or social condition that may indicate a condition of disease (Hegyvary, 1991). For PLWHA, antiretroviral therapy (ART) has changed HIV to a chronic and manageable disease (Martinez et al., 2012). However, compared to other chronic illnesses (e.g., diabetes or hypertension), PLWHA are still a vulnerable group who experience multiple physiological and psychological symptoms resulting from the disease itself, from side effects of ART, and from other medications related to comorbidities (Lalanne et al., 2015; Roman & Chou, 2011).

Studies found that many PLWHA (30%) presented with high symptom burden, with seven or more symptoms at the same time being common (Wilson et al., 2016). Fatigue, fever, headache, nausea/vomiting, diarrhea, weight loss, pruritus/itching, chills, rash, sweat, dyspnea, cough, muscle pain/joint pain, numbness/pain in feet, and poor sleep were among the most prevalent and distressing physical

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symptoms for PLWHA (McGowan et al., 2014; Peltzer, 2013; Wakeham et al., 2010; Wilson et al., 2016). In addition, PLWHA also deal with burden related to psychosocial problems. Studies have shown that sleep disturbances and fatigue were one of the major unpleasant symptoms among Chinese PLWHA (Chen et al., 2013; Zhu et al., 2019). Further, Chinese PLWHA often face mental health crises after receiving their HIV diagnosis (Chen et al., 2011).

Fear, anxiety, sadness, and depression are common problems among PLWHA, and some of these symptoms are more prominent in the later stages of illness (Chu & Selwyn, 2011). Not surprisingly, the prevalence of depression was 46.5% among HIV-positive men who have sex with men (MSM) in Shanghai, China (Pan et al., 2017). Worrying about their health condition was one of the major symptoms PLWHA associated with depression, followed by feeling unhopeful about the future (Liu et al., 2018).

Untreated symptoms are likely to impact activities of daily living and can lead to poor quality of life and nonadherence to HIV regimens (Baran et al., 2014; Gay et al., 2011). Therefore, effective symptom management is essential for HIV-positive individuals to maintain their quality of life (Holzemer, 2002; Tsai, Hsiung, & Holzemer, 2002). A recent meta-analysis identified that self-management of pain and symptoms (such as fatigue, headache, etc.) in PLWHA is still under development (Nkhoma et al., 2018), which implies that PLWHA have a high need for effective self-management interventions.

Many symptom management interventions offered by healthcare providers (HCPs) might not be the need of PLWHA (Simpson et al., 2013). Therefore, self-report is the "gold standard" for understanding the symptom experience in PLWHA (Simpson et al., 2013; Walling et al., 2016). Thus, HCPs can solve the unpleasant symptoms on site after interviewed with PLWHA.

Unmet needs are defined as the differences between those services judged necessary and those services actually being received (Carr & Wolfe, 1976). Unmet need for symptom management is defined as the descriptions given by patients who have unmet needs in the current management of symptoms (Hwang et al., 2004). Measurement of patient-reported unmet needs for symptom management will reflecting the deficits in HIV care (Snyder et al., 2010; Walling et al., 2016). Thus, the level of unmet needs reported is an important indicator of whether inconsistencies exist between patients' needs and HCP' perceptions of the level of care they are providing.

The morbidities and distress resulting from HIV-related symptoms can lead to unmet needs across a range of domains. Current studies focus on the need for symptom management in the HIV-positive population; however, they do not specifically discuss the unmet symptom management needs of PLWHA (Chen et al., 2013; Fu, 2014; Shadloo et al., 2018). Studies have focused on descriptions of unmet symptom management needs in cancer (Walling et al., 2016) and end-of-life care (Khandelwal et al., 2017). One study found that psychiatric disorders were found in 50.2% for PLWHA in Iran and only 22% had received minimally adequate treatment (Shadloo et al., 2018). In China, one study has shown that the major needs of symptom management were rash, shortness of breath, and blurred vision (Fu, 2014). Chen, Shiu, et al. (2013) have also reported that Chinese HIV-positive individuals experienced digestive discomfort, skin rashes, numbness, memory loss, nightmares, and dizziness, along with depressive mood.

