Stress and Psychosocial Adjustment among People Living with HIV/AIDS in China

SU, Xiaoyou

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ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

Thesis/Assessment Committee

Prof. Sian GRIFFITHS (Chair)

Prof. Joseph LAU (Thesis Supervisor)

Prof. Winnie MAK (Thesis Co-supervisor)

Prof. Samuel WONG (Committee Member)

Dr. Amy Ho (External Examiner)

Abstract

Abstract of thesis entitled:

Stress and Psychosocial Adjustment among People Living with HIV/AIDS in China

Submitted by **Su Xiaoyou**

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Abstract (English)

Introduction

Mental health issues are prevalent among People Living with HIV (PLWH). Most studies to date have been conducted in Western countries. Instrumentation, conceptualization and theoretical models of stress-coping-mental health relationships among PLWH are important but theoretical and practical differences exist in the context of different cultures and quality of care services.

Objectives

The aims of the study were 1) to develop a new Perceived Stress Scale for People Living with HIV (PSSHIV) using a 'bottom-up' approach; 2) to validate the Brief COPE inventory among Chinese PLWH; 3) to describe levels and patterns of perceived discrimination, stress, resources, coping strategies and psychological outcomes; 4) to investigate determinants of perceived stress, and 5) to investigate relationships between perceived discrimination, perceived stress, resources, coping strategies and psychological well-being (i.e. depression and quality of life). No study of this type has previously been conducted in China.

Subject and Methods

To achieve Aim 1, PLWH in two Chinese cities were interviewed for item generation (n=58) and validation (n=215). Aims 2 to 4 were achieved through another survey (n=258) conducted in the same cities. Participants were recruited from the registry of the Centers for Disease Control and Prevention and from users of hospital services and Methadone Maintenance Treatment clinics. Standard statistical methods were used for validation studies. Univariate, multivariate and hierarchical logistic and linear regression methods were used for data analysis. Most scalar variables were validated in previous studies.

Results

The newly developed PSSHIV (8 factors) and the rearranged version of the Brief COPE (6 factors) were validated and found to have acceptable psychometric properties. Of all participants, 63.3% showed moderate/severe depressive symptoms. 'Problem-solving and Acceptance' and 'Self-blame and Denial' were commonly used coping strategies. Socioeconomic status (SES), perceived discrimination, and optimism were significantly associated with overall stress and some of the subscales of PSSHIV. Perceived stress appeared to mediate the relationship between perceived discrimination and psychological well-being. In addition to perceived stress, social support and some particular coping strategies (negative association: 'Problem-solving and Acceptance'; positive associations: 'Negative Venting and Avoidance' and 'Self-blame and Denial' positively predicted depression) were associated with depression. Similar though not identical results were found using quality of life as the outcome. Personal resources and coping strategies, however, did not buffer the relationship between stress and depression and quality of life.

Conclusions

The results showed that depression is prevalent among Chinese PLWH. Perceived discrimination is a source of stress, which is multi-dimensional and significantly associated with mental health outcomes. Perceived stress, social support and coping strategies had independent effects on mental health outcomes but there were no interaction effects as suggested by some Western studies. The Brief COPE was validated and had a structure different from the original, again supporting the importance of cultural variations. Our results hence provide useful instrumentations (PSSHIV and Brief COPE) as well as a good foundation for the development of theories and interventions specific to the needs of the PLWH in China. Care services should include elements of stress management and formation of positive coping strategies.

Abstract (Chinese)

簡介

愛滋病感染者中心理健康問題十分普遍。許多相關的研究均在西方國家。愛滋病感染者中壓力-應對方式-心理健康關係研究中使用的量表、基本概念和理論模型具有十分重要的理論和實際意義，並取決於文化因素和關懷服務的水準。

目的

本研究的目的爲 1）採用‘自底向上法’開發一個新的中國愛滋病感染者的感知壓力量表；2）在中國愛滋病感染者中驗證簡明因應量表；3）描述感知歧視、感知壓力、應對資源、應對方式及心理健康狀態的水準和模式；4）研究感知壓力的決定因素；5）研究感知歧視、感知壓力、應對資源、應對方式同心理健康狀態（如抑鬱和生命質

量）的關係。在中國未有過類似的研究。

研究對象和方法

爲達到目的 1，研究者在中國兩個城市對愛滋病感染者進行訪談完成了條目採集(n=58)和驗證研究(n=215)。在同樣兩個城市進行的另外一次調查(n=258)完成了目的 2 至目的 5。研究對象由疾病預防控制中心的登記資料、醫院和美砂酮診所的病人中招募。量表的驗證研究中，研究者使用了標準統計學方法進行了分析。本研究使用了單變量分析、多變量分析及分層 logistic 和線性回歸等方法進行了資料分析。本研究使用的多數量表均在以前的研究中得到過驗證。

結果

新開發的愛滋病感染者的感知壓力量表（8 個因子）及重新整理過的簡明因應量表經驗證具有良好的心理測量學特徵。63.3%的受訪者表現了中度和重度抑鬱症狀。‘解決問題和接受’及‘自責和拒絕’是感染者常用的應對方式。社會經濟地位、感知歧視和樂觀感同感知壓力量表的總量表和一些子量表的分數顯著相關。感知壓力被證明對感知歧視和心理健康狀態關係有仲介效應。除了感知壓力外，社會支持和一些應對方式（負相關：‘解決問題和接受’；正相關：‘消極宣洩和逃避’和‘自責和拒絕’也被證明與抑鬱有關。當生命品質作爲因變量時，結果相似但不完全相同。應對資源和應對方式對感知壓力同抑鬱及生命質量的關係並沒有緩衝效應。

結論

本研究結果顯示中國愛滋病感染者中抑鬱症狀是普遍存在的。感知歧視是感染者壓力的來源，而壓力是多維的並同感染者的心理健康有顯著相關。感知壓力、社會支

持和應對方式對心理健康狀態有獨立效果，但並非如西方的研究所證實的有相互作用。簡明因應量表雖然經驗證但其結構同原創的量表十分不同，這又進一步強調了文化差異的重要性。本研究的結果爲建立符合中國愛滋病感染者需求的理論和干預提供了良好的基礎。對感染者的關懷服務應考慮壓力管理中的相關因素和鼓勵感染者採用積極的應對方式。

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Finally I want to thank my family. The encouragement and support from my beloved husband and never-ending support from my parents and my brothers are always powerful sources of inspiration and energy.

List of Contents

Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-retroviral Treatment
CDC	Center for Disease Control and Prevention
CFA	Confirmatory Factor Analysis
EFA	Exploratory Factor Analysis
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immune-deficiency Virus
ICC	Intra-class Correlation Coefficients
IDU	Injecting Drug Users
MSM	Men who have Sex with Men
OIs	Opportunistic Infections
PLWH	People Living with HIV
QoL	Quality of Life
SES	Socioeconomic Status
UNAIDS	Joint United Nations Program on HIV/AIDS
WHO	The World Health Organization

Chapter 1 Literature review

1.1 HIV/AIDS Epidemic

1.1.1 Global AIDS epidemic

Though the global prevalence of HIV has tended to level off since the year 2000 due to behavioral prevention programs, the overall number of PLWH has continued to rise, due to population growth, ongoing number of new infections each year, and, more recently, the life-prolonging effects of antiretroviral therapy (ART) [1].

Globally, there were an estimated 33 million people living with HIV in 2007 (Figure 1.1). The annual number of new HIV infections declined from 3.0 million in 2001 to 2.7 million in 2007 [2].

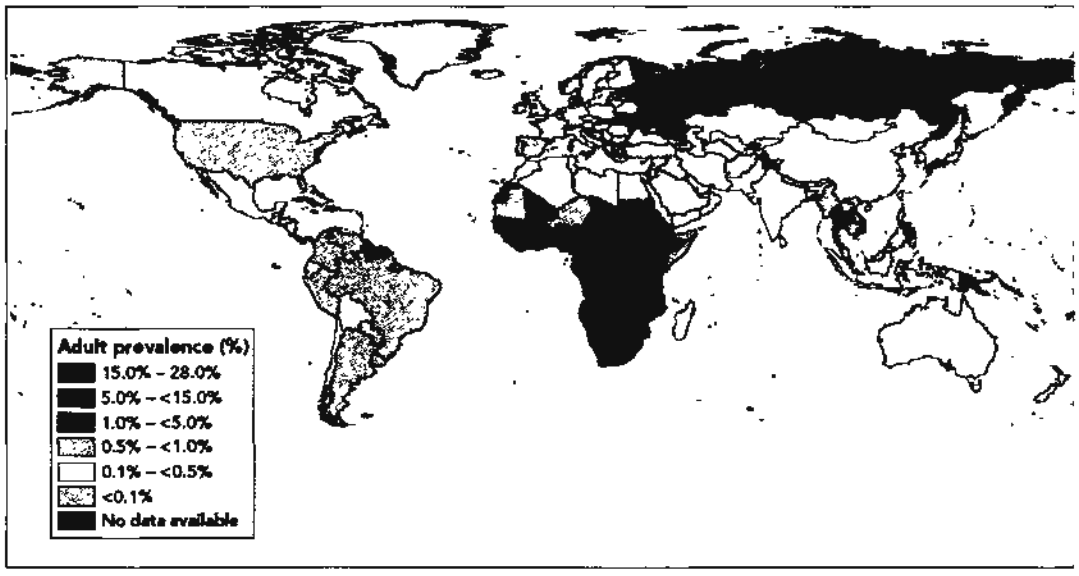
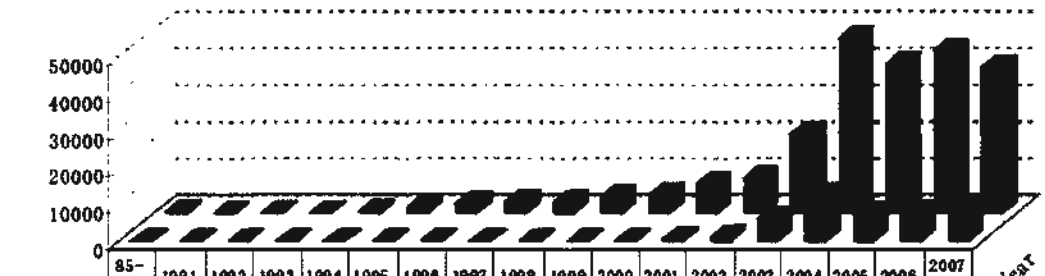


