Is antiretroviral medication adherence associated with self-compassion and HIV-related stigma among people living with HIV in Shanghai, China?

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Declaration

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Abstract

Anti-retroviral medication (ARV) adherence plays an important role in successful treatment outcome and preventing further transmission. However, stigma is recognized as an obstacle to achieve optimal ARV medication adherence. Previous studies suggest that self-compassion may play a role in self-regulation of health promotion, which may improve medication adherence. Also, self-compassion may be a protective factor in coping with stigma. The objectives of this study were 1) to examine the association between demographic characteristics and ARV medication adherence; 2) to examine the association between self-compassion and ARV medication adherence; 3) to examine the association between stigma and ARV medication adherence; 4) to examine whether self-compassion modifies the association between stigma and ARV medication adherence. A cross-sectional survey with 107 participants in Shanghai, China was used in this secondary data analysis, within which 88 participants reported currently being on ARV medication. Logistic regression was used to test the association between medication adherence and independent variables: demographic characteristics, stigma and self-compassion. Bivariate correlation between self-compassion and stigma was also examined. To examine interaction, the analysis of the association between stigma and adherence was stratified by self-compassion. Participants who reported higher level of education, having health insurance, full time employment and enough income tended to be more adherent to medication. Categorical general perceived stigma was positively associated with adherence. Self-compassion was not significantly related to medication adherence, but sensitivity analysis showed that if two outliers were excluded, self-compassion was associated with medication adherence (AOR 1.10, 95% CI 1.00-1.21). Negative correlations were found between self-compassion and general perceived

stigma and between self-compassion and stigma subscales. However, no significant interaction

was detected for self-compassion to modify the association between stigma and adherence.

Background

HIV/AIDS has been transformed from a fatal disease to a chronic one with the coming and wide spread access to antiretroviral (ARV) medication. However, optimal medication adherence is needed to achieve successful viral suppression and immune restoration. Meanwhile, HIV-related stigma is not only associated with poor mental health but also commonly cited as a barrier for people living with HIV (PLWH) to practice optimal adherence. Self-compassion, on the one hand, may improve compliance to medical recommendations through enhancing self-regulation; on the other hand, could buffer negative feelings and protect psychological functioning, which has an implication to counter negative effects of stigma.

With the coming of ARV medication, morbidity and mortality of HIV infection has decreased largely (Palella et al., 1998). A cohort analysis of life expectancy change from 2000 to 2007 in the United States of America (the USA) and Canada suggested that the life expectancy of a twenty-year-old HIV-infected person on ARV medication was approaching that of the general population (Samji et al., 2013). However, to benefit the most from treatment, medication adherence is important. Medication adherence is defined as "taking prescribed medications on-time with correct dosage, and following corresponding restrictions in diet and lifestyles" (Osterberg and Blaschke, 2005; WHO, 2003). The purpose of adherence to medication is to keep the ARV concentration in the blood at a steady level that can suppress viral replication, as well as restore, maintain and enhance immune function, through which the disease progress is halted and HIV-related illness and death are prevented. While optimal adherence has been linked with better physical function, general health, social functioning and mental health (Wang et al., 2009), sub-optimal adherence may increase the risk of treatment failure (The US Department of Health

and Human Services, 2009 updated). Not being able to suppress viral load under the level of detection implies a risk of selection of drug-resistant strains and, consequently, limitations of treatment effectiveness as well as future medication selectivity (Chesney, 2003). In contrast, an undetectable viral load dramatically reduces the possibility of further HIV transmission (Attia et al., 2009). This finding has later translated into the "treatment as prevention" approach (Williams et al., 2011). Thus the importance of medication adherence is stressed in antiretroviral treatment programs.

Nevertheless, adherence is not simply a take-it-or-not question. Although an ARV regimen is a life-saving treatment, taking ARV medication is a life-long activity, consisting of daily decisions made as a final result subjected to diverse external elements. To achieve optimal and sustained adherence thus depends on a consideration of a number of factors. Chesney (2000) pointed out that personal factors such as substance use, together with the nature and effects of medication as dietary restriction, inconvenient medicine-taking frequency, burden of pill count and side effects were inversely associated with medication adherence. Moreover, some contextual and environmental factors also contribute to poor adherence, such as low accessibility to medicines, lack of money for transportation, low quality of doctor-patient relationship, and social isolation (Rajabiun et al., 2007; Nam et al., 2008; Thrasher et al., 2008; Kip et al., 2009). Above all, HIV-related stigma is widely cited as one of the factors that constitutes a barrier to proper medication adherence (Rintamaki et al., 2006; Rao et al., 2007; Sabin et al., 2008; Dlamini et al., 2009; Katz et al., 2013).

The definition of stigma varies. While Stafford and Scott (1986, as cited in Link and Phelan, 2001) suggested that stigma "is a characteristic of persons that is contrary to a norm of social unit," Jones et al. (1984, as cited in Link and Phelan, 2001) indicated that stigma "is a

mark that links one to a stereotype." Link and Phelan (2001) pointed out that the great variability in the definition of stigma was probably due to the concept being relevant in an enormous series of circumstances, from disability to mental illness, from sexual minorities to drug use; and that, hence, research on stigma was multidisciplinary. Contributions to the knowledge on stigma came from sociologists, anthropologists, psychologists and so on.

As early described in Goffman's work (1963), stigma is a trait that has an extensively negative social implication – and is consequently discredited – in the cultural setting. If a person is known, be it by the public or by oneself, to possess this trait, the negative entailment of the trait is simultaneously attached to the individual. Disadvantageous consequences such as social disqualification, limited life opportunities, and negative change in social identity may thus be incurred (Berger et al., 2001). Steward and colleagues (2012) concluded that stigma is a systematic mechanism by which social interaction and behaviors are regulated.

Accordingly, stigma is an interpersonal process as well as a social process that undermines health promotion. Corrigan (2004) addressed how stigma may affect whether a person with mental health problems who might benefit from treatment actually seeks treatment. He observed stigma as having two parts: public stigma, referring to public labels and attitudes toward mental illness; and self-stigma, which is the consequently negative self-image of being mentally ill. While public stigma deprives mentally-ill people from social opportunities, self-stigma diminishes self-esteem and confidence in one's future. When seeking treatment becomes "evidence" that proves mental illness, it preclude those who suffer from mental illness from seeking treatment, in order to avoid the public labels and to escape from involving in self-devaluation.