An understanding of the prevalence and presence of symptoms is important to guide and design an effective symptom management in PLWHA. Therefore, in this paper, we investigate the prevalence and potential factors of Chinese PLWHA self-perceived unmet needs and their current HIV-related symptoms.

### 3. Theoretical framework

Based on the HIV-related self- and family management theoretical framework (Wang, Chen, et al., 2016), we revised the model to more closely fit the current study (see Fig. 1). This framework highlights the

facilitators of and barriers to the PLWHA, as well as proximal and distal outcomes. We added potential HIV-related factors (e.g., HIV perceived stigma) as it was affected by unmet symptom management needs.

Symptoms and stresses vary in PLWHA. For instance, while some individuals have more issues with disclosing their HIV status, others report health access difficulties (Wang, Chen, et al., 2016). In addition, some PLWHA have sought more family and social support while living with HIV (MacCarthy et al., 2018; Wang, Chen, et al., 2016). Particularly, PLWHA have reported higher needs when the symptoms were more severe (Osse, Vernooij-Dassen, Schade, & Grol, 2007).

In the current study, we hypothesized that personal factors (self-management capability and symptom management needs), health status (symptom severity), and HIV specific factors (HIV perceived stigma) will affect proximal outcome (biological outcome and symptom management) and distal outcome (unmet symptom management needs).

## 4. Methods

### 4.1. Study site

This cross-sectional study was conducted at Shanghai Public Health Clinical Center (SPHCC) in Shanghai, China from April to September 2017. SPHCC is an infectious disease hospital focusing on treating all the infectious diseases, including severe acute respiratory syndrome (SARS), HIV/AIDS, hepatitis B and C, and other sexually transmitted diseases. Patients with comorbidities and any infectious diseases are treated in the tertiary setting (Chen et al., 2010). As such, SPHCC is one of the preeminent infectious disease hospitals in Southern China. All study procedures were reviewed and approved by the institutional review board of the School of Nursing, Fudan University.

### 4.2. Sample

Study participants were recruited from the outpatient or inpatient wards with confirmed HIV diagnosis. Eligible participants were required to be: (a) HIV diagnosed, (b) receiving care at SPHCC, (c) able to read and communicate in Chinese/Mandarin and (d) aged over 18. Patients who were unable to complete the questionnaire, had other chronic diseases (such as heart disease, diabetes, tuberculosis) or severe cognitive impairment were excluded.

### 4.3. Measurement

Symptom management was assessed using a self-administered 49-item questionnaire as the outcome measure. This measure has been widely used and adapted from a pre-established survey (Holzemer, Hudson, Kirksey, Hamilton, & Bakken, 2001; Justice et al., 2001). Symptoms that were highly related to HIV (e.g., fatigue, fever, rash, diarrhea, and depression) were included in the questionnaire. Patients indicate for the previous four weeks what symptoms were present along with the symptom severity. If a symptom was present, then participants rate the degree of the need for symptom management (0 = No demand, 1 = Weak demand, 2 = Moderate demand, 3 = Strong demand). They then answer a follow-up question on whether their needs have been met (Yes/No/Not asked). Sample questions are: During the last 4 weeks, did you need help from HCPs to relieve your symptom of rash? If the answer is yes, then, the follow-up question is: During last 4 weeks, did you get the help from the HCP that you asked for? Patients who responded no to the latter question are identified as having an unmet need for that symptom (score = 1). The scores of the total unmet needs for symptom management range from 0 to 49, with higher scores indicating more unmet needs. The instrument has been shown to have good expert validity with a content validity index (CVI) of 0.918 and Cronbach's alpha coefficients of the needs and unmet needs domains at 0.968 and 0.954, respectively (Zhu, Hu, Guo, & Williams, 2019).