Fig. 1.1 A global view of HIV infection, 2007. 33 million people [30 – 36 million] living with HIV, 2007

1.1.2 HIV/AIDS in China

1.1.2.1 Reported HIV infections

As of October 31 of 2009, China had recorded 319,877 HIV infections, 102,323 of which had developed into AIDS. China has had 49,845 AIDS deaths since it detected its first HIV infection in 1985, the Minister of Health—Chen Zhu, said during the 5th Conference of International Cooperation Programs on HIV/AIDS in China [3]. Since there is no updated official report issued on HIV epidemic in China since the end of 2007, most of the data are from the joint assessment in 2007 [4]. The cumulative number of HIV People Living with HIV/AIDS (PLWH) in China reported at the end of October 2007 was 223,501, including 62,838 AIDS cases and 22,205 recorded deaths. The estimated result of the Ministry of Health, UNAIDS and WHO showed, by the end of 2007, approximately 700,000 people in China were HIV positive (range 550,000-850,000). The HIV prevalence among China's population is 0.05% (range 0.04-0.07%). Figure 1.2 shows the annual reported number of people who are HIV positive and living with AIDS in China since 1985. The cumulative number of PLWH in Yunnan, Henan, Guangxi, Xinjiang, Guangdong and Sichuan accounts for 80.5% of the total reported numbers in China [4].



	85-90	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007 1-10
AIDS	5	3	5	23	29	52	38	126	136	230	233	714	1028	6120	12652	7550	7909	8539
HIV/AIDS	492	216	261	274	531	1567	2649	3343	3306	4677	5201	8219	9732	21691	47606	40711	44070	39866

Fig. 1.2 Annual reported HIV positives and AIDS cases in China 1985-2007 (As of October 2007)

1.1.2.2 Transmission mode

By the end of October 2007, among the cumulative number of PLWH, 38.5% were infected via intravenous drug use (IDU), 19.3% were via former blood and plasma collection, 17.8% were through heterosexual transmissions, 1% through homosexual transmission, 4.3% via blood transfusion and blood products, and 1.2% through mother-to-child transmission (MTCT). The transmission mode for the remaining 17.9% was unknown [4].

1.1.2.3 Social roots of HIV epidemic in China

Social roots for the spread of AIDS in China include unbalanced development between eastern and western regions of the country, poverty, a huge mobile population, inadequate investment in public health, as well as social problems such as drug abuse and sex work [5].

Among the 700,000 PLWH in China, about 500,000 PLWH have not been identified. Meanwhile, the follow-up rate is low among the reported PLWH, due to the high mobility of the individuals and other difficulties in tracking and follow-up. The high proportion of PLWH who do not know their status and the difficulties of following-up HIV infected individuals are major risk-factors behind the potential for the further spread of the infection [4]. Furthermore, the risk behaviors of IDUs, men who have sex with men (MSM), and female sex workers (FSWs) play an important role on the emerging HIV infection in the past two decades.

Historically, IDU and commercial blood/plasma collection were the primary sources of HIV infection in China; but in recent years, infection through sexual transmission is growing

the fastest. Sexually transmitted cases have increased from 7.2% in 2002 to 43.6% in total infections by the end of 2005 [6]. In 2007, heterosexual transmission of HIV has accounted for 44.7% of new infection cases and become the dominant mode of HIV transmission. Meanwhile, the infection rate among MSM is increasing rapidly. Although the proportion of reported HIV/AIDS cases attributable to IDU has decreased, HIV prevalence among IDUs has increased [7, 8].

Drug use, especially injection drug use, is widespread in China and is a major contributor to the rapidly expanding HIV epidemic [9]. While HIV infections through all transmission routes are increasing in absolute numbers, the majority of HIV infections (43.9% of reported HIV cases) are still attributed to IDUs [9]. It has recently been reported that the HIV/AIDS epidemic is spreading into the general population in China [10]. Drug users may serve as a bridge linking HIV infection from the high-risk population to the low-risk population [11]. The number of registered drug users in China increased from 70,000 in 1990 to more than one million by the end of 2002. Due to underreporting, the actual number of drug users is far greater than the number reported [12]. Although drug use patterns vary from region to region in China, general trends suggest a shift from opium smoking to heroin that is either smoked or increasingly injected. Sharing needles and syringes is a common drug practice with rates as high as 60% or even greater in some regions [13, 14].

The trend of HIV spread from high-risk groups to the general populations also occurred mainly through sexual transmission [15]. While HIV prevalence across China remains low (0.05% in 2005), prevalence among FSWs exceeded 1% in some locations and was reported to be as high as 10% in some province [16, 17]. Surveillance data in 2007 shows that 60% of FSWs do not use condoms every time [4]. FSWs in China typically work in entertainment establishments (EEs) such as saunas, beauty parlors, karaoke bars, nightclubs, teahouses, reflexology (foot massage) parlors, and hotels, where managers provide them with the

opportunity to meet clients. Women who are not associated with EEs are low end FSWs working on the streets or in their rented residence [18]. Commercial sex work is illegal in China and periodic public security crackdowns force FSWs to go underground, but ultimately seem to have little effect on their numbers, which are estimated to be 4-6 million or even as high as 10 million [19].

There are between 2 and 8 million MSM in China, and the rapidly rising prevalence of HIV/AIDS among this high-risk population draws worldwide concern [20]. At the present time, MSM have become one of the high-risk groups for HIV infection and other sexually transmitted diseases (STDs) because of their active sexual activities without protection [21]. It is estimated that 70% of MSM have had sex with more than one partner in the past 6 months, and only 30% use condoms for anal sex, while 50% use condoms when they have commercial homosexual encounters [4].

Stigma and discrimination of PLWH remains a serious problem in HIV transmission. Because of this, individuals with high risk behaviors avoid voluntary HIV testing and PLWH are afraid to disclose their HIV status. This increases the risk of HIV spreading further. Field investigations showed nearly 40% of people shun contact with PLWH, and two-thirds of PLWH experience severe depression and may consider suicide. [4]. A study found that the levels of HIV/AIDS knowledge and acceptability of VCT among the Chinese adults were low. The main barriers to HIV testing included perceiving oneself as low risk, fear of unsolicited disclosure, and fear of stigma and discrimination that would result from taking the test [22].

1.1.2.4 Policies on Treatment and Care

For most of the PLWH in China, the provision of affordable and accessible

anti-retroviral therapy (ART) that patients can tolerate and doctors can readily supervise is a key challenge. On World AIDS Day 2003, Premier Jiabao Wen announced a national AIDS control policy; 'Four Frees and One Care' (free treatment, free Voluntary Counseling and Testing (VCT), free Prevention of Mother to Child Transmission (PMCT) and free schooling for AIDS orphans, and provision of social relief for HIV/AIDS patients) [5]. However, financial access to HIV care and treatment can be difficult for many people in China, where the government provides free antiretroviral drugs but does not cover the cost of other medically necessary components, such as lab tests and drugs for opportunistic infections [23].

The Chinese government began rolling out antiretroviral therapy (ART) in 2002 under the Four Frees, One Care policy and, by August 2008, the policy covered more than 52,000 patients [24]. Furthermore, in July 2004, the Ministries of Health and Finance, recognizing that opportunistic infections (OIs) also created a heavy financial burden for patients, directed provincial and local authorities in high HIV-prevalence areas to provide OI drugs at "no or reduced charge" for "AIDS patients in economic hardship" [25]. A number of provinces, including Henan, Anhui, Hubei and the relatively wealthy municipalities of Beijing and Guangzhou, have adopted policies subsidizing various aspects of care, from providing some OI drugs free of charge to covering a fixed amount of hospitalization costs per year [26, 27]. However, implementation of these policies can be uneven within provinces. In addition, a person must have *hukou* (an official residency registration card) to be eligible for these benefits, thus excluding many migrant workers. Furthermore, in the majority of the country not covered by such initiatives, cost is even more likely to be a barrier to accessing care [23].

With the government providing free testing and treatment, people living with HIV/AIDS and people at risk are now voluntarily seeking testing and collaborating more

frequently with health care workers. However, the relatively weak public health infrastructure of China, insufficient capacity of professionals on treatment and care to HIV/AIDS patients, and the limited versions of generic antiretroviral drugs made in China are still obstacles for PLWH in China in receiving sufficient support and care [5]. A national survey showed a cumulative immunologic treatment failure rate of 50% after 5 years free ARV treatment since 2002, due to the limited availability of second-line regimens [24].

1.1.2.5 Financial and manpower allocation on mental health care

Although mental health issues are increasingly being recognized by the government and health care workers in China, the financial resources allocated to this area of health remain very limited. Like other developing countries, China has grossly inadequate human resources and infrastructure to promote mental health. A review of mental health systems in various countries has reported that more than 60% of European countries spend more than 5% of their health budget on mental health care [28]. By contrast, the proportion of the mental health budget to total health budget is only 2.35% in China. China has fewer psychiatrists (1.29 per 100000 people) and psychiatric nurses (1.99 per 100000 people) than many high-income countries (10.5 and 33.0, respectively), such as the USA, the UK, Japan, Finland, and France [28]. It is therefore hardly surprising that the needs of China's millions of PLWH cannot at present be met.