To capture how PLWH perceive, Berger et al. (2001) focused on the perspective of 318 PLWH across the United States and provided a conceptualized model of perceived stigma. Given the individual's perception of societal attitudes toward PLWH and his or her personal feelings of being HIV infected, perceived stigma refers to the awareness of actual or potential disadvantageous consequences. After exploratory factor analysis (EFA), they identified four components that consist of perceived stigma – personalized stigma, disclosure concern, negative self-image and concern with public attitudes toward PLWH – as well as one single higher-order factor that could be conceptualized as general perceived stigma.

Mental health problems and poor well-being have been found to be common among PLWH. A systematic review estimated that the prevalence of depression among PLWH on ARV medication was 34%, and that of anxiety was 28%. The prevalence of both was higher than in the general population (Lowther et al., 2014). Research suggests that poor mental health outcomes and well-being could be linked with stigma (Major and O'Brien, 2005). Berger and colleagues (2001) proposed that one may experience negative changes in self-image and emotional reactions toward those who stigmatize in response to stigmatization. According to Corrigan and colleagues (2004, 2006), the negative change in self-image – termed "self-stigma" – would diminish self-esteem and self-efficacy. Using a clinical sample of 221 HIV-positive men and women, Vanable et al. (2006) explored the relation between stigma-related experiences and depression. They pointed out that stigma was associated with depressive symptoms, after controlling for background characteristics and other correlates; consistently, those who reported higher stigma also received more psychiatric treatment within the preceding year. A similar finding was found in a survey of 229 PLWH in Southern India: it revealed that having experienced discrimination, perceiving stigmatizing attitudes from others, and self-stigma were

associated with high levels of depression (Steward et al., 2008). Furthermore, one study suggested that stigma would decrease medication adherence through damaging mental health. In a cross-sectional survey of 720 PLWH in the USA, Rao and colleagues (2012) found that poorer medication adherence was associated with higher level of stigma and depressive symptoms, and that depressive symptoms partially mediated the association between stigma and medication adherence.

Self-compassion has been proposed as a psychological construct that describes how compassionate would one treat oneself when facing difficulties, such as failure or feeling inadequate (Neff, 2003a; Neff, 2003b), and recent research on self-compassion suggests that it is associated with positive psychological functioning and general well-being (Neff, 2003a; Neff, 2011; Neff et al., 2007a and 2007b; Leary et al., 2007). In this light, self-compassion may play a role to enhance mental health. Also, it has been suggested as a factor that improves compliance to medical recommendations. Self-compassion entails three components: self-kindness, common humanity, and mindfulness. Self-compassion involves a desire to alleviate one's suffering and to heal oneself with kindness through being receptive to and affected by one's own suffering, rather than escaping or disconnecting from it. Self-compassionate people would offer a nonjudgmental understanding of their own pain, inadequacy and failure, so that their own faults and flaws could be seen in the broader aspect of shared human experience, whereby oneself – along with others – is acknowledged fully as a human being: limited and imperfect. Meanwhile, mindfulness – "a balanced state of awareness" of one's emotions and general condition in reflection of the outside world (other individuals, community, and society) – also plays an important role in self-compassion. Being objectively aware of one's emotions allows one to avoid exaggerating or suppressing these emotions – neither running away from nor running away with the feelings

(Goldstein & Kornfield, 1987, as cited in Neff, 2003b). Not being dragged away by the emotions leaves space for self-kindness to occur and for a broader perspective to come into one's view. Also, being aware of one's general condition prevents one's failing from unnoticed or neglected; rather, it reminds the person that some actions should be taken to improve well-being, yet in a tender and forgiving way (Neff, 2003b).

Terry and Leary (2011) suggested that self-compassion would enhance self-regulation of health-related behavior. Self-regulation is a process that includes the following steps: 1) selecting health goals; 2) engaging in behaviors to reach the goals; 3) monitoring goal progress; 4) adjusting behavior or goals when sufficient progress is not being made (Baumeister and Heatherton, 1996, as cited in Terry and Leary, 2011). Self-compassion would help people set goals that are realistic, i.e. within and individual's capability to achieve, as well as are targeted toward improving one's well-being rather than fulfilling others' expectations. It is also suggested that self-compassion is associated with conscientiousness, thus, instead of self-indulgence, self-compassion is associated with self-initiated actions (Neff et al., 2007b), through which health goals can be reached. Moreover, self-compassion could predict adaptive emotional reactions (Neff et al., 2007a) and could mitigate negative feelings that drain out resources for self-regulatory care, which implies a better compliance to medical recommendations (Brion and Menke, 2008). With mindfulness, which helps being aware of one's own status, self-compassionate people could pay more attention not only to their emotional fluctuations, but also their health problems, since research suggests that people with high self-compassion would seek advice from doctors sooner than those with low self-compassion (Terry et al., 2013). While people sometimes fall back to habitual behavior when establishing a behavior change, self-compassion could facilitate reengagement in the establishing process, since self-compassionate

people may recognize that change is a process rather than a once-off thing. Therefore, they would be more likely to forgive their failures and to restart, instead of staying in self-criticism or giving up (Terry and Leary, 2011). In a self-compassionate approach, PLWH would realize that adhering to ARV medication is a way to stay healthy, so they would take steps to improve their well-being in spite of unpleasant habitual changes in daily life. The adaptive feature of self-compassion was related to better adjustment, including lower stress, anxiety and shame in a sample of PLWH in the US (Brion et al., 2014), leaving self-compassionate PLWH with more regulatory resources to focus on medication adherence. When they occasionally miss a dose, instead of spending time on blaming themselves for their forgetfulness, they may be reminding themselves they are in a process, and take proactive action to prevent missing a dose from happening again.

Studies have linked self-compassion with well-being and better mental health. Neff (2003a) carried out a survey on a sample of 391 undergraduate students in the USA and found that self-compassion had a negative correlation with anxiety and depression, as well as a positive correlation with life satisfaction. She later did another study with a sample of 232 undergraduate students in the USA to examine the relation between self-compassion and other self-attitudes and psychological constructs. It was suggested that self-compassion was related to self-esteem, yet differed from self-esteem in that self-esteem was significantly associated with narcissism, while self-compassion – one dimension of which is "common humanity" that emphasizes interconnectedness with others – did not express such self-centered and disassociating features. Besides, self-compassion was negatively associated with both rumination and thought suppression, which in turn comfirmed the negative correlation with depression (Wenzlaff and Luxton, 2003). Also, its positive association with emotional process coping indicates that self-

compassion would be a helpful coping resource. Allen and Leary (2010) further elaborated the role of self-compassion in coping. They argued that self-compassion was related strongly to positive cognitive restructuring, which involves reframing one's view of a stressful situation in less dire terms; and that it was negatively related to escape and avoidance, which were associated with negative psychological health (Penley et al., 2002).