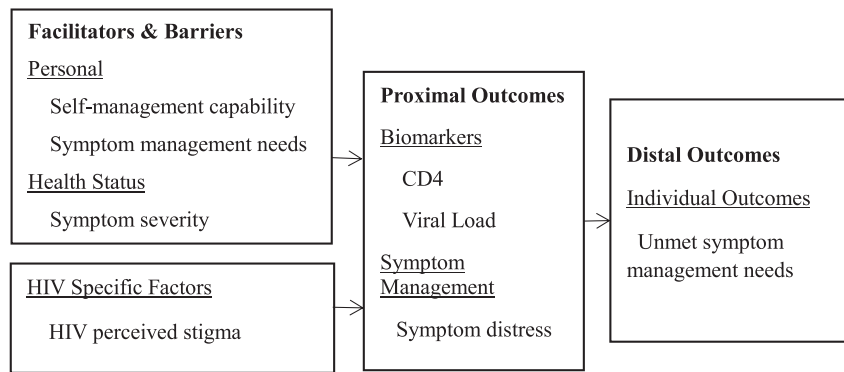


Fig. 1. The modified symptom-management framework in the HIV-positive Chinese individuals.

Symptom burden was adapted from a pre-established survey and assessed via paper-and-pencil questionnaire (Holzemer et al., 2001; Justice et al., 2001). The symptom burden questionnaire consisted of 23 somatic symptoms and 26 psychological symptoms. Patients were asked to rate each of the 49 items (a) the severity of symptoms on a scale from 0 (not at all) to 3 (very severe), and (b) how much the symptom distressed him or her on a scale from 0 (not at all) to 3 (very much) during the preceding 4 weeks. The total score was obtained by calculating a mean of the responses to all the items. Higher mean scores indicate more severe symptoms.

HIV perceived stigma was assessed using the Expanded Everyday Discrimination Scale (Williams et al., 2008), as described in a related paper (Zhu, Hu, Guo, & Williams, 2019). With the permission of the original author, we had the scale translated into Chinese by two experts on the current research team then back-translated by another two experts in English. Finally, the four experts reviewed the Chinese version and the English version for its equivalence to the original scale. The scale included 10 items and responses ranged from “almost every day” (1) to “never” (4). The score range was 10–40, with the higher score representing lower perceived stigma. The instrument showed good expert validity (CVR = 1.00), and Cronbach’s alpha coefficient was 0.91 in the present study.

Self-management capacity was assessed by a single item: What do you think of your ability to manage your own health? The answer was rated on a Likert scale ranging from very good (1) to very bad (5). The higher the score, the lower the self-management capacity.

Demographic and clinical-related variables included gender, age, marital status, education level, current employment status, time since HIV diagnosis, ART use status, latest CD4+ T-cell count, and latest viral load (see Table 1).

#### 4.4. Sample size

The sample size was determined according to the item numbers of the main scale being included in the survey. It was proposed that the sample size should range from 5 to 10 times the item numbers (Wu, 2010). Given that the main instrument symptom management for PLWHA applied in the survey contained 49 items, it was estimated that 350 participants would be enough.

#### 4.5. Data collection

Potential participants were recruited from both the inpatient and outpatient wards at SPHCC. Study participants were informed of the study to ensure that participation was voluntary. After researchers securing study consent, all participants received a copy of their signed consent form. Participants received an electronic pill dispenser and an HIV care pamphlet after they completed the survey as the appreciation. The study surveys were completed within 20 min on average.

Table 1

Participant characteristics and unmet needs for symptom management.