1.2 Mental health problems faced by PLWH in the world

HIV infection affects all dimensions of a person's life: physical, including logical, social, and spiritual aspects. Though the life expectancy of PLWH has increased significantly with the advent of highly active antiretroviral treatment (HAART) [29], HIV

infection is regarded as a chronic illness and a traumatic and stressful experience. A diagnosis of HIV can lead to poor psychological adjustment, including self-blame, denial, fear of disclosure, stigma, low self-esteem, isolation and feelings of depression [30]. The PLWH face uncertainty not only with regard to physical survival, but also about medication, its side effects, and drug resistance, and experience a new life situation with numerous aspects of consideration including stigma, relationships with others, sexual life, economic cost of medication, potential impairments on employment-related issues, etc. [31].

1.2.1 Mental health problems at different stages of HIV infection

Notification of a positive HIV test result is usually associated with severe distress. Occasionally the reaction may be extreme and the person would require intense support [32]. Following infection there is usually a fairly long period of asymptomatic HIV infection, lasting 10 years on average or more. Anticipated losses, such as those affecting health and physical independence, employment, self-esteem, support of family and friends, and future, among many HIV infected persons, will need attention at this stage [33]. Among symptomatic individuals, the majority of surveys have found higher levels of anxiety, depression, and other psychological symptoms compared with negative controls, or with asymptomatic PLWH [34, 35]. Moreover, it has been shown that terminally ill people with AIDS feel less hopeful than similarly ill patients with cancer [36], possibly because of fears of rejection and isolation.

1.2.2 Depression among PLWH

1.2.2.1 Prevalence of depression among PLWH

The coexistence of depression and medical illness has been the focus of a great deal of attention in the past several years. Depression appears to occur in at least 25% of medical

patients, although estimates vary based on measurement criteria, type and stage of medical disease, and level of depressive severity [37]. Previous studies suggest that people with HIV often suffer from depression and anxiety disorders as they adjust to the HIV diagnosis, struggle with the meaning of a positive HIV test result, adapt to life with a chronic, life-threatening illness, anticipate and receive news of the disease progression, and witness the death of friends and family [38, 39]

Although prevalence estimates vary, the literature suggests that one-third to one-half of PLWH experience symptoms of depression. Depressive symptoms appear to vary by population, and have been observed in 30% of women [40], 21-58% of MSM [41-43], and 33% of IDUs of both genders [44]. Bing et al.[45] found a 36% one-year prevalence of depression among a large national sample of HIV-positive men and women in the United States. A meta-analysis of studies comparing HIV-positive with HIV negative samples showed that major depressive disorder occurred nearly twice as often among HIV-positive samples than HIV-negative patients [46].

1.2.2.2 The impact of depression to PLWH

Depressive symptoms can impact HIV disease outcomes through multiple mechanisms. Depression can reduce the motivation to seek health care, impair adherence to treatment, decrease quality of life, and increase mortality among people living with HIV/AIDS [47].

Depression and adherence to medical advice

Highly Active Antiretroviral Therapy (HAART) has been proven extremely effective in reducing morbidity and mortality of HIV infection [48]. However, it is not easy to take medication regularly and for long periods of time, especially if the regime is complicated, the tablets are many, side effects occur, and the process reminds the person of their illness.

Adherence is the degree to which a person's behaviors (e.g. taking medications, attending treatment sessions, executing lifestyle changes) coincides with medical or health advice [49]. Adherence is critical for the prevention and treatment of medical disease. Multiple studies have demonstrated that HIV-infected patients with high levels of ARV adherence (>90%–95%) have greater reductions of plasma HIV RNA levels, are more likely to achieve an undetectable viral load, and have better immunologic responses to HAART as measured by change in CD4 lymphocyte count [50-54].

Depression may influence the development and progression of disease directly via physiological pathways or indirectly via behavioral pathways [55]. Adherence to treatment regimens is one possible behavioral pathway by which depression affects physical health. Individuals who are depressed may be less likely to adhere to various aspects of their treatment regimens, and this lack of adherence may produce poorer health outcomes. Depressive symptoms have been indicated to be associated with lower levels of adherence to medication regimens, development of drug resistance HIV and treatment failure [56, 57]. Both prospective [58-60] and cross-sectional [61, 62] studies using measures of structured interview of medication adherence and BDI or CES-D for depression found a negative correlation between higher levels of depression and poorer levels of adherence.

Depression and disease progression among PLWH

Several studies indicated that depressive symptoms are associated with disease progression and death in individuals with HIV prior to the development of effective HIV antiretroviral therapies (e.g. HAART), and these associations have been magnified since the introduction of these more effective therapies [41, 63-69]. Depressive symptoms may impact survival and disease progression through biologic factors mediated through CD4 T and CD8 T cells [41, 63, 65]; CD56 and CD16 natural killer (NK) cells [70, 71] or through health-related

behaviors, since it has been shown that patients presenting depressive symptoms are more likely to have an early discontinuation or delayed initiation of HIV antiviral therapy [41, 55, 67, 72, 73]. A relationship between depression and faster disease progression and a decline in CD4 counts was reported [65]. In this study, women with chronic depressive symptoms were twice likely to die than women with limited or no depressive symptoms. Chronic depressive symptoms were also associated with significantly greater decline in CD4 cell counts, especially among women with baseline CD4 cell counts of less than 500 x 106/L and baseline viral load greater than 10000 copies/μL[65].

Depression and high risk behaviors among PLWH

Although many HIV positive persons reduce risk behaviors subsequent to learning that they are infected, a considerable number of HIV positive persons find this challenge difficult. For example, in Weinhardt et al's sample, 13% to 19% reported unprotected vaginal or anal intercourse with partners whose serostatus was negative or unknown [74]. Moreover, 18% of injecting drug users reported that they had shared injection needles with other partners [75]. Other individuals who are not aware of their serostatus may also transmit the disease. Seropositive persons continue to engage in unprotected sexual behaviors that place others at risk for infection and place themselves at risk for contracting secondary infections (e.g. syphilis, gonorrhea, herpes-virus-6) that may accelerate HIV disease [76, 77].

The mood states, such as depression, seem to subsequently affect people's sexual functioning including engaging in unsafe sex. Kelly et al. found in a small sample of HIV-positive men that the frequency of high-risk sexual practices was related to depression [78], and this trend was also found in other studies [79-82]. Risk behaviors including risky sexual practices or self-medication with alcohol or drugs were also an observed influence of depressive symptoms among HIV/AIDS. A study evaluated 375 depressed patients for

co-morbid drug dependence revealed that the onset of depressive episodes preceded alcohol dependence and drug abuse [83]. In another sample of 127 men and 15 women with HIV infection in the United States, high-risk behavior among persons with HIV infection was predicted by both recreational drug use and by higher levels of depression [80]. Associations between depression and HIV risk behaviors among IDUs have been described in several studies. Latkin and Mandell reported depression to be highly correlated with increased injection frequency [84]. Camacho etc. and Simpson etc. both described independent associations between injection risk behaviors (syringe and injection equipment sharing) and composite measures of psychological dysfunction that included depression [85, 86].

1.2.2.3 Factors related to depressive symptoms in PLWH

Many factors contribute to depressive symptoms in PLWH, including HIV disease and side effects associated with treatment [87]. Further, psychosocial factors like stress, optimism, social support, and coping strategies also correlate with depression in HIV-infected people [88, 89]. These factors influence components of interventions to reduce depression and improve the well-being of PLWH. For example, cognitive behavioral stress management interventions affect HIV viral load more than medication adherence training alone [90] and provide sustained reductions in depression [91]. Similarly, intervention techniques that focus on medication adherence and strategies to cope with stress significantly lower depression scores in depressed PLWH [92, 93].

1.2.3 HIV/AIDS-related stigma and discrimination

Another complicating and often compromising facet of living with HIV is HIV-related stigma. Stigma has been defined as 'an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society' [94]. Stigma may either be directly experienced by an individual or may be perceived, when the

individuals fear that negative attitudes or discrimination would occur if their HIV status was known by others. In the epidemic's third decade, one third of countries lack laws protecting people living with HIV from discrimination. According to nongovernmental reports, only 33% of countries use performance indicators or benchmarks for the reduction of HIV-related stigma and discrimination [2].

Recent research demonstrated that HIV-related stigma continues to be pervasive in Western countries [95]. For example, a majority of individuals involved in a Kaiser Family Foundation survey reported some discomfort with the idea of working with someone who was HIV-positive, with 30% reporting they were "somewhat comfortable" and 21% "not too comfortable" or "not comfortable." This survey also identified high levels of misconception about HIV transmission and found a relationship between these continuing misconceptions and stigma [96]. The high levels of stigma identified in the general population are reflected in the experiences of individuals with HIV. For example, in a study of women and men living with HIV in New York, 41% stated that others had acted negatively toward them after learning of their HIV status [97]. Rintamaki and colleagues found that 56% of men reported moderate-to-high levels of concern for stigma as a result of taking HIV medications [95]. High levels of stigma and discrimination have also been identified in less wealthy nations [98-100]. In a study of HIV-infected individuals in South Africa, one third of participants reported experiencing discrimination because of their HIV status, and over half reported fearing negative responses if they disclosed their HIV status [98].

HIV/AIDS-related stigma and discrimination have had a substantial impact on PLWH. HIV-related stigma leads to fear of HIV disclosure, social rejection [101], inadequate social support [102], suicidal thoughts[103], decreased self-esteem, and depression [104]. HIV-related stigma also may be a factor in determining lack of support in these individuals [102] and has been shown to be inversely related to knowledge of HIV transmission and access to

antiretroviral treatment [105] . Several studies also described an association of stigma with medication adherence [106] and increased risky sexual behavior [107] among individuals living with HIV/AIDS [108].

1.2.4 Quality of life among PLWH

Most people believe that HIV/AIDS is an exclusive consequence of homosexuality, commercial sex, and illicit drug abuse. In reality, the majority of HIV infection in China occurs in rural areas, usually among people with poor literacy and low income. Though the knowledge about HIV/AIDS was enhanced among PLWH and general population in recent years, the discrimination and stigmatization of HIV/AIDS patients in the community has inevitably led to a culture of denial. Without a supportive environment, these patients have suffered from serious stress and depression.