By the end of 2011, there were close to 445,000 PLWH being reported in China. Of these 174,000 were diagnosed with AIDS, and 93,000 were reported death. It was epidemiologically estimated that 780,000 people were living with HIV, accounting for 0.06% of the total population. Sexual transmission was the primary mode of transmission. While the national prevalence remained low, the epidemic was concentrated in subgroups such as sex workers, men who have sex with men and drug users in some areas (UNGASS, 2012). In response to the HIV/AIDS epidemic, China government has implemented the "Four Frees and One Care" policy as early as 2003, in which ARV medication was offered for free for HIV/AIDS patients without insurance in urban areas and all patients in rural areas (Wu et al., 2007; Sun et al., 2010). The number of AIDS patients receiving ARV medication thus increased from 100 in 2003 to 80,000 in 2009 (Sun et al., 2010). However, the expenditures for hospitalization and laboratory tests, such as CD4 counts and viral load, are not covered by the program. In addition, PLWH have to pay for transportation when they seek health services if they live far from the hospital (Starks et al., 2008). Through qualitative interviews with 29 PLWH receiving health care in Beijing, Starks and colleagues (2008) identified stigma and fear of discrimination as one of the barriers to medication adherence. Similarly, stigma and mental health issues, including HIV-related anxiety and feeling of isolation, were repeated themes in another qualitative study that took place in

Southern China (Sabin et al., 2008). Moreover, stigma was found to mediate the association between self-efficacy and medication adherence (Li et al., 2011).

Statement of the problem

Medication adherence is important for a successful treatment outcome of HIV infection. While free ARV medication is accessible in China, difficulties with adherence is one of the reasons for discontinuing treatment and development of drug resistance. Meanwhile, stigma remains an obstacle for PLWH to keep adhering to ARV medication. Self-compassion, on the other hand, may improve medication adherence through enhancing self-regulation and it may serve as a resource to cope with stigma and to mitigate the effect of stigma on mental health. Thus it may buffer the negative impact of stigma on medication adherence.

Justification of study

Limited numbers of studies have examined the association between self-compassion, stigma and medication adherence, and even less in China. More evidence is needed to examine the suggestions from previous research. This project is an attempt to expand the knowledge of self-compassion and add information to the literature, whereby future intervention could be informed if self-compassion is to be incorporated into HIV programs. Because the degree of self-compassion is cultural sensitive and may differ from site to site (Neff et al., 2008; Birkett, 2014), previous study results from elsewhere may not reflect the situation in China. Thus they may not be useful to inform intervention. Information from study conducted in China is required.

Research question

The research questions are "Is ARV medication adherence associated with self-compassion and HIV-related stigma?" and "Does self-compassion modify the association between stigma and medication adherence?"

Hypothesis

It is hypothesized that 1) self-compassion is positively associated with ARV medication adherence; 2) higher level of stigma is negatively associated with ARV medication adherence; and 3) self-compassion would reduce the association between stigma and ARV medication adherence, namely, those who are more self-compassionate are more adherent to medication than those who are less self-compassionate under the context of stigma.

General objectives

The goal of this project was to investigate the relationship among self-compassion, stigma and ARV medication adherence using a clinic sample of HIV infected people from Shanghai, China.

Specific objectives

The specific objectives were:

1) to examine the association between demographic characteristics and ARV medication adherence;

2) to examine the association between self-compassion and ARV medication adherence;

3) to examine the association between stigma and medication adherence;

4) to examine whether self-compassion modifies the association between stigma and ARV medication adherence.

Methodology

Participants and settings

This study was based on a secondary analysis of data from a multisite cross-sectional survey conducted by the International Nursing Network for HIV/AIDS Research. The original study recruited PLWH from Canada, China, Namibia, Thailand, Puerto Rico and the USA. Only the participants from China were included in this analysis.

Data were collected during November 2009 to March 2010 at the Shanghai Public Health Clinic Center (SPHCC), which is one of the specialist hospitals for HIV care in China. Potential study participants were approached directly by clinic staff during their hospitalization or routine visits and informed about the study; those who were interested were then referred to the researchers. To be enrolled in the study, participants had to meet the following criteria: 1) self-reported HIV-positive serostatus; 2) age 18 years or older; 3) ability to provide informed consent. A total of 107 participants were recruited. After recruitment, screening for eligibility and obtainment of informed consent, participants were introduced to a computer-assisted interview.

Instrument

There were around 250 questions in the questionnaire. Other than those topics being utilized in current analysis, the questionnaire included topics such as engagement of health care provider, depression scale, anxiety scale, self-esteem scale, self-efficacy scale in relation to medication adherence and chronic disease, quality of life scale, sense of coherence scale, substance use assessment, and sexual risk behavior assessment. Participants took 40 minutes on average to accomplish the questionnaire.

The instrument was translated from English to Chinese. The translation process, through which the reliability of translated measures was ensured, involved forward translation by an expert whose native language was Chinese, and back translation. The translated questionnaire was reviewed, adjudicated and pilot tested by the research team. A consensus meeting was held to approve the translated version of the questionnaire (Rose et al. 2014).

Measures

Demographic background

The questionnaire contained questions about the participants' age, sex, race, education level, health insurance, having children or not, and work status. Participants were also asked which year they got infected, current CD4 count, as well as whether they had been diagnosed with AIDS.

Stigma indicator

The questionnaire included Berger's 40 item Perceived Stigma Scale (PSS) (Berger et al., 2001) and participants were asked to respond according to a four-point Likert scale, where 1=strongly disagree, 2=disagree, 3=agree, and 4=strongly agree. Based on the data collected from Shanghai, an EFA was done and three factors were identified. At first, there were five factors with eigenvalue greater than one. After rotation and only retaining items with loading more than 0.5, no item was kept for the fifth factor, and only one item for the fourth factor. The only item that loaded 0.52 for the fourth factor simultaneously loaded 0.50 for the second factor. To simplify the analyses, a three-factor model was selected. These three factors altogether accounted for 75.3% of variance of the stigma data collected.

The three-factor model contains 30 items in total. As it is a three-factor model, three sub-scales were developed. No positive stated item were included in sub-scales, thus sub-scale scores were generated by summing up all points of the items included in the scales. Higher score indicates higher stigma. The first scale, "experienced stigma," captures respondents' personal feelings or experiences of being mistreated because of having HIV. Sample items are "People don't want me around their children once they know I have HIV" and "People seem afraid of me once they learn I have HIV". The second scale, "Fear of disclosure and public attitude," indicates the respondents' fear about the consequences of disclosure, or how they perceive the public attitude toward PLWH. For example, "Since learning I have HIV, I worry about people discriminating against me" and "Most people believe that a person who has HIV is dirty." The third scale, "negative self-image," refers to feeling dirty, ashamed or guilty because of having HIV. Items such as "Having HIV makes me feel unclean" fall under this sub-scale. There were 13, 10 and 7 items in each sub-scale respectively; and the Cronbach alpha was 0.95, 0.94, and 0.91, respectively. The association between medication adherence and the three factors was examined using binary logistic regression analysis.