Variables	Classification	N (%)	Unmet needs	
			Mean (SD)	U or H (p)
Age(y) (Mean = 38.6)	18–30	102 (27.8)	3.14 (5.34)	2.167
	31–40	131 (35.7)	2.67 (5.00)	(.539)
	41–50	72 (19.6)	3.46 (5.80)	
	51–78	62 (16.9)	3.52 (5.82)	
Gender	Male	335 (91.3)	3.19 (5.51)	4941.000
	Female	32 (8.7)	2.13 (3.76)	(.439)
Marital status	Married	116 (31.6)	2.81 (4.13)	14,343.500
	Other (single, divorced, unknown)	251 (68.4)	3.23 (5.88)	(.810)
Educational level	Elementary school	25 (6.8)	3.08 (3.63)	2.528
	Middle school	55 (15.0)	3.38 (4.92)	(.470)
	High school	70 (19.1)	2.70 (5.22)	
	College or above	217 (59.1)	3.16 (5.74)	
Current employment status	Yes	163 (44.4)	2.23(3.83)	14,494.000
	No	204 (55.6)	3.79 (6.29)	(.026)*
Ward	Inpatient	198 (54.0)	3.33 (5.61)	15,284.500
	Outpatient	169 (46.0)	2.83 (5.13)	(.131)
Months HIV positive (mean = 28)	1–6	141 (38.4)	3.11 (4.66)	1.736
	7–18	57 (15.5)	3.19 (6.71)	(.629)
	19–36	59 (16.1)	3.07 (5.90)	
	37–286	110 (30.0)	3.05 (5.28)	
Taking ART	Yes	307 (83.7)	3.16 (5.54)	9009.000
	No	60 (16.3)	2.77 (4.55)	(.777)
Viral Load (copies/ml)	0–499①	126 (34.2)	2.69 (4.79)	51.959
	500 and above②	32 (8.7)	3.00 (4.82)	(.000)*
	Do not know③	77 (20.9)	5.79 (6.59)	①,② < ③,④
	Never tested④	45 (12.2)	5.69 (6.78)	
CD4 count (cells/mm <sup>3</sup> ) (Mean = 279)	0–199	128 (34.8)	2.78 (4.46)	10.339
	200–299	56 (15.2)	5.20 (8.22)	(0.070)
	300–399	40 (10.9)	2.48 (4.12)	
	400–499	30 (8.2)	2.67 (5.75)	
	500 and above	47 (12.8)	2.70 (5.03)	

\* Total N = 367, including missing data; p < .05.

#### 4.6. Data analysis

Data analysis was performed using Statistical Package for Social Sciences (SPSS), version 17.0. Means and standard deviations (SDs) were presented for continuous variables (e.g., age, symptom burden, HIV perceived stigma, self-management capability). Frequency and percentage were presented for categorical variables (e.g., gender, marital status, educational level, and unmet symptom management needs). Differences between unmet symptom management needs and demographic variables were analyzed. All assumptions for each statistical test were checked. Since those variables did not meet the

assumptions for *t*-test or ANOVA, nonparametric alternatives (Kruskal-Wallis test, Mann-Whitney test) were used.

Pearson's correlation coefficient tests were used in the analysis of the correlation between unmet symptom management needs and symptom burden, HIV perceived stigma, and self-management capability. Multiple regression analysis was used to determine the unmet symptom management needs predicting factors of PLWHA by analyzing the significant independent variables (current employment status, recent viral load, symptom burden, HIV perceived stigma, and self-management capability) with unmet symptom management needs as a dependent variable. An initial investigation was conducted to ensure the non-violation of the regression assumptions of multicollinearity, normality, linearity, and homoscedasticity. Recent viral loads were dichotomized into two categories (viral load known vs unknown). Statistical significance was set at  $p \leq .05$ .

## 5. Results

### 5.1. Characteristics of participants

A total of 450 eligible participants was contacted and 390 were recruited and completed the study. Data for 367 participants was analyzed, with an acceptance rate and validity rate of 87% and 94%, respectively. The mean age was 38.6 years and ranged from 18 to 78 years old. Most of the participants were male (91%) and had attended at least middle school or higher (34% middle or high school, 59% college or above). More than half (68%) of them were not married. The majority of participants were unemployed (56%), and from the inpatient (54%) ward. A large majority (84%) were currently taking ART. The mean of diagnosis time was 28 months, with 279 cells/mm<sup>3</sup> for the latest CD4 count. More than one-third (34%) of the participants had their most recent HIV viral load undetectable at less than 500 copies/ml blood (see Table 1). In addition, mean score of HIV perceived stigma was 33.38 (SD: 7.29) and self-management capacity was 2.81 (SD: 1.16).

### 5.2. Symptom burden

Cronbach's alpha coefficient was 0.98 in the present study. Mean score for symptom burden was 0.29 (SD: 0.40) out of a total possible score of 3. Table 2 shows the rank order of individual symptom burden. Among the individual symptoms, fatigue had the highest score for symptom severity, followed by insomnia/abnormal dreams, fever, unwanted weight loss, and decreased appetite. For symptom distress, fatigue was most distressing, followed by insomnia/abnormal dreams, fever, decreased appetite, and unwanted weight loss.