Impaired quality of life (QoL) is frequently observed, with depression in patients suffering from HIV infection [109]. Common problems include fear of dying, concerns regarding expensive treatment, feelings of guilt towards their family, loneliness, difficulty with adherence to rigid medication regimens, and physical and psychological discomfort associated with the infection and HAART treatment [110-113]. These factors have contributed to the deterioration of patients' quality of life (QoL), and have, in some cases, led to a hostile mentality and antisocial behavior [114].

1.3 Mental health study among PLWH in China

Most of the psychological data among HIV/AIDS sufferers is derived from the Western context and its generalizability to China is not known. The context of HIV infection in China differs from that in the West and is important to understand, as it may affect neuropsychiatric outcomes. Unlike the U.S., where the HIV epidemic started within the homosexual

population, HIV infection in China is concentrated in three high-risk populations: injection drug users (IDUs), commercial plasma donors, and sex workers. However, in recent years, the HIV epidemic has started to spread from these high-risk groups to the general population [115].

Mental health studies among PLWH in China are relatively rare and the results are seldom published in international journals. The rate of depression differs using different measures and among different populations. A study showed 92% mainland rural former blood donors (FBD) had moderate to severe depression using the Beck Depression Inventory [116]. Another study in China showed 97.53% HIV/AIDS patients had anxiety symptoms using HAMA (Hamilton anxiety scale) and 98.77% HIV/AIDS patients had depressive symptoms using HAMD (Hamilton depression scale) [117]. A relevant study in Hong Kong demonstrated 17.7% depression among HIV/AIDS people in Hong Kong using Profile of Mood States [118].

To testify whether findings in western countries pertain to China, the NeuroAIDS teams at the HIV Neurobehavioral Research Center (HNRC) at the University of California, San Diego (UCSD), China CDC, and the Mental Health Institute at Peking University conducted a neurocognitive feasibility study in China in early 2004. In this study, current (past week) severity of depressive symptoms was measured by the 21-item Chinese version of the Beck Depression Inventory (BDI-I). Findings of this study indicated that almost 79% of the HIV-positive group compared to 4% of HIV-negative group met criteria for lifetime major depression. HIV positive individuals also reported more depressive symptoms currently. In terms of current suicidal ideation (BDI-item 9), 64% in the HIV-positive group compared to 9% in HIV-negative group had some current suicidal thoughts. In those HIV-positive subjects who met major depressive disorder (MDD) criteria after HIV diagnosis, only 9% had received depression treatment, yet 18% had persisting active suicidal thoughts [119].

A study comparing PLWH (former plasma/blood donors) and non-PLWH in rural China indicated that PLWH reported higher prevalence of symptoms of depression, anxiety, and stress. Absence of HAART, poor physical function, and perceived discrimination from relatives and friends, were associated with depression, anxiety, and stress [120]. Another case control study conducted in Beijing showed a 79% of HIV-positive but just 4% of HIV-negative groups reported life-time major depression. In those HIV-positive subjects who met major depression disorder criteria after HIV diagnosis, only 9% had received depression treatment, yet 18% had persisting active suicidal thoughts. The evidence of high rates of major depression and suicidality in HIV-infected persons in China and few had sought mental health assistance, suggests a need to increase awareness of psychiatric comorbidity and access to mental health services [119].

There are several possibilities of the underlying causes of the seemingly higher rate of the major depression and suicidality among PLWH in China, compared to Western countries. First, the widespread belief in HIV infection as terminal illness, due to lack of HIV/AIDS education in China [121]. Second, social stigmatization may lead to more severe consequences (e.g., divorce, job loss, isolation) than those in some Western cultures [122]. Third, though free care and treatment were partly or fully provided to some of the PLWH by the government, the majority of the HIV/AIDS patients are still under a significant financial burden as a result of imperfect medical insurance and social welfare system [119]. High risk of depression among PLWH warrants the exploration of the relevant factors, and intervention for depression should be incorporated in the comprehensive care of these HIV infected persons.

Stigma and discrimination among PLWH in China

Although attitudes toward PLWH have improved since the Chinese government made

antiretroviral treatment available in 2002 and enacted generally strong legislative protection [123], HIV-related stigma is still widespread and believed to be a major factor limiting the willingness of individuals to seek HIV-related health care in China. The stigmatizing attitudes toward PLWH exist among general populations in rural and urban areas, and even among professionals of the health service centers. Exclusion and isolation are the primary manifestations of stigma in China [124] and PLWH are likely to lose jobs or chances to study if they disclose their HIV status [125]. A study conducted in rural China reported respectively 13.7%, 37.4%, and 38.4% PLWH perceived discrimination from their family members, relatives/friends, and neighbors [120].

A survey among 780 health professionals in Yunnan reported that 23% of health professionals thought HIV was a disease of 'low-class and illegal' people, 48% of health professionals thought that PLWH should not be allowed to get married, and 30% of the health professionals were unwilling to treat an HIV-infected individual [126]. Stigma associated with HIV may severely affect both physical and mental health. In one study in China, PLWH reported that stigma caused them to feel depressed, anxious, sad, valueless, and guilty and even caused psychiatric disorders [127]. Consistent with the findings from Western countries, stigma also has a negative effect on PLWH's access to health care, medication adherence, social interaction, and social support in China [128]. One of the reasons people hold negative attitudes toward PLWH is because of a low level of knowledge and frequent misconceptions about HIV infection. A survey of 12,270 persons in seven provinces in China showed that only 43% had accurate HIV knowledge [129]. In Anhui province, with one of the highest HIV prevalence rates in China, 17% of the rural residents had never heard of HIV or AIDS [130]. Although most people could recite the three main routes of HIV transmission, most also believed in the possibility of transmission through casual contact [124].

1.4 Stress-related study among PLWH

1.4.1 Psychological stress and its impact among PLWH

HIV/AIDS affects almost every aspect of a person's life and is associated with numerous stressors including relationships, employment, stigmatization and physical symptoms [131, 132]. The stress caused by these stressors appears to play an important role in the process of adaptation to HIV/AIDS [133]. Individuals with HIV disease face a variety of stressors that contribute to their overall levels of stress, but little is known about the dimensions of stress that are most problematic. There is some association between stress and drinking alcohol, smoking, and high-risk sexual behaviors among HIV/AIDS people [81]. Greater subjective life stress is also associated with an increased rate of early HIV disease progression in prospective research [47, 134]

1.4.2 Models used in the stress study among PLWH

The psychosocial researchers on HIV/AIDS study are often interested in several aspects of PLWH after they know their own HIV infection status, including the coping strategy PLWH have applied; the interaction of the individual resources and his/her environment; the reason some people's lives deteriorate in every aspect, whereas others can keep their life as well as, or surpass the quality they previously possessed. There are 3 major existing stress-related models elucidating the relationship between stress and other variables during the adjustment procedure.

Stress and coping model [135] applied to HIV/AIDS is based on the fundamental premise that adjustment to HV/AIDS infection is determined by illness parameters and three types of hypothesized mediational components: cognitive appraisal, coping strategies, and coping resources [133, 136]. This model has been adopted both by international researchers [89, 137] and

Chinese researchers [138] to find means to assist PLWH to cope with the numerous problems. The concepts in this model will be interpreted in detail in the following sections.

The stress-related growth model [139, 140] has also been used among individuals living with HIV/AIDS [141, 142] to explore positive change and the relevant factors contributing to growth in the lives of PLWH that they attribute to their illness experience. This model provides the groundwork to design interventions to promote growth such as positive health-related behavioral changes, improvements in social relationships, positive self changes, etc.

The stress moderator model provides a conceptual framework for assessing the client's resources as he or she attempts to address the psychosocial issues that may occur as a result of HIV infection. This model is suitable for use in the counseling process by the clinical psychologist to carry out cognitive behavioral interventions to acute and chronic stress of PLWH [143]. The model has four components: special characteristics of seropositivity, social support, situation and client characteristics. The first component of the model, *special characteristics of seropositivity*, underscores that a diagnosis of seropositivity is most likely catastrophic to nearly all who receive it. Every one who is infected experiences events including stigma, progressive deterioration (physical and neurological), and the timing in one's life when HIV infection occurs (typically, young adulthood, leading to premature death). This component provides the counselor with a sense of the boundaries in which responses to HIV infection can occur. *Social support* is the second component of the model. This component describes the interpersonal and institutional support networks available to the seropositive client. Interventions can be designed to increase social support, thus making it a useful focus of clinical work. *Situation*, the third component of the model, refers to the characteristics of HIV as a major life event including the source or cause of the client's becoming infected, timing, onset of symptoms, changes in roles, and stage of adjustment to

HIV infection (e.g., early adjustment, acceptance, preparation for death). *Client characteristics*, the final component of the model, refers to characteristics of the client including psychosocial competence, appraisal style, gender, race, state of health, and life-style cofactors. These characteristics might affect the progression of the disease as well as psychological responses to HIV infection. Many of these characteristics can be modified through clinical interventions and are therefore important to consider in a model of counseling [143]. This model has been widely utilized in cognitive-behavioral stress management among PLWH [144, 145].

Since little has been reported on patterns of coping and adaptation in persons with HIV disease in China and their psychological well-being of Chinese PLWH, this study represents an effort to address this gap in the research literature. Consistent with the recommendation that theory-driven models be used in HIV/AIDS adjustment research [146], the study was guided by a conceptual model of coping with chronic illness. The influential stress and coping model developed by Lazarus and Folkman's [135], conceptualizes adaptation to chronic illness as a function of the complex interplay of significant life events, disease/treatment factors, appraisal processes, external/internal personal resources and coping behavior. Elements of this model have been utilized in research on adjustment to a number of chronic illnesses, including HIV disease [147]. The purpose of this study is to find the stress confronted by Chinese PLWH, status of psychological well-being and the effect of psychosocial factors (coping resources and coping strategies) during the adjustment to HIV infection, based on the stress and coping model developed by Lazarus and Folkman in 1984. Therefore, stress-related growth model and the stress moderator model were not utilized in this study.