Since Berger's 40 item PSS also is meant to measure a higher-order factor, conceptualized as "general perceived stigma," the association between medication adherence and the overall score on the Berger scale was assessed. The overall score was calculated by reversing the score of positive stated items and then summing up the points of all the 40 items.

The association between stigma and self-compassion and between stigma and medication adherence were assessed using binary logistic regression with continuous stigma scales (three subscales and one overall). To investigate whether stigma has an association with adherence in a non-linear way, stigma scores were also categorized. To categorize, plots with x-axis being

stigma score and y-axis being percentage of adherence were made for each continuous stigma scale. Then stigma was categorized depending on how the line graph was shaped to capture the non-linear features of each stigma scale. The line graph for experienced stigma was almost a horizontal line. The cut-off points were then set at the quartiles. There were four categories for each stigma scales, named "very low," "low," "high," and "very high." The cut-off points for each stigma scale are shown in Table 1.

Table 1: Cut-off points for categorical stigma

Categories	General perceived stigma	Experienced stigma	Fear of disclosure and public attitude	Negative self-image
Very low	46-85	13-22	10-20	7-12
Low	86-105	23-32	21-26	13-18
High	106-135	33-42	27-34	19-22
Very high	136-152	43-52	35-40	23-28

Self-compassion indicator

A 12 item brief version of the Self-Compassion inventory (BVSCI) (Kemppainen et al., 2013) derived from Neff's 26 item Self-Compassion Scale (SCS) (Neff, 2003a) was used in the questionnaire. Analyzing data from 391 undergraduate students in the USA, Neff identified three factors and their corresponding counterparts – self-kindness versus self-judgment, common humanity versus isolation, and mindfulness versus over-identification – as six subscales in the full 26 items scale (Neff, 2003a). Leary invented a short version of this scale. Two items per subscale were selected based on their factor loading to make up the 12 item inventory. After validation with three non-clinical samples of 117 adult community members, 281 participants

from a psychological subject pool and 161 graduate students, the coefficient for the correlation between the short version and the original one was 0.92 and internal consistency was high for the short version with Cronbach's alpha of 0.82 (Leary M, as cited in Kemppainen et al., 2013).

For each of the 12 self-compassion items, the participants in the current survey were asked to grade how frequently they would deal with difficult situations in a certain manner on a five-point Likert scale, where 1=almost never, 2=rarely, 3=sometimes, 4=frequently and 5=almost always. Sample items were "When I'm feeling down, I tend to obsess and fixate on everything that's wrong," and "When I'm going through a very hard time, I give myself the caring and tenderness I need." The final score for each participant was generated by first reversing the points of negatively stated items and then summing up all the points for the 12 items, giving a theoretical range from 12 to 60. The internal consistency reliability for the current sample was acceptable with Cronbach's alpha being 0.77.

ARV medication adherence

Adherence to the prescribed ART medication was measured by the question "For the past 30 days, what percent of the time were you able to take your medications exactly as your doctor prescribed them?" (Walsh et al., 2002) Participants made a mark on a visual analogue scale from 0% to 100%, and then a percentage would be judged and interpreted by the computer.

The initial plan was to use adherence as a continuous variable and employ linear regression. However, the density graph of the residuals of adherence did not fall close to the imposed normal distribution line (with the same mean and variance). Moreover, after running a linear regression model with adherence as the dependent variable and stigma as the independent variable, a plot of the observed versus predicted values (obtained using the command "regplot")

revealed that the observed values of adherence were not symmetrically distributed around the predicted diagonal line. Another plot (obtained using the command "rvfplot2") showed that the residuals for adherence against the predicted value were not distributed symmetrically around horizontal line of zero. The two above findings implied that the assumptions of linearity (an important assumption for linear regression) did not hold. Therefore adherence to medication was dichotomized into two groups. Those who reported 95% adherence or higher (Paterson et al., 2000; Alcorn and Thaczuk, 2008) were conceptualized as optimal adherent, the rest as sub-optimal adherent.

Data analysis

Percentages and averages were calculated to examine participants' characteristics. Continuous variables such as age, duration of infection and CD4 counts were checked for whether normal distributed. If not, medians and ranges are presented. The Chi square test and the Wilcoxon-Mann Whitney test were used to examine gender differences for each demographic variable. The correlation between self-compassion and stigma were obtained using the command "corr". Logistic regression was used to test the association between adherence and the independent variables: demographic variables, stigma and self-compassion. All odds ratios are presented as both crude OR and adjusted OR (controlled for sex, age and level of education). The assumptions of normality and linearity were checked for stigma and self-compassion, and were found to be hold. A sensitivity analysis for the association between self-compassion and adherence was conducted where participants with outlier values were excluded from the analysis, and locally weighted regression plots (LOWESS plots, obtained using the command "lowess") were made to compare the associations with and without these participants. Each value on the

lowess curve is determined by neighboring data, thus the curve indicates the trend of the association between two variables. To examine whether there was any interaction between self-compassion and stigma, the analysis of the association between stigma and adherence was stratified by self-compassion (higher or lower than mean value). The software STATA 13.0 was used for all statistical operations.

Ethical considerations

Informed consent was obtained from each study participant before enrollment. Computer-assisted interview was used to ensure privacy. All study procedures in Shanghai were reviewed and approved by the institutional review boards of SPHCC. The University of California-San Francisco (UCSF) secured approval for the overall study data from each site, including Shanghai, China. Code numbers were used to protect the confidentiality of study participants. (Chen, Shiu, and Yang et al., 2013; Chen, Wantland, and Reid et al., 2013)

Results

Participants' characteristics

Among a total of 107 participants, there were 90 (84%) males and 17 (16%) females. The age of the participants ranged from 23 to 59, with the median age being 36. One third of all held a bachelor degree or higher, 37% accomplished high school education, and 22% finished elementary education. Half of them reported having children. Forty-seven (44%) of them had no job when they took part in the survey, and 80 (75%) claimed to have no health insurance. The duration of being infected with HIV ranged from one to seventeen years, with the median being three years. Fifteen participants (14%) had been diagnosed with AIDS. The median CD4 count was 200 cells/mm3, ranging from 0 to 950 cells/mm3. Female participants were more likely to have health insurance and children.