**Table 2**

Ten most severe, distress symptoms and symptom management needs reported by study participants.

Rank	Symptom burden		Symptom management needs <sup>c</sup>
	Severity (mean ± SD)	Distress (mean ± SD) <sup>c</sup>	
1	Fatigue <sup>a</sup> (0.76 ± 0.93)	Fatigue <sup>a</sup> (0.58 ± 0.94)	Fatigue <sup>a</sup> (0.93 ± 1.23)
2	Insomnia/abnormal dreams <sup>a</sup> (0.70 ± 0.96)	Insomnia/abnormal dreams <sup>a</sup> (0.57 ± 0.91)	Fever <sup>a</sup> (0.83 ± 1.15)
3	Fever <sup>a</sup> (0.69 ± 1.03)	Fever <sup>a</sup> (0.56 ± 0.97)	Insomnia/abnormal dreams <sup>a</sup> (0.81 ± 1.08)
4	Unwanted weight loss <sup>a</sup> (0.59 ± 0.99)	Decreased appetite <sup>a</sup> (0.47 ± 0.90)	Unwanted weight loss <sup>a</sup> (0.76 ± 1.20)
5	Decreased appetite <sup>a</sup> (0.57 ± 0.94)	Unwanted weight loss <sup>a</sup> (0.41 ± 0.86)	Decreased appetite <sup>a</sup> (0.72 ± 1.12)
6	Rash <sup>a</sup> (0.48 ± 0.82)	Little interest in doing things <sup>b</sup> (0.37 ± 0.77)	Blurry vision <sup>a</sup> (0.68 ± 1.12)
7	Feeling stress <sup>b</sup> (0.46 ± 0.85)	Feeling stress <sup>b</sup> (0.37 ± 0.81)	Difficulty concentrating <sup>a</sup> (0.68 ± 1.11)
8	Cough <sup>b</sup> (0.44 ± 0.81)	Feeling down <sup>b</sup> (0.37 ± 0.81)	Rash <sup>a</sup> (0.65 ± 1.04)
9	Memory loss <sup>a</sup> (0.43 ± 0.72)	Cough <sup>b</sup> (0.37 ± 0.80)	Memory loss <sup>a</sup> (0.64 ± 1.08)
10	Little interest in doing things <sup>b</sup> (0.42 ± 0.77)	Rash <sup>a</sup> (0.35 ± 0.77)	Feeling stress <sup>b</sup> (0.61 ± 1.03)

<sup>a</sup> Somatic symptoms.

<sup>b</sup> Psychological symptoms.

<sup>c</sup> Possible range: 0–3.

**Table 3**

Ten most frequently reported unmet needs for symptom management.

Rank	Item	Unmet need	
		N	% <sup>c</sup>
1	Fatigue <sup>a</sup>	54	14.7
2	Feeling stress <sup>b</sup>	42	11.4
3	Feeling down <sup>b</sup>	41	11.2
4	Insomnia/abnormal dreams <sup>a</sup>	38	10.4
5	Feeling fearful <sup>b</sup>	38	10.4
6	Little interest in doing things <sup>b</sup>	34	9.3
7	Feeling nervous <sup>b</sup>	34	9.3
8	Decreased appetite <sup>a</sup>	33	9.0
9	Self-abasement <sup>b</sup>	31	8.4
10	Muscle/joint pain <sup>a</sup>	29	7.9

<sup>a</sup> Somatic symptoms.

<sup>b</sup> Psychological symptom.

<sup>c</sup> Percentage of participants reporting each symptom.