1.4.3 Stress and coping model

Stress and stressors

There are many formulations of the term stress. Lazarus stated that it is inappropriate to define psychological stress as either the stimulus or triggering event (the stressor) or as a response or reaction (organic reaction generated by the stressor) [148]. Lazarus and Folkman defined psychological stress as a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being [135]. This definition focuses on the transactional perspective of stress; both internal and external conditions must exist for a stress response to occur, and it is precisely the relation between them that generates the occurrence of stress and its individual characteristics. This explains why individuals can respond differently to the same stimulus and, depending on their history, experiences, and personal characteristics, they tend to manifest different interpretations and coping styles in each situation [149]. Stressors, namely the stress stimuli, are environmental events that have the potential for arousing threat. Lazarus and Cohen spoke of three types of stressors: major changes, often cataclysmic and affecting large numbers of persons, major changes affecting one or a few persons, and daily hassles [150].

Appraisal

Although certain environmental demands and pressures produce stress in substantial numbers of people, individual and group differences in the degree and kind of reaction are always evident. People and groups differ in their sensitivity and vulnerability to certain types of events, as well as in their interpretations and reactions. Cognitive appraisal has been defined as the evaluative process that reflects the person's subjective interpretation of an event in terms of threat, challenge, and controllability [135].

Coping strategy

In the stress and coping model developed by Lazarus and Folkman, coping is defined as

constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. Two major functions of coping are emotion-focused coping and problem-focused coping. In general, emotion-focused forms of coping are more likely to occur when there has been an appraisal that nothing can be done to modify harmful, threatening, or challenging environmental conditions. Problem-focused forms of coping, on the other hand, are more probable when such conditions are appraised as amenable to change [135].

Coping resources

The ways people actually cope depend heavily on the resources that are available to them and the constraints that inhibit use of these resources in the context of the specific encounter. Coping resources are relatively stable characteristics of an individual's disposition and environment, and refer to what is available when an individual evaluates a situation and develops their coping strategies [151, 152]. Optimism (an internal coping resource) and the availability of social support (an external coping resource) have received the most attention in the literature on coping resources and adjustment to chronic illness.

People's actions are greatly influenced by their expectations about the consequences of those actions. These expectancies are thought to be relatively stable across time and context, and as forming the basis of an important characteristic of personality. This characteristic is labeled as dispositional optimism, and formally defined as the tendency to believe that one will generally experience good vs. bad outcomes in life [153, 154]. Several perspective studies have linked optimism to better health [154] and better adjustment to failed medical procedures, such as in vitro fertilization [155]. A study examining the relationship between dispositional optimism and distress among a group of gay and bisexual men found that optimists reported significantly less distress than did pessimists among both the HIV positive and the HIV

negative men [156]. There are several pathways through which optimism may influence physical health and psychological well-being. First, optimism may influence people's efforts to avoid illness altogether by increasing attention to information about potential health threats [157]. Second, ample evidence suggests that optimism predicts active coping in stressful situations and lower levels of avoidant coping, denial, and disengagement [158, 159]. Third, optimists report taking better care of themselves when they have life-threatening illnesses, such as AIDS [160]. Optimism may also affect health outcomes through its influence on the maintenance of positive mood among people managing severe stressors [160, 161].

Social support can be defined as information from others that one is loved and cared for, esteemed and valued, and part of a network of communication and mutual obligations [162]. Previous research suggests that there are several types of support that may function as different kinds of resources [163, 164]. *Appraisal support* from others involves helping an individual to understand the stressful event better and what resources and coping strategies might be mustered to deal with the event. *Tangible assistance* involves the provision of material support, such as services, financial assistance, or goods. *Informational support* involves the provision of specific information about a stressful event and resources for coping with it. *Emotional support* reassures an individual that he or she is a valuable person cared for by others. These types of social support may operate proactively to offset or minimize stressful events before they become major stressors; they may operate to help reduce the impact of an existing stressor; or they may act as buffers against high levels of stress [161]. Social support is known to reduce psychological distress during stressful times [165] and may be especially helpful in reducing psychological distress in vulnerable populations, such as the elderly, the recently widowed, or victims of sudden severe life events such as PLWH [93, 166].

Stress and coping process

Regardless of how stressor, appraisal, coping strategy and coping resources are defined, the prime importance of stress and coping process is that they affect adaptational outcomes. When confronted with a stressor or constellation of stressors, individuals are hypothesized to consider their coping resources and, given these resources, to make a decision as to which coping responses to employ. In a relatively basic formulation of the stress and coping process, the constellation of stressors and the appraisal accordingly, coping resources, and coping responses will determine the extent to which the process leads to increased or decreased psychological distress [167].

The coping process is dynamic, with appraisal, coping, and emotion influencing each other as the coping process progresses and as the situation unfolds and changes [168]. A basic tenet of stress and coping theory is that the coping process needs to be assessed within the context of the stressful situation [135]. According to the theory, it is more useful to ask what people do to cope with a particular stressful event rather than to ask what they do to cope in general, because both the responses used and the effectiveness of those responses depend on characteristics of the situation [168].

1.4.4 Stress and coping study in HIV/AIDS

It has been well documented that, depend upon the way of coping and the level of social support, being HIV-infected affects people's mood states [169, 170]. In spite of the many health and social problems faced by PLWH, it is a remarkable fact that many people find effective ways of coping successfully with the impact of infection, making use of personal and external resources to deal with the difficulties, and at the same time avoiding the development of mental health problems. However, a substantial proportion of PLWH suffered substantial mental health difficulties, and it is very important to identify the factors that lead to such problems, so as to prevent their onset, if at all possible, by modifying these

causal factors, or by means of early identification of people experiencing problems [171].

1.4.4.1 Coping strategies

Presumably, success in coping with a chronic health threat is influenced by a number of factors, including available social and relationship supports, pre-existing general coping style, competing life stressors unrelated to HIV status, extent of clinical illness symptoms etc. Thus, it may be possible to identify factors that predict severity of emotional distress among people who have HIV infection. If so, information could be gained to potentially (a) identify persons who are at increased vulnerability for emotional distress associated with their HIV illness and who will require and benefit from intensive mental health follow-up, (b) identify factors that are associated with elevated distress and are therefore relevant to the content and aims of psychotherapeutic interventions, and (c) identify periods in the HIV illness spectrum when persons may be most vulnerable to distress and when psychological intervention is most needed [80].

The use of particular coping strategies was found to affect the level of stress and adaptation differentially. For example, coping by means of denial was associated with a more rapid progression to AIDS and higher levels of depression [71], whereas problem-focused coping was associated with a higher quality of life of PLWH [172]. Moneyham et al. reported research on coping in chronic conditions of HIV infection, and indicated that the use of avoidance coping strategies was consistently associated with increased psychological distress including anxiety, depression, and poor adjustment [173]. Moderating effect of coping strategy between stress and psychological health was also reported among HIV-infected persons in the previous empirical study [174-176].

1.4.4.2 Coping resources

Despite the research on psychosocial predictors has been focused on the negative predictors such as stressful life events and avoidant coping, the field of behavioral medicine is now expanding to incorporate a new focus on positive factors that may contribute to health outcomes [177]. Social support and optimism are most widely researched positive psychosocial predictors among PLWH.

Social support may be an important factor in attenuating the stress experienced by HIV-positive individuals. The stress-buffering hypothesis of social support [178] refers to protection that social support provides against the effects of stressful events and situations. This protective effect of social support is thought to operate both by contributing to the resources available to individuals to cope with the stressor, as well as by reducing the stress response to the stressor [178]. High levels of perceived social support were related to greater use of positive coping and seeking support; lower levels of social support were related to greater use of self-destructive coping [179]. Lower perceived social support has been shown to be a significant predictor of emotional distress among HIV-positive individuals [80]. However, the protective effect of social support was not unanimous among PLWH in the prior empirical studies. Some HIV studies have reported social support to be a predictor of better health; some others have failed to find a significant association, including one that found a negative association [180, 181].

Optimism is generalized expectation of positive outcomes. This disposition has received much attention in relation to health and adaptation to disease [154, 182]. Optimism may lead a person to cope more adaptively with stress and have better psychological well-being [154]. Optimism has been linked to positive emotion, effective problem solving, academic and occupational achievement, satisfaction with social relationships, better physical health,

health-promoting behaviors, and longer life [183]. Moreover, growing evidence suggests that the buffering effects of optimism are independent of the detrimental effects of depressive symptoms or its correlate pessimism [184]. Optimism has been found to moderate the impact of stress on psychological well-being among men with HIV [147]. Among PLWH, optimism was proved to be related to better ART adherence, less use of cigarettes or illicit drugs and higher CD4 counts.

1.4.5 Current existing stress scales

There are many instruments to measure psychological stress up to now.

The Perceived Stress Scale (PSS) [185] is a standard measure of general stress in one's life. It uses a 5-point response scale from never (0) to very often (4) to measure the degree to which situations in one's life are appraised as stressful. A number of studies have established its reliability and validity [186].

The Stress, Coping and Personality Inventory (SCOPE-i) was used to measure stress-related factors. This inventory was developed by the Department of Psychology, Institute of Mental Health, as a psychometric tool for assessing stress in the workplace. The inventory was divided into three sections- Part 1: Stress in the Workplace with 135 items measuring work overload, environmental stressors, responsibilities, personal constraints, role conflicts/ambiguity, organizational tension, career limitations, and relationship difficulties. Part 2: Personality factors with 80 items that measure hardiness, anxiety, optimism, hostility and perfectionism. Part 3: Coping Skills with 70 items that measure problem-focused coping, avoidance, seeking social support, and acceptance/growth [187].

Depression, Anxiety, and Stress Scale (DASS) consists of three self-reported subscales (each with 7 items) that have been designed to measure the negative emotional states of

depression, anxiety, and stress. Participants were asked to rate the extent to which they experienced each state over the past weeks on a 4-point Likert rating scale [188]. The stress subscale measures the psychological tension and agitation of the study subjects and has been proved a reliable subscale[188] .