While seventeen participants (16%) had never taken ARV medication, eighty-eight (82%) participants stated that they were currently on ARV medication, and two (2%) had started taking ART yet had had stopped because of a recommendation from their health care providers. Thus only the 88 responses are used in medication adherence-related analyses. Among these 88 participants, 75 (85%) were male and 13 (15%) were female. The distributions of other demographic characteristics for participants on ARV medication were comparable to all participants. However, while female participants on ART reported median age of 47, the median age of their male counterparts was 37. Females on ARV medication also reported two years longer median length of infection, less likely to have a full time job and more likely to have children than males on ARV medication.

Among the 88 participants who were currently on ARV medication, 53 (60%) were classified as optimally adherent, and 35 (40%) were classified as sub-optimally adherent. No significant gender difference was detected in adherence.

Table 2: Participants' demographic characteristics and categorical stigma

Demographic variables	*Category*	Among total 107	Among 88 who currently on ART
Sex	male	90 (84%)	75 (85%)
	female	17 (16%)	13 (15%)
Race	Han	100%	100%
Education	grade school	24 (22%)	19 (22%)
	high school	40 (37%)	35 (40%)
	technical/vocational school	8 (7%)	6 (7%)
	bachelor	32 (30%)	25 (28%)
	master	3 (3%)	3 (3%)
Have children	yes	52 (49%)	48 (55%)
	no	55 (51%)	40 (45%)
Health insurance	yes	27 (25%)	20 (23%)
	no	80 (75%)	68 (77%)
Work status	no work	47 (44%)	38 (43%)
	part time	17 (16%)	15 (17%)
	full time	43 (40%)	35 (40%)
Income (self-report)	inadequate	40 (37%)	34 (39%)
	barely adequate	48 (45%)	40 (45%)
	enough	19 (18%)	14 (16%)
AIDS diagnosis	yes	15 (14%)	13 (15%)

	no	92 (86%)	75 (85%)
On ART	never	17 (16%)	0
	currently	88 (82%)	88 (100%)
	stopped	2 (2%)	0
Age	median, range	36, 23-59	38, 24-59
Duration of infection (year)	median, range	3, 1-17	4, 1-17
CD4 count	median, range	200, 0-950	195, 4-950
General perceived stigma	Very low	11 (10%)	7 (8%)
	Low	24 (23%)	21 (24%)
	High	66 (62%)	54 (62%)
	Very high	5 (5%)	6 (6%)
Experienced stigma	Very low	4 (4%)	3 (3%)
	Low	30 (28%)	23 (26%)
	High	59 (56%)	50 (57%)
	Very high	13 (12%)	11 (13%)
Fear of disclosure and public attitude	Very low	9 (9%)	6 (7%)
	Low	15 (14%)	9 (10%)
	High	60 (57%)	54 (62%)
	Very high	22 (21%)	18 (21%)
Negative self-image	Very low	15 (14%)	10 (11%)
	Low	47 (44%)	40 (46%)
	High	31 (29%)	27 (31%)
	Very high	13 (12%)	10 (11%)

Note: for stigma scale of all participants, N=106; for stigma scale of participants on ARV medication, N=87.

All 107 participants reported on all items in the self-compassion scale. The mean self-compassion score was 38.7 (SD = 6.1). On the stigma items, 106 participants reported (Table 3). No significant gender differences were found for self-compassion score, the score of general perceived stigma and the three sub-scales. The numbers and percentages of participants in each stigma category were illustrated in Table 2.

Table 3: Stigma scores (N=106)

	Mean	SD	Range	No. of item
General perceived stigma	109.8	19.2	46-152	40
Experienced stigma	35.9	7.5	13-52	13
Fear of disclosure and public attitude	29.6	6.3	10-40	10
Negative self-image	17	4.6	7-28	7

Association and interaction analysis among variables

Although none of the associations between ARV medication adherence and demographic variables were significant (Table 4), some tendencies can be seen. Those who reported higher level of education, having health insurance, full time employment, and enough income expressed higher ARV medication adherence.

Table 4: Crude ORs and adjusted ORs for the association between demographic variables and adherence (N=88)

Demographic variables	Category	No. (%) optimally adherent	Crude OR (95% CI)	Adjusted OR (95% CI)

Sex	Male	44 (59%)	Ref	
	Female	9 (69%)	1.59 (0.45-5.61)	1.86 (0.50-6.99)
Education	Grade school	11 (58%)	Ref	
	High school	20 (57%)	0.97 (0.31-3.00)	0.90 (0.28-2.90)
	Technical/vocational school	2 (33%)	0.36 (0.52-2.50)	0.32 (0.04-2.49)
	Bachelor	17 (68%)	1.55 (0.45-5.33)	1.40 (0.37-5.21)
	Master	3 (100%)	-	-
Having children	Yes	28 (58%)	0.84 (0.36-1.98)	1.16 (0.32-3.72)
	No	25 (63%)		
Health insurance	Yes	15 (75%)	2.37 (0.77-7.26)	2.04 (0.64-2.48)
	No	38 (56%)		
Work status	No work	21 (55%)	Ref	
	Part time	8 (53%)	0.93 (0.28-3.07)	0.95 (0.27-3.41)
	Full time	24 (69%)	1.77 (0.68-4.60)	1.69 (0.55-5.21)
Income	Inadequate	19 (56%)	Ref	
	Barely adequate	25 (63%)	1.32 (0.52-3.34)	1.11 (0.38-3.22)
	Enough	9 (64%)	1.42 (0.39-4.15)	1.02 (0.22-4.80)
AIDS diagnosis	Yes	7 (54%)	0.74 (0.22-2.41)	0.85 (0.25-2.87)
	No	46 (61%)		
Age			0.99 (0.95-1.03)	0.99 (0.94-1.04)
Duration of infection (year)			1.08 (0.93-1.25)	1.08 (0.93-1.26)
CD4 counts			1.00 (0.998-1.004)	1.00 (0.998-1.004)

Self-compassion was not associated with optimal medication adherence at the beginning,

but the association became significant after excluding two participants with outlier value. The

crude odds ratio for self-compassion was 1.09 (95% CI 0.999-1.18). After adjustment for sex, age and level of education, the odds ratio was 1.08 (95% CI 0.99-1.18). In other words, adherence tended to be higher with higher levels of self-compassion, but the association was not significant. We examined the relationship between self-compassion and adherence with a scatter plot and found two outliers: two participants with a self-compassion score of 30 (i.e. low) were optimally adherent. When we did a sensitivity analysis and excluded these two participants with outlier values, the adjusted odds ratio was 1.10, (95% CI 1.00-1.21; N=86). Two LOWESS curves showed the before-and-after difference clearly (Figure1a and 1b). Before the two participants were excluded, the curve indicated that, when self-compassion was within the range of 30-35, its association with adherence was negative; while when the self-compassion score was more than 35, its association with adherence was positive. When excluding two participants from the analysis, the association between self-compassion and adherence was positive.