### 5.3. Symptom management needs and unmet needs

Table 2 outlines the symptom management needs for PLWHA. In general, the ten top-scoring symptom management needs were mostly related to somatic symptoms like fatigue, fever, insomnia/abnormal dreams, unwanted weight loss, blurred vision, difficulty concentrating, rash, memory loss and diarrhea, with the exception of “feeling stress,” which was a psychological symptom. For this study, Cronbach's alpha values of the needs and unmet needs domains were 0.98 and 0.92, respectively. The mean score of total unmet symptom management needs was 3.10 (SD: 5.39, Range: 0–38). More than half (53%;  $N = 195$ ) had at least one unmet need for symptom management in the 4 weeks before the interview. Unmet needs ranged from 2.5% for hump on back of neck/shoulders to 15% for fatigue. Fatigue, feeling stress, feeling down, insomnia/abnormal dreams, and feeling fearful were among the most common symptoms to result in unmet symptom management need (Table 3).

Significant differences for unmet needs were found in current employment status (Mann-Whitney  $U = 14,494.000, p = .026$ ) and viral load (Kruskal-Wallis  $H = 51.959, p < .01$ ). Being unemployed was associated with a higher likelihood of reporting unmet needs; post hoc tests revealed that PLWHA with recent viral load undetectable or barely detectable had a lower likelihood of reporting unmet needs than those with viral load untested or “do not know.” Detailed information is presented in Table 1. Symptom burden ( $r = 0.451, p < .01$ ), HIV perceived stigma ( $r = -0.251, p < .01$ ), and self-management capacity ( $r = 0.302, p < .01$ ) were determined to be significantly associated with unmet symptom management needs.



**Table 4**  
Factors associated with unmet symptom management needs.

Predicting variables	Unstandardized coefficient $\beta$	Standardized coefficient $\beta$	t-Test	p value	Collinearity statistics		$R^2$ change	F
					Tolerance	VIF		
(Constant)	-0.041		-0.021	.983				41.545
Symptom burden	6.597	0.447	8.513	.000*	0.824	1.214	0.290	
HIV perceived stigma	-0.124	-0.156	-3.618	.002*	0.929	1.076	0.032	
Self-management capacity	0.925	0.189	3.543	.000*	0.800	1.249	0.028	
Current employment status	2.302	0.193	3.988	.000*	0.965	1.036	0.027	

R: 0.614;  $R^2$ :0.377; Adjusted  $R^2$ :0.368; VIF: Variance inflation factor.

\*  $p < .05$ .

#### 5.4. Predictors of unmet symptom management needs

The combination of the variables showed that symptom burden, HIV perceived stigma, self-management capacity, and current employment status were significant predictors of overall unmet symptom management needs of PLWHA and explained 38% of the total variance ( $F = 41.545$ ,  $p < .001$ ). Symptom burden was the most significant predictor, and separately accounted for 29% of variance among unmet symptom management needs, followed by HIV perceived stigma (3.2%), self-management capacity (2.8%), and current employment status (2.7%). Beta weights showed that more symptom burden, more HIV perceived stigma, lower self-management capacity, and being unemployed predicted higher unmet symptom management needs (see Table 4).

## 6. Discussion

This paper presents the factors influencing unmet symptom management needs in PLWHA in Shanghai, China. The overall unmet symptom management needs score (3 out of 49) indicated that PLWHA's unmet needs for symptom management were relatively low. However, the unmet needs ranged from 3% for hump on back of neck/shoulders to 15% for fatigue. These results reflect the wide variation in unmet symptom management needs for PLWHA. Also, the study participants reported a high level of symptom burden and HIV-related stigma and low level of self-management capacity. In addition, for those who are currently unemployed, they often complained of high levels of unmet symptom management needs.

In this study, more than half (53%) of PLWHA reported at least one unmet symptom management need, which was significantly higher than for other studies. In cancer cases, only 15% (791 of 5422) of them complained of one or more unmet needs require for symptom management (Walling et al., 2016). However, it is worth noting that the above comparison comes from different assessment tools used in different settings and that the healthcare services studied were focused on symptoms experienced by participants in Western countries. Contrast this with our study, which examined patients receiving HIV care in China.