Most other stress measures are situation or population specific scales: Caregiver Strain Index [189], African-American Women's Stress Scale (AWSS) [190], Stress scale for medical personnel [191], Instrument measures Stress among software professionals [192], etc. Furthermore, some scales are not directly measure the stress levels, instead they measure the stressors, such as the life events, daily hassles.

1.4.6 Stress measures used among PLWH

In order to accurately assess the role of stress in the process of adaptation to HIV/AIDS, it is important to differentiate between two stress-related concepts: stressful life-events, and the stress that results in accordance with how these life-events are appraised [136]. Stressful life-events are environmental demands, such as the characteristics of the illness and associated stressors of living with HIV/AIDS, which have the potential for arousing threat, whereas appraisal has been defined as an individual's subjective interpretation of a stressful life-event. When confronting environmental demands, individuals evaluate whether the demands pose a potential threat, or challenge (primary appraisal), and whether they have sufficient control over the situation (secondary appraisal). If an illness-related demand is appraised by an individual as taxing or threatening, and limiting opportunities for personal growth, and/or as uncontrollable, the event is likely to be perceived as stressful [135]. Measuring both of these components (the stressor and appraised stressfulness) of the stress-coping process is required in order to elucidate the role of stress in adaptation [193].

Limitations of existing measures of stress used among PLWH

Some of the published literature investigating stress in HIV/AIDS used structured interview schedules[68]. In this study, the researchers conducted a semi-structured interview using the Psychiatric Epidemiology Research Interview [194]. Subjects indicated which of the 111 stresses they had experienced during the preceding 6 months. Interviewers questioned participants in detail about the context of endorsed events and difficulties. The limitation of the interview schedules is their lack of systematic examination of the types of events perceived by PLWH.

Some other studies used the Perceived Stress Scale (PSS) or its modified version for HIV/AIDS research [58, 185, 195-197]. The Perceived Stress Scale is a 14-item measure of the degree to which life situations are appraised as "unpredictable, uncontrollable, and overloaded" [185]. In the area of HIV/AIDS, it has been found that perceived stress was related to a number of stressful events and rated stress of events [81, 185, 198]. The Chinese version of the Perceived Stress Scale had been validated in 2003 [199]. However, the scales have not undergone thorough test development strategies and consequently no validity or reliability data exists to support the use of these inventories among PLWH [200].

Many studies investigating stress in HIV/AIDS have utilized established generic life-event scales [201] or modified the Life Experiences Survey [202, 203]. These scales are not specific for HIV/AIDS and cannot indicate the stress among HIV/AIDS subjects culturally and situationally.

Some other researchers have developed life-event scales specifically for their HIV-related studies [81, 152], but they lack validity or reliable data in the study. Stressful life events developed by Nott KH [152] is a inventory based on the Gay Affect and Life Events Scale [204] including 34 items, producing three primary life-event values: an index of the overall stress experienced in the previous six months, the number of events experienced and

the mean stress value of these events. It had been completed with preliminary validation among 95 self-identified homosexual men.

Prior to this study, only one validated HIV stress scale was published, in 2002 by Pakenham [205], prior to the one developed in the present study. The study subjects are 132 homosexual/bisexual men with HIV/AIDS in Australia, and this scale did not mention the medication-related stress which is the greatest concern of Chinese PLWH with the advent of ARV therapy. Meanwhile, in terms of cultural differences, Chinese people are more concerned about family or financial issues, etc, and the influence of religion is not as powerful as in Western countries. Most PLWH desire to have a child to extend their life, but they are deeply afraid of transmitting HIV from mother to child. In addition, although the Chinese government has launched the free ARV therapy in some provinces, it has only covered part of the population up to now. As for opportunistic infection, the HIV/AIDS patients need to pay the medical expenses themselves and the PLWH in China face a heavy financial burden in the long run. Due to cultural differences and the difference of transmission categories between Australia and China, and the time which has passed since the study was initiated, large scale ARV therapy has been extended nowadays, therefore it is not quite appropriate to generalize this stress scale to HIV infected people in China.

Generally, validity will be context-dependent. A measure may be valid in one context and with one sample but not another. For example, an IQ test may be a valid measure of intelligence among Western, middle-class people but not among people from a very different cultural background unless rigorous validation process has been carried out to demonstrate its validity and reliability on this new target population [206]. The HIV/AIDS stress scale specifically for Chinese people will be useful in providing data to design psychological intervention to enhance the quality of life of those with HIV/AIDS and improve the health delivery services and social policies in China.

Chapter 2 Overview of the current study

2.1 Rationale of the study

2.1.1 Importance of stress-mental-health research and service gap

Advances in HIV treatment have resulted in PLWH living longer and led to heightened attention on co-morbidities such as mental health problems over the lifespan of PLWH [207]. The average rate of depression among PLWH worldwide is estimated to lie between 22 and 45% [208], while in China the rate of depression varies (70% to 90%) depending on measures used [116, 117, 119]. Mental health issues present challenges for risk reduction, adherence to care and quality of life of PLWH. Despite substantial attention to mental health problems among PLWH in the past decade, these problems continue to present a significant barrier to maintaining health and secondary prevention [207].

While sexual transmission of HIV infection has increased in recent years, historically the primary sources of HIV infection in China were IDU and commercial blood/plasma collections, [6] and most PLWH were extremely impoverished. Voluntary counseling and testing (VCT) for HIV is essential for prevention, access to care and treatment [209]. However, fear of unsolicited disclosure, stigma and discrimination are barriers for PLWH in accessing and using VCT and other relevant services from public resources [210].

In China, doctors in Centers for Disease Control and Prevention and hospitals are usually responsible for the surveillance, reporting, prevention screening and treatment of HIV. However, the public health infrastructure of China remains relatively weak. Hospitals and clinicians in some provinces of China were poorly equipped to manage AIDS-related opportunistic infections, as evidenced by the reported 49% AIDS mortality rate in 2002, and to prescribe antiretroviral therapy (ART) when it became available in 2003 and 2004 [211].

Though the competence of physicians in HIV care has improved significantly through training programs in recent years, there remains much room for improvement [212].

Besides the insufficient capacity of physicians working on HIV/AIDS in China, the proportion of the mental health budget to total health budget in China is much lower than in European countries (2.35% vs. 5%). Also, China has fewer psychiatrists and psychiatric nurses than many high-income countries, such as the USA [28]. Although Chinese mental health policy is increasingly emphasizing community-based care over institutionalized care, the actual development of community services in nearly all of China is still in the initial stages of development [213]. In addition, China still lacks mental health legislation at the national level, while 78% of countries , were covered by mental health laws in 2005 [214]. This has provided PLWH in China, especially those living in rural and poor urban areas, with fewer opportunities for care relative to the rest of the world. .

Furthermore, though the Chinese government has provided free testing and treatment for HIV for several years [25], the treatment and care policies in China have been implemented unevenly in different regions. For instance, a person must have an official residency registration card in order to be eligible for certain treatment and care services in certain provinces, and the cost of treatment is often a barrier to accessing appropriate care [23]. Also, PLWH in China often suffer from immunologic treatment failure due to the limited availability of second-line regimens [213].

In summary, insufficient capacity of professionals to treat and care for people with HIV/AIDS [28], widespread stigma and institutional discrimination [215], and imperfect treatment and care policies in China [213] remain obstacles for PLWH in China in receiving adequate support and care. As a result, poor mental health status among Chinese PLWH is common.

2.1.2 Socio-cultural differences between China and Western countries

Stigma associated with HIV/AIDS stems from the underlying stigmatization of sex (e.g., homosexuality and sex work) and intravenous drug use, the two main paths of HIV transmission globally [216]. Thus, PLWH often carry a double stigma: towards the disease itself, and towards the associated deviant behavior [217, 218]. PLWH are often blamed for their wrongdoings: for men, this would include behaviors such as being homosexual or bisexual or having sex with sex workers, and for women, being commercial sex workers [219].

In China, a conservative country influenced by a thousand years of Confucianism, homosexuality, prostitution and IDU are widely stigmatized [129]. In contrast, although opposition toward lesbian, gay, bisexual, and transgender (LGBT) rights remains prevalent among Western populations [220], the hostile feelings might not as strong as in China, since some Western countries have legislation to protect these population and their rights [221]. Compare to Chinese culture, Western culture is more tolerant to such behaviors. Also, laws regulating sex work in China are more stringent compared to some Western countries. In some Western countries, prostitution is either legal or considered a grey zone though accompanied with many types of criminality such as women and drug trafficking [222].

When exploring issues related to coping strategies, past studies have sought to consider the influence of social context on coping with difficulties [223]. While Western societies stress individualism, Chinese societies place more importance and emphasis on collectivism. In Chinese societies, social relationships comprise the basis of individual status. Maintaining social relationships is more important than pursuing personal goals [224]. In China, a person is educated to be responsible to the family and society. However, the stigma and discrimination associated with HIV in China renders it difficult for PLWH to disclose diagnostic information to family members [122]. A person may feel disgraced (losing face) if

others know about his/her HIV infection. Continuity of the family tree is also important in traditional Chinese culture [225]. Under the one-child policy [226], the family line risks being discontinued through a person with HIV choosing not to have a child or infecting the child vertically.

An increase in spirituality/religiousness after HIV diagnoses are made has been reported, and this has been associated with better health outcomes [227]. In China, though the effect of religion is emerging in recent years, atheism was dominant several decades ago under the rule of Chinese Communist Party.[228] . Also, while some PLWH may adopt certain forms of thought avoidance, such as fatalism, others may be optimistic and active in coping with the disease [229].

2.1.3 Stress-mental health research among PLWH in China

Because the HIV epidemic, its social context and the services provided to PLWH in China differ from Western countries, it is important to examine and understand the role of psychosocial factors during the process of adjustment to HIV infection in order to provide appropriate services to Chinese PLWH.