Figure 1a: LOWESS curve with all participants included
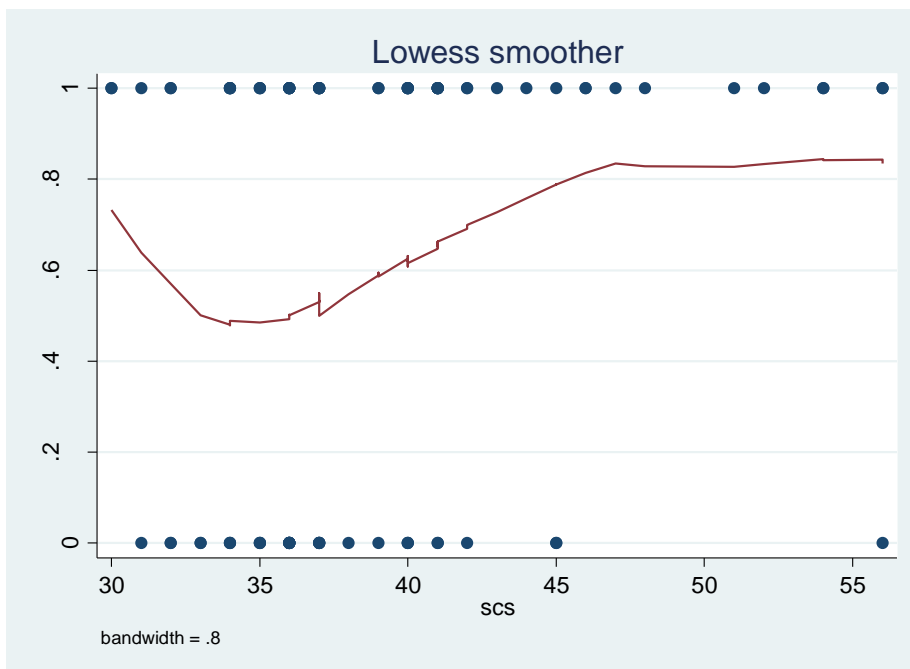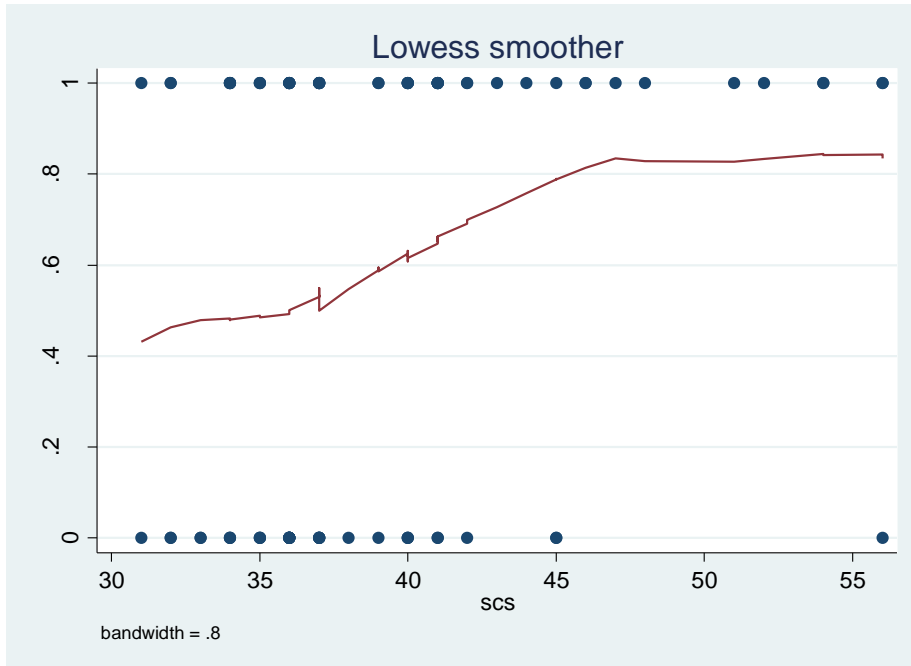

bandwidth = .8

Figure 1b: LOWESS curve after excluding two participants

Self-compassion was negatively associated with stigma (Table 5). It correlated inversely with "general perceived stigma," "experienced stigma," and "negative self-image". However, self-compassion was not associated with "fear of disclosure and public attitude".

Table 5: Correlation between self-compassion and each stigma scale (N=106)

	Correlation	p-value
General perceived stigma	-0.20	0.037
Experienced stigma	-0.21	0.029
Fear of disclosure and public attitude	-0.01	0.851
Negative self-image	-0.40	0.000

A positive association was noticed between stigma and medication adherence. In the initial linear regression model, only the association between "fear of disclosure and public attitude" and adherence was significant. When using categorized stigma, the association between "general perceived stigma" and adherence became significant. Compared with the "very low" category, the other three categories (stigma score gets higher in order) had odds ratios of 15.93, 9.88, and 23.23, respectively.

When the sub-scales were categorized, the ORs for "experienced stigma" and "fear of disclosure and public attitude" were high, although the associations (except one) were not significant (Table 6a and 6b).

Table 6a: Analysis between adherence and stigma as continuous variable (N=87)

AOR (95% CI)	ARV medication adherence
General perceived stigma	1.02 (0.99-1.04)
Experienced stigma	1.04 (0.97-1.11)
Fear of disclosure and public attitude	1.09 (1.01-1.19)
Negative self-image	1.01 (0.92-1.11)

Table 6b: Analysis between adherence and stigma as categorical variable (N=87)

AOR (95%CI)	General perceived stigma	Experienced stigma	Fear of disclosure and public attitude	Negative self-image
Very low	Ref	Ref	Ref	Ref
Low	15.93 (1.51-167.75)	3.85 (0.28-52.15)	3.46 (0.26-45.31)	1.06 (0.25-4.54)
High	9.88 (1.08-90.38)	4.21 (0.33-54.52)	9.89 (1.06-92.42)	0.66 (0.15-2.95)
Very high	23.23 (1.07-504.86)	4.09 (0.26-64.62)	8.33 (0.76-91.35)	1.63 (0.25-10.52)

After stratifying by self-compassion score, we found that the high self-compassion group had a similar odds ratio as low self-compassion group for the association between medication adherence and stigma as continuous variable (Table 7a). However, when analyzing using stigma as categorical variable, distinctive odds ratios were observed between the two self-compassion groups (Table 7b), yet the confidence intervals overlapped. Hence, no interaction was detected.