In addition, this study indicated that fatigue was one the major symptoms in both frequency and severity. Fatigue is among the most prevalent and distressing of symptoms among people living with many chronic illnesses (Solano, Gomes, & Higginson, 2006), including PLWHA in China (Barroso & Voss, 2013; Fan, Luo, Sun, Yang, & Yu, 2011; Leserman, Barroso, Pence, Salahuddin, & Harmon, 2008). Furthermore, fatigue was associated with worse health status (Dacosta Dibonaventura, Gupta, Cho, & Mrus, 2012) and had a negative impact on ART adherence (Gay et al., 2011). A study conducted with 190 newly diagnosed PLWHA in two hospitals in Beijing found that 42% patients request more medical attention for fatigue (Cai, 2017). However, fatigue is often overlooked and gets less attention from HCPs (Chen, Lee, et al., 2013). All of these studies strongly suggested that HCP in China should deliver a feasible and individually tailored

intervention to combat fatigue, more rest or increasing exercise level should be considered for different individuals.

Also, in this study, the top 10 most needed items were all related to somatic symptoms, except for one related to mental health. This echoed previously observed phenomenon that many Chinese people tend to keep their mental discomfort to themselves and rarely talk about the issues with others (Chen, Shiu, et al., 2013; Wang et al., 2016; Zhou & Hearst, 2016). Also, it might because in this study, more than half (54%) of the study participants were inpatient, which means that they were in need for the physical symptoms management. Other possibilities are that many PLWHA did not seek help for psychological symptoms because mental discomforts are highly stigmatized in Chinese society; therefore, they did not seek treatment for their psychological distress (Kagee & Martin, 2010). Furthermore, HIV is highly stigmatized in China (Burki, 2011), PLWHA are hesitate to seek psychosocial support generally (Yang et al., 2015).

Currently, there are no providers on site at the Shanghai infectious disease hospital to provide mental health assessment and treatment for PLWHA. This study highlights the need for improvement of mental health treatment and care for PLWHA. Several strategies can be used to improve mental health care for PLWHA. For example, special training should be provided for HCPs (nurses, social workers) who will be working with the PLWHA in order to help them identify mental health symptoms and referred to psychologist and/or psychiatrist. Also, educate PLWHA and general population to understand mental health is one parts of the overall health.

This study showed that symptom burden was a significant predictor of unmet symptom management needs, which is similar to several other publications (Cheng, Wong, & Koh, 2016; Li, Lin, Zhou, Xu, & Xu, 2019; Lo, Yates, & Chan, 2018). In Chinese culture, patients tend to trust advice coming only from their primary physicians (Chen et al., 2010). However, physicians often do not focus on educating patients with chronic diseases in self-management techniques. Nurses were the HCPs who could and should focus on assisting the unmet symptom needs of PLWHAs to perform adequate self-management.

In a collective culture like China's, nurses should aware of the social norms and how that can enhance self-management in PLWHA (Wang, Chen, et al., 2016). In addition, there are expectation gaps between HCPs and PLWHA. Studies reported that PLWHA expectation of services and the actual experience of services can be quite different (Norberg et al., 2019). In China, studies have shown that even when physicians provide an acceptable level of care to PLWHA, PLWHA may expect more and better care in various aspects, e.g., mental health (Chen et al., 2010).

In this study, symptom burden (29%) was the strongest factor predicting unmet needs. As shown in our results (Table 2), participants reported fatigue, insomnia, fever, unwanted weight loss, and decreased appetite. These physical symptoms can lead to mental distress (Chen, Shiu, et al., 2013). Taken together, the symptom burden can increase unmet needs in symptom management. These findings suggest the urgent need to design a culturally appropriate intervention to decrease symptom burden.

In this study, HIV perceived stigma also predicted unmet symptom management needs. When some HCPs mistreated PLWHA by categorizing them as “contagious,” PLWHA were discouraged from returning to those unfriendly providers (Alexandra, Brewington, Kathryn, Hayness, & Zaller, 2017). Also, perceived stigma can discourage them from seeking healthcare services and can delay their disclosure of their HIV status to HCP and their family members (Zhang, Miege, & Zhang, 2011). Social stigma especially is a barrier to seeking healthcare in the MSM population (Pilgrim et al., 2019). Thus, intervention to decrease HIV-related stigma in the society is urgent. While HCP delivering care to PLWHA, HCP should also use motivate interview skills to decrease stigma in PLWHA. Surveys assessing personal values regarding infectious disease, and especially HIV, should be conducted by all HCPs. Understanding HCPs' attitude toward PLWHA is key to providing quality care in this population. Those providers who are not perceived as kind and caring by PLWHA should be replaced.