In the West, the stress and coping model [135] is often used to explain stress and coping processes when people are confronted by stressful events. The model suggests that an individual experiences stress when stressors and daily hassles exceed his/her resources. Such stress may cause serious emotional distress, including depression and poor quality of life [230]; however, coping resources and coping strategies can either buffer or eliminate the effect of stress and, thus, decrease depressive symptomatology and improve quality of life.

There are few evidence-based studies that thoroughly investigate stress perception, coping resources, coping strategies, and psychological well-being experienced by PLWH in

China Due to the socio-cultural differences between Western and China alluded to previously, conceptual frameworks of stress and coping may be very different in these two contexts. Therefore, the aim of this study was not to test existing theories, but rather to develop a new conceptual framework suitable for Chinese PLWH and provide an empirical and exploratory basis for future theory building.

Therefore, we developed a perceived stress scale suitable for Chinese PLWH with items generated from patients' perspectives. The Brief COPE inventory was also validated among Chinese PLWH. Based on the validated Chinese instruments, psychosocial factors, levels of psychological well-being, and the determinants of perceived stress and psychological well-being were examined. The main effect and moderating effects of coping resources and coping strategies on the effect of perceived stress to psychological well-being were investigated. The results of the present study suggest that stress management interventions can be carried out by focusing on specific stress aspects and providing appropriate coping resources and coping strategies, hence improving the psychological well-being of PLWH. Also, within this framework, it is possible to develop a specific stress and coping model that accurately describes the situation among PLWH in China and provide theory-based evidence for further research.

2.2 Aims and hypothesis

The aims of the present study are:

(1) To develop a new perceived stress scale among PLWH in China via a 'bottom-up' approach.

Initial domains of the scale were identified through literature review, in-depth interviews and panel discussion. The initial domains of the scale were generated from

in-depth interviews with PLWH and doctors managing PLWH. After the initial domains were identified, PLWH with different acquisition routes of HIV were interviewed to collect the items of the scale. The collected items were then independently reviewed by a panel which considered their clarity, potential redundancy, and the ratings attached to the items. A questionnaire survey was then conducted for the validation study of the scale. Exploratory factor analysis was performed to identify factors. The reliability and validity of the scale were also tested.

(2) To validate the Brief COPE inventory (COPEHIV) among Chinese PLWH.

Coping is an important and commonly used component in psychological studies. The factor structure of the Brief COPE inventory was examined before use in this study. Confirmatory factor analysis was first used to test two previously specified conceptual structures of the Brief COPE. Upon poor fit of previous models, exploratory factor analysis was performed to investigate the structure of the Brief COPE. Six new factors were derived and found to have acceptable psychometric properties specifically reflecting the Chinese cultural context.

(3) To describe levels/patterns of perceived discrimination, stress, coping resources, coping strategies and psychological outcomes.

Stress, coping resources and coping strategies are the main elements of the previous stress and coping model. Perceived discrimination was assumed to be one of the major stressors of PLWH in China. Optimism and social support were adopted as main coping resources in this study. Depression and Qol were used as variables of psychological well-being. To understand the importance of PLWH's adjustment processes, descriptive analysis was utilized to examine the status of psychological well-being, commonly endured stress types, key coping strategies and levels of coping resources/discrimination

across background factors (e.g. SES, transmission route). To determine the patterns of stress levels among individuals, we clustered participants on the basis of their eight stress domains of PSSHIV using Ward's method [231]. Prevalence of depression was calculated using the cut-off values of BDI-II provided by the Chinese Behavioral Sciences Society [232].

(4) To investigate determinants of the PSSHIV.

This aim investigated: 1) the levels of perceived discrimination, optimism, social support and perceived stress among PLHW in China, and associations between background variables (demographic, socio-economic and HIV-related variables) and perceived stress; 2) whether perceived discrimination was a risk factor for perceived stress, whilst optimism and social support were protective factors of perceived stress; 3) whether social support and optimism moderate the association between HIV-related perceived discrimination and perceived stress among PLWH. Such multiplicative interaction effects have not been reported in the literature.

(5) To investigate relationships between perceived discrimination, PSSHIV, resources, coping strategies and psychological well-being (depression and quality of life).

The hypotheses tested include 1) whether the stressor and stress have independent effects on psychosocial well-being, 2) whether coping resources have independent and additional effects to those of the stressor-stress model on psychosocial well-being, 3) whether coping resources interact with stress to determine psychosocial well-being, 4) whether coping strategies have independent and additional effects to the model containing the stressor, stress, coping resource variables and, 5) whether coping strategies interact with stress to determine psychosocial well-being.

A model containing socio-demographic variables was fit first, then other variables (perceived discrimination, perceived stress, coping resources, interaction terms between coping resources and perceived stress, coping strategies, interaction terms between coping strategies and perceived stress) were sequentially added to see whether these variables improved model fitness

2.3 Guiding definitions

Psychological stress is defined as a relationship between the person and the environment that is being appraised by the person as taxing or exceeding his or her resources and hence endangering his or her well-being [135].

Coping resources are relatively stable characteristics of an individual's disposition and environment, and refer to what is available when an individual evaluates a situation and develops his or her coping strategies [151, 152]. Optimism (an internal coping resource) and the availability of social support (an external coping resource) have received the most attention in the literature on coping resources and adjustment to chronic illness.

Construed as dispositional rather than situation-specific, *optimism* has been defined as the generalized expectation of favorable outcomes [153].

Social support is a multidimensional construct broadly defined as the 'psychological and material resources available to individuals through their interpersonal relationships '[social network]' [233].

Coping has been defined as constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person [135].

2.4 Structure of the present study

This dissertation consists of 10 chapters in total. Apart from the literature review, methods, and concluding chapters (chapters 1 to 3 and chapter 10), this study consists of 3 main parts. Part one is the instrumentation part (chapters 4 and 5) in which PSSHIV and the Brief COPE were developed and validated; part 2 describes the levels/patterns of discrimination, stress, coping resources, coping strategies and psychological well-being of PLWH (chapters 6 and 7); and part 3 investigates the determinants of perceived stress and psychological well-being in PLWH (chapters 8 and 9).

Chapter 1 is a literature review related to the current thesis, covering the HIV/AIDS epidemic, mental health problems faced by PLHW, mental health studies among PLWH in China, stress-related studies among PLWH, and includes an overview of the present study.

Chapter 2 introduces the rationale, aims and hypothesis of the study.

Chapter 3 describes the study subjects and methods. Information about study sites (Hengyang and Shenzhen), recruitment methods, measurements and statistical analysis are listed. Two surveys were conducted for this dissertation. Firstly, a HIV/AIDS specific perceived stress scale was developed and validated through a qualitative study and a cross-sectional survey (survey one). Domains and items of the scale were collected from PLWH and the doctors providing treatment and care for them. A series of exploratory factor analyses (EFA) were conducted to generate the structure of the scale. Based on the EFA, correlations between the stress subscales and several other measures related to perceived stress were performed to test the construct validity of the scale. Survey two was also carried out in Hengyang and Shenzhen. It recruited those who had not participated in survey one. Measurements including the perceived discrimination scale, the perceived stress scale developed from survey one, and scales measuring other elements in the stress

and coping model such as coping resources (optimism and social support), coping strategies and psychological well-being (depression and health distress) were included.

Chapter 4 describes the procedure and results of developing the perceived stress scale for people living with HIV/AIDS in China. A qualitative study was conducted first to identify the initial domains of the perceived stress scale. Based on this, items were collected and cleaned for further factor analysis. Through a series of EFA, eight subscales were extracted and shown to have good reliability and construct validity. The eight subscales are: social/psychological problems, sexual relationship, functional problems, social acceptance/rejection, work-related issues, family/offspring concerns, accessibility to medical treatments, and concerns about medical treatment outcomes. The Cronbach's alphas of the eight subscales were satisfactory. The correlations between the subscales and other relevant measures (the global Perceived Stress Scale, the Medical Outcomes Study HIV Health Survey and the Depression, Anxiety and Stress Scale) showed good construct validity of the newly developed perceived stress scale.

In Chapter 5, confirmatory factor analysis (CFA) was performed first to test if the structures used were suitable for the present data. The 14 separate subscales of the original Brief COPE were shown to have a relatively low Cronbach's alpha and thus not be acceptable in psychological studies. Furthermore, the combined subscales used in previous studies (adaptive versus maladaptive coping; Emotion-focused coping, Problem-focused coping and Dysfunctional coping strategies) were also shown to have a poor fit with the current data in CFA. After finding that the structures used in previous studies did not fit the data well, the structure of the Brief COPE was explored using EFA, and six factors were generated. The six factors were named 'Problem-solving and Acceptance', 'Negative Venting and Avoidance', 'Support Seeking', 'Self-blame and Denial' 'Reliance on Spirituality' and 'Humor and Self-distraction'. These six factors appeared to have

acceptable reliability and validity.

Chapter 6 is about the distinction of groups of individuals characterized as having different profiles of stress levels when confronted with HIV infection. A series of cluster analyses were utilized and two stress groups (high stress and low stress group) were identified. Characteristics such as individual variables (optimism, coping strategies), relationship variables (social support, perceived discrimination) and psychological status (depression and QoL) were compared between the different groups.

Chapter 7 describes the distribution of perceived discrimination, coping resources, coping strategies and psychological well-being (depression and health distress) across different background characteristics of the study participants. This chapter also describes the prevalence of depression using cut-offs of the Chinese version of the Beck Depression Inventory II (C-BDI-II) across the overall sample and different background groups. Univariate and multivariate analysis were applied to determine relevant background variables related to the above variables.

Chapter 8 investigates the risk factors (perceived discrimination) and protective factors (optimism and social support) for perceived stress; and examines whether optimism and social support could moderate the effect of perceived discrimination on perceived stress. Perceived discrimination was found to be a significant factor in predicting perceived stress, while optimism and social support did not moderate the effect of perceived discrimination on perceived stress. The determinants of stress subscales were also investigated.