Table 7a: Interaction analysis of self-compassion and stigma (as continuous variable) on adherence

AOR (95% CI)	High self-compassion group	Low self-compassion group
General perceived stigma	1.03 (0.98-1.07)	1.02 (0.99-1.06)
Experienced stigma	1.04 (0.94-1.15)	1.06 (0.97-1.16)
Fear of disclosure and public attitude	1.13 (0.98-1.29)	1.07 (0.96-1.20)
Negative self-image	1.04 (0.88-1.22)	1.05 (0.92-1.21)

Table 7b: Interaction analysis of self-compassion and stigma (as categorical variable) on adherence

AOR (95% CI)	Category	High self-compassion	Low self-compassion
General perceived stigma	Very low	Ref	Ref
	Low	5.31 (0.33-85.16)	2.33 (0.10-55.69)
	High	4.47 (0.28-72.51)	1.13 (0.06-22.26)
	Very high	-	-
Experienced stigma	Very low	Ref	Ref
	Low	3.84 (0.16-94.73)	0.51 (0.07-3.70)
	High	2.71 (0.11-64.38)	0.99 (0.18-5.40)
	Very high	3.45 (0.09-129.00)	-
Fear of disclosure and public attitude	Very low	Ref	Ref

	Low	0.25 (0.02-3.04)	1.42 (0.06-32.69)
	High	1.13 (0.17-7.45)	3.75 (0.35-40.30)
	Very high	-	2.42 (0.16-36.68)
Negative self-image	Very low	Ref	Ref
	Low	0.84 (0.12-6.08)	2.22 (0.16-29.80)
	High	1.86 (0.12-29.26)	1.27 (0.10-16.99)
	Very high	0.76 (0.04-14.24)	5.05 (0.27-94.02)

Note: omitted data was due to collinearity.

Discussion

In this secondary analysis of data from a cross-sectional survey of 107 PLWH, a positive association between categorized general perceived stigma and medication adherence emerged. Sub-scale analysis indicated that this positive relation was mainly due to an association between "fear of disclosure and public attitude" and adherence. No association was found between self-compassion and optimal ARV medication adherence, except after excluding two participants with outlier values. Self-compassion was negatively correlated with general perceived stigma, experienced stigma and negative self-image. No interaction between self-compassion and stigma on medication adherence was detected. Those who had higher level of education, health insurance, full time employment and adequate income tended to report higher adherence, but the associations were not significant.

In the initial analysis, self-compassion was not associated with optimal adherence. In the sensitivity analysis in which two participants with outlier data were excluded, a significant positive association was found between self-compassion and optimal adherence. This finding indicated that self-compassion is related to health promoting behavior, which is aligned with previous studies (Terry et al., 2013; Brion et al., 2014). Terry and Leary (2011) suggested that self-compassion may boost health-related behavior through successful self-regulation, which involves setting a goal and engaging in behavior toward reaching that goal.

In the context of ARV treatment, the goal would be to achieve successful viral suppression and to maintain immune function through appropriate adherence to medication. Adherence to medication does not merely mean "taking the medicine," but requires taking the medicine on a specific time and in a specific way, which result in inconveniences for PLWH.

Also, negative feelings – such as anger, self-criticism of health status, self-blame for contracting disease or being reminded of HIV infection – may come along with medication and have negative impact on adherence (Brion and Menke, 2008; Brion, Menke and Kimball, 2013; MacDonell et al., 2013; Rintamaki et al., 2006). To respond to this predicament, self-kindness offers comfort to oneself to ease the pain and feelings of misfortune. The dimension referred to as "common humanity" may help to realize that the inconveniences incurred are experienced by lots of other PLWH, so that they would not feel isolated on the way to "reaching the goal." Mindfulness may play a role that balances the rational and the negative emotions, for example, to find a balance between accepting the disease and self-denial; between benefits of medication and having to change habitual lifestyle; between starting to take medicine and staying in self-blame. In other words, self-compassion may buffer inconveniences, through which medication adherence may be enhanced. Therefore, the finding here is in line with Terry and Leary's suggestion.

When eliminating data from two participants who reported low self-compassion (score = 30) with optimal adherence, a significant association emerged. Scrutinizing the other responses of the two participants with outlier data, one of the participants' reported adherence was plausible, the other was questionable. One of the two reported very high adherence self-efficacy and fair CD4 count (330 cells/mm3), while the other one reported rather low adherence self-efficacy and low CD4 count (90 cells/mm3), indicating either treatment failure or incorrect reporting of adherence.

Examining how the participants' demographic background was related to medication adherence, the tendencies that those who had better socioeconomic status and had health insurance would report higher adherence were in line with previous studies (Peltzer and Pengpid,

2013; Chen, Yang, and Liu, 2010). As PLWH have to pay out of pocket for transportation and lab and hospitalization fees, having health insurance to cover healthcare-related costs, as well as a full time job which could translate into adequate income, may improve ARV medication adherence. Level of education is usually related to not only having a full time job and income but also the level of health literacy (Van der Heide et al., 2013). The US Institute of Medicine (2004) defined health literacy as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions." Lack of health literacy may not merely be an obstacle to health information and health care, but lead to lack of knowledge to appropriately use medication (Nutbeam, 2008), whereby the association between level of education and medication adherence could be explained.

A few studies suggest that self-compassion may buffer against negative self-feelings, including shame and concern with others' judgments. Also, self-compassionate people tend to reframe a stressful situation in a more positive light and recognize their role in negative events without being overwhelmed by negative emotions (Leary et al., 2007; Allen and Leary, 2010; Brion et al., 2014). This indicates that self-compassion may play a role in countering stigma. However, previous studies examining the association between self-compassion and stigma are limited. The present analysis may be the first attempt to examine the association between self-compassion and stigma among PLWH. Not surprisingly, self-compassion was negatively correlated with negative self-image, experienced stigma and general perceived stigma.

Both the mistreatment that PLWH expect or experience as well as the perception of possessing discreditable attributes may lead to negative evaluation of oneself (Goffman, 1963, as cited in Berger et al., 2001). Yet, self-compassion, as relevant to emotional regulation and coping

(Neff, 2003b; Allen and Leary, 2010), may put up a protection against stigma. With mindfulness, people are more likely to be aware of their own emotions in a less harmful way when it arises. For example, some PLWH may feel guilty, unclean or find their infected body disgusting; and they often experience apprehension and rejection by others. Yet the non-judgmental, receptive and detaching features of mindfulness may allow them to sense and cognize this negative information without being drowned by the negative emotions incurred. This may help preclude them from being dragged away or ruminate in a negative circle. Besides, with self-kindness and a sense of common humanity, self-compassionate people may approach negative emotions with comfort and understanding (Neff, 2003a; Neff, 2003b). Instead of self-criticism and self-pity, self-compassionate people may treat themselves with sympathy – to realize that having negative emotions arising after being mistreated is reasonable; and to recognize that such negative events are a broad human experience, not only shared with other PLWH, but also with a variety of other marginalized groups. To sum up, self-compassion may serve an emotional regulating function when dealing with perceived stigma. The items in the subscales "experienced stigma" and "negative self-image," all refer to respondents' personal experiences and thoughts. Thus, the correlation detected between self-compassion and experienced stigma may be a result of experienced stigma negatively affecting an individual's self-compassion. The causal direction could be the other way, i.e. those who are more self-compassionate may report less experienced stigma. However, as experiences are something that have already happened and in reality cannot be changed, we believe more in experienced stigma affecting self-compassion.