In this paper, we found that self-management capacity was also associated with unmet symptom management needs. Positive relationships with HCP enhance self-management capacity, leading to better ART adherence and consequently, enhanced CD4 counts and stronger immune function. As a result of improved relationships PLWHA experience fewer symptoms and may not need additional care (Chen et al., 2018). Effective self-management is considered critical to quality of life (Chen, Shi, & Li, 2013). Previous research reports that self-management interventions are effective at improving PLWHA's pain and physical symptoms (Millard et al., 2016; Nkhoma, Seymour, & Arthur, 2015). However, with multiple comorbidities, PLWHA will need more assistance in keeping up all the self-management strategies (Coventry, Fisher, Kenning, Bee, & Bower, 2014). Therefore, HCPs should pay more attention to how patients to manage their unpleasant symptoms (Wang, Chen, et al., 2016).

Finally, in this paper, current PLWHA employment status also predicted unmet symptom management needs. That said, unemployed patients were more likely to have unmet needs for self-care. One study reported a similar result, showing that not being employed was associated with HIV-related symptom burden (Peltzer, 2013). It is possible that having a job can distract PLWHA from focusing on unpleasant symptoms. Therefore, assisting stable PLWHA to participate in more social activities might distract their attention from unpleasant symptoms.

## 7. Limitations

There are several limitations in this study. First, this is a cross-sectional study, which could carry result bias. Longitudinal research is thus needed to determine causal relationships. Second, most of the study participants were male. Therefore, we cannot assume HIV-positive women experiencing the similar symptoms burden. Third, this study was conducted in a metropolitan area in China, where patients have better access to healthcare services compared to PLWHA in more resourced-limited areas. Therefore, the results should not be generalized to other geographic areas in China. Fourth, symptom burden, current employment status, self-management capacity, and HIV perceived stigma explained only 38% of the total variance in unmet symptom management needs. The unexplained variance of the unmet needs for future studies to go beyond the factors investigated in the current project. Fifth, since our study only investigated from patients point, we suggest future research to study HCP' attitude and behavior toward PLWHA's unmet symptom management needs.

## 8. Conclusion

Despite the limitations, this study presented several significant factors related to unmet needs for symptom management of PLWHA. We found that symptom burden, HIV perceived stigma, self-management capacity, and current employment status were significant

predictors of overall symptom management unmet needs. To minimize unmet symptom management needs, future interventions should focus on improving symptom burden, decreasing HIV perceived stigma, and increasing self-management capacity. The study findings highlight that PLWHA experienced more unmet psychological symptom management needs in Shanghai, China. Therefore, it is urgent to tackle the barriers that influence PLWHA's behavior toward their psychological symptom management. Besides, it is necessary to train HCPs who are working with PLWHA on identification of mental health symptoms and to refer PLWHA to mental health care providers. With better understanding of PLWHA's unmet symptom management needs, HCP can design a tailored intervention for PLWHA. In addition, considering the long-term and the chronic nature of HIV infection, further study should consider assessing other potential factors such as social support (family, HCPs).

## 9. Relevance to clinical practice

Unmet symptom management needs can negatively impact PLWHA's ability to cope and manage their illness, as well as limit their ability to access healthcare resources. It is urgent to design a culturally appropriate intervention to combat those unmet needs for symptom management.

First, HCPs should pay attention to PLWHA regarding their prevalent symptoms and encourage PLWHA to talk about how they are feeling and what they are doing now to identify mental health symptoms. Second, since nurses are at the forefront of clinical care and have the capacity to affect patients' emotional health and health behaviors, training nurses and social workers might be able to help to close the mental health treatment gap in PLWHA. Finally, self-management manuals and on-line videos should be provided to assist PLWHA find potential strategies to decrease their discomfort. Additionally, we recommend PLWHA to actively engage in social activities to help distract their attention from the unpleasant symptoms.

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## Declaration of competing interest

The authors have no conflict of interest to declare.

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