The correlation between self-compassion and negative self-image may be due to some items in the "negative self-image" subscale reflecting characteristics of self-judgment and isolation, which are also part of self-compassion scale. Thus, the moderately strong inverse

correlation was predictable. On the contrary, the items measuring "fear of disclosure and public attitude" are focusing on attitudes and thoughts affecting HIV-infected people more in general. The findings indicate that self-compassion is more strongly related to personally felt stigma.

One unexpected finding was that stigma was positively associated with medication adherence. In contrast, previous studies have cited stigma as a barrier to adherence in China (Starks et al., 2008; Sabin et al., 2008). However, the present positive association could be attributed to "fear of disclosure and public attitude." As this sub-scale captured how PLWH perceived public attitude, the higher scores may imply that the respondents cared more about others' opinion, whereby public discourse and others' opinion would have more influence on their behaviors. Therefore, one possible explanation for the positive association here could be that, it is the degree to which others' opinion has an impact on PLWH's behaviors that contributes to higher medication adherence. For example, "taking medicine" is generally regarded as a responsibility for someone who has disease, because a mature, independent adult should be responsible for taking care of him-/herself. In addition, in a cultural context that praises family responsibility as in China, taking medicine when having a disease is regarded as a responsibility not only for yourself but also for your family (Fredriksen-Goldsen et al., 2011). HIV infection would not be an exception, especially when the medication is offered for free, from which the public may hold an impression that there is no barrier to the access of medication. This discourse shapes those who adhere to medication as "good" patient and those who do not as "bad" patient. People who care more about others' opinion or others' valuing, would under this discourse practice higher adherence in order to be a "good" patient – take medicine for self and for family.

Secondly, although HIV/AIDS is a highly stigmatized disease, to be stigmatized requires being identified as a prerequisite. Infection with HIV is not a physical disability which can be recognized by appearance when a patient receives ARVs and responds well to the treatment. It needs a characteristic for the public to distinguish an infected individual from a "discreditable" to a "discredited" person. Ironically, taking ARV medication would invite a series of question that put PLWH in risk of disclosure, if not be recognized as a sign of having HIV. Therefore, if stigma here is conceptualized as disclosure concern, which refers to respondents' efforts on HIV status control, and to escape the consequence of being known as an infected individual, another possible explanation of the positive association could be that, the more PLWH adhere to ARV medication, the higher is the risk they would be discovered as having HIV, thus, the more concern and fear they would have regarding the consequence of disclosure. People who are optimally adherent have to take the medicine at a specific time wherever they are, which exposes them and may lead to disclosure. Hence, those who reported higher adherence may also express more fear of consequence of disclosure. Similar results were found in Vanable and colleagues' (2006) survey among a clinical sample of 221 PLWH in the USA in 2001-2002: people who disclosed their status to a broad range of social contacts experienced stigma more commonly.

No significant interaction was detected to support the hypothesis that the association between stigma as a continuous variable and medication adherence would be different among PLWH with high self-compassion compared to those who were less self-compassionate. Yet when including stigma as a categorical variable, the two self-compassion groups had quite different AORs. Considering that this study was based on a small sample size, we cannot rule out that we could have found significant interaction if given a higher sample size. Nevertheless, the patterns of interaction differed across stigma subscales. High self-compassion seemed to

reinforce the positive association between general perceived stigma and medication adherence.

The pattern for experienced stigma was similar to the pattern seen for general perceived stigma.

In contrast, high self-compassion appeared to reduce the association between adherence and

"fear of disclosure and public attitude". In other words, hypothesis number 2 did not hold. It is

difficult to explain the observed tendencies.

Limitations

There are several limitations of this study. Firstly, this study used a clinical sample of 107

participants who attended the same HIV specialized hospital in Shanghai. The participants were

likely to be a selected group of PLWH as they were motivated to respond to a questionnaire with

250 questions. Also, since potential participants were recruited in a clinic, those who refused to

return to the clinic or did not return regularly due to economic difficulties or other reasons would

not have the possibility to be recruited. This non-random sample restricts the generalizability of

the findings. Secondly, no causality can be concluded due to cross-sectional study design.

Thirdly, the small sample size not only renders the analysis being very sensitive to extreme data

points, and this may have been the case in the analysis of the association between self-

compassion and adherence; but also means less power to detect real differences between the

groups. Fourthly, several potential biases may decrease the validity of the findings, such as recall

bias and social desirability. For example, participants may have understood that optimal

adherence was what the researchers wanted to adhere, whereby an incorrect adherence

percentage may have been reported. Fifthly, although self-compassion was not significantly

associated with ARV medication adherence, it could be associated with other behaviors that the clients believe to be health promoting, such as Chinese medicine.

Conclusion

This study found that ARV medication adherence was positively associated with general perceived stigma, experienced stigma and fear of disclosure and public attitude. No association was found between self-compassion and adherence and between demographical variables and adherence. Self-compassion did not modify the association between stigma and adherence.

Recommendations

A larger sample size would help the analysis be less sensitive to outlier data. Participants could be recruited from several clinic settings and the data could be pooled to increase the generalizability. If the non-significant associations between demographic variables and adherence indicate real tendencies, PLWH without health insurance and full-time employment may need extra support to be adherent. Also, a detailed, clear and easily-understood medicine using instruction and HIV/AIDS care-related information could be prepared for PLWH with lower level of education in the case of lack of health literacy. As compassionate mindful training has been developed, it could be incorporated in ART programs to enhance medication adherence, or in mental health clinics for PLWH, those who suffer from stigma, to improve psychological functioning. Yet additional research is needed to replicate this study's findings and to add information on the relationship between self-compassion, stigma and medication adherence.

Prospective study designs such as a cohort study may help to clarify the causal direction, and experimental design (compassionate mindfulness training intervention versus non-intervention) may provide information about the efficiency of self-compassionate training to improve medication adherence.

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