Chapter 9 examines the predictive effect of perceived discrimination and perceived stress on psychological well-being (represented by the depression and health distress domains of quality of life) first. A model containing socio-demographic variables was

applied first, followed by perceived discrimination, perceived stress, coping resources. Interaction terms between coping resources and perceived stress, and coping strategies and their interaction terms with perceived stress were sequentially added to the model.

Chapter 10 is the concluding chapter. The overall results, limitations and implications of the study are summarized.

2.5 Summary

This study is one of the first to look at the effects of stress and coping processes on the psychological well-being of PLWH in China using exploratory methods. Instead of using existing instruments and theories, we built up our own instruments in the Chinese context and empirically investigated the relationships between variables.

Chapter 3 Subjects and methods

3.1 The study sites

3.1.1 Hengyang of Hunan Province

Hunan province is a main entrance for drug traffic from south-west China to mainland China. It is among the provinces having top numbers of drug users. Till the end of 2007, there were around 59,000 heroin addicts in the Hunan province and the number of estimated drug-users was over 200,000. Most of the drug-users are injecting drug-users, who are highly prone to HIV infection via syringe-sharing behavior. The entertainment establishments-based sex workers and clients might be another cause of the HIV epidemic. Furthermore, the numbers of migrant workers was up to 10 million till year 2006, and these people lack HIV/AIDS relevant education and knowledge and are more inclined to be part of the population acquiring and transmitting HIV.
(Source: http://www.hn.chinanews.com.cn/news/szws/20071130/25286.shtml, Hunan province CDC and Hengyang city CDC).

Hengyang city is located in the south of Hunan province. It is the biggest city and the center of politics, economics and the culture of southern Hunan. It is also a traffic hinge connecting south and north China and east and west China. Since the first HIV case detected in overseas returnee workers, the number of accumulated HIV/AIDS cases in Hunan province was around 4,700 by the end of 2007. Hengyang city is the area with the most severe HIV epidemic in Hunan province, and accounts for 44.67% (over 2000 cases) of the total infected cases in Hunan province. The main transmission category is injecting drug use (86.7%) (unpublished data from Hengyang CDC).

3.1.2 Shenzhen of Guangdong Province

Shenzhen is located in the southern part of the Guangdong Province, on the eastern shore of the Pearl River Delta. Neighboring the Pearl River Delta and Hong Kong (located just south of Shenzhen), Shenzhen's location gives it a geographical advantage for economic development. In 1980, the first Special Economic Zone of China was built in Shenzhen. From then on, Shenzhen became a highlighted city of China, one known for its rapid economic growth. Shenzhen is one of the most developed cities in the Chinese market economy, with a population of around 12 million, but among them only about two million registered as permanent residents. Each year, more and more people come to Shenzhen to try to find employment. As a result, the city has become increasingly crowded.

Shenzhen city began to carry out HIV surveillance from 1988, and the first HIV case was found in 1992. Up to now the six district CDCs in Shenzhen city are all eligible to perform HIV screening and the Shenzhen city CDC is responsible for conducting the confirmatory test. With the scaling up of the HIV surveillance, more and more people received HIV screening test voluntarily and passively and a huge number of HIV/AIDS cases were reported. The accumulated number of the overall reported HIV/AIDS cases at the end of 2008 was around 3,000. The reported number of detected HIV/AIDS cases in 2008 increased by 36.3% compared to 2007 (unpublished data from Shenzhen CDC).

The ratio of male to female HIV/AIDS cases in Shenzhen was about 3:1 to 4:1. Most of the cases were under 40 years old and fewer than 40% had a senior high school or above education. Detected HIV/AIDS cases came from almost all provinces, cities and autonomous regions, even Hong Kong and Taiwan. In 2008, the major HIV transmission category of the confirmed HIV cases was changed from IDU to sexual transmission (27.6%

vs. 61.1%). This indicated the critical role of the prevention of sexual transmission of HIV (unpublished data from Shenzhen CDC).

3.2 Survey one: Development of the Perceived Stress Scale for PLWH

3.2.1. Aims

The main purpose of survey one is to develop and validate a new Perceived Stress Scale for PLWH in China. Such scale is potentially useful in service provision and evaluation of intervention.

3.2.2 Recruitment of study participants

Survey one consists of two parts: Item generation study (study 1) and validation study (study 2). The inclusion criteria were the same for both studies: Chinese PLWH who were 18 and 60 years old and had known about their HIV seropositive status for at least 2 months.

A total of 273 PLWH were recruited from Shenzhen city (Guangdong Province, China) and Hengyang city (Hunan Province, China) by convenience sampling during September 2006 through July 2007. They were invited by doctors from CDCs via telephone number they left at CDC or invited at the time they found services (CD4 test or counseling); patients went to HIV clinics or MMT clinic were also referred to the trained interviewers by the doctors on duty. With written informed consent, they were interviewed face-to-face by trained interviewers in private rooms in the local CDC. 73 of the PLWH participated in the study 1. Among them, 28 PLWH from Shenzhen and 30 PLWH from Hengyang received an in-depth interview from the author of the thesis; 15 PLWH in Hengyang received pilot test for questionnaire administered by the author of the dissertation and 2 doctors in Hengyang CDC. The rest of 200 study participants completed questionnaire interviews of validity study for the HIV/AIDS stress scale in study 2. 143 of them were from Shenzhen and 57 of

them were from Hengyang. The overall response rates for study one and Study 2 were respectively 86% and 77% (number of individuals being interviewed divided by the number of individuals being approached).

Five doctors and one nurse from the Shenzhen CDC, and three doctors from the Hengyang CDC administered the face-to-face interviews. They were trained by the first author on the questionnaire structure, the logistics of the study and interviewing skills. The interviewers cross-checked the questionnaires on sites. No personal information was recorded in the questionnaire and a monetary reimbursement of 50 yuan (6.25 US$) was offered to the participants for their time used in the interview. Approval was obtained from the ethics committee of the Chinese University of Hong Kong. The response rates for Study 1 and Study 2 were respectively 86% and 77% (number of individuals being interviewed divided by the number of individuals being approached).

3.2.3 Measurements

Background characteristics

Participants were asked to report information about their background characteristics such as age, gender, educational level, marital status, working status. Participants were also asked how they thought HIV had been transmitted in their case, whether they were on antiretroviral treatment and how long they had been diagnosed with HIV.

The Perceived Stress Scale

The Perceived Stress Scale (PSS) was used in this study. It consists of 14 items, using a 5-point response scale from never (0) to very often (4). It was significantly correlated with a number of stressful events, and rated level of stress in PLWH and in other populations [81, 185]. The Chinese version of The Perceived Stress Scale was validated; the Cronbach's alpha was

0.78 [199].

The Medical Outcomes Study HIV Health Survey

The Medical Outcomes Study HIV Health Survey (MOS-HIV) was used to assess the Quality of life (QoL) among HIV-infected people [31, 234]. It has 10 domains (namely, general health, physical function, role function, social function, cognitive function, pain, mental health, energy/fatigue, health distress, and quality of life) and a single item of health transition. It was used to evaluate effectiveness of treatments and programs, as well as factors predicting well-being of PLWH [235, 236]. A Chinese version (35 items) of MOS-HIV was validated, with the Cronbach's alpha of the subscales ranging from 0.78 to 0.90 [237].

The Depression, Anxiety, and Stress Scale

In this study, the brief version of The Depression, Anxiety, and Stress Scale (DASS-21), which consists of three self-reported subscales (each with 7 items) was used to measure the negative emotional states of depression, anxiety and stress [238]. Participants rated it according to their experience over the past weeks on a 4-point Likert rating scale from not apply at all (0) to most of the time (3). The Chinese version of DASS-21 was validated in 2001 among an immigrant Chinese population in Australia [239].

3.2.4 Statistical analysis

A series of exploratory factor analysis (EFA) were conducted to identify the potential structure of the Perceived Stress Scale among PLWH. After the underlying dimensions were determined via EFA, item-total correlation coefficients, split-half correlation coefficients and Cronbach's alpha values were calculated to evaluate the internal reliability. Pearson correlations were conducted to identify the concurrent validity of the scale.

3.3 Survey 2: Stress, coping and psychological adjustment among PLWH

3.3.1 Aims

In the second survey of the study, we examined the construct of the Brief COPE and the interrelationship of perceived discrimination, optimism, social support, perceived stress, coping strategies and psychological well-being (depression and health distress) among PLWH.

3.3.2 Recruitment of study participants

Procedure and participants

The study population included mainland Chinese PLWH between the ages of 18 to 60 years whose positive HIV status had been confirmed for at least three months. From September 2007 through January 2008, 193 PLWH were recruited from Hengyang, Hunan Province (IDU: 67.2%, heterosexuals: 20.8%, MSM: 3.1%) and 65 PLWH were recruited from Shenzhen, Guangdong Province (IDU:6.2%, heterosexuals: 43.1%, MSM: 33.8%). The participants were recruited from Centers for Disease Control and Preventions (CDCs), HIV clinic in hospital and Methadone Maintenance Treatment (MMT) clinic. Participants were only interviewed once in the case that an individual was identified by multiple sources. PLWH were contacted via phone or invited while they were utilizing some HIV-related services (such as having CD4 test, attending MMT clinic, counseling from the hospital/CDCs or when receiving prescribed drugs from the hospital).

In Hengyang, respectively 69 and 200 PLWH with phone numbers kept in the registries in Hengyang CDC and the third hospitals were approached by phone and being invited to join the study. At least 2 calls were made before a phone number was considered to be invalid. Among the 269 phone numbers approached from the two sources, 139 eligible

PLWH were contacted via phone calls and 100 of them (71.9%) participated in the study. 82 other respondents (19 from the Hengyang CDC, 60 from the 3rd hospital) were invited to join the study while they were utilizing some HIV-related services and 65 (79.3%) joined the study. A total of 35 (had not been invited from the CDC and the 3rd hospital) PLWH who attended the MMT clinic were invited to join the study and 28 (80%) of them completed the questionnaire. In Shenzhen, 95 phone numbers of PLWH were selected from the registry kept by the CDC; 60 respondents were contacted via phone and 40 of them (66.7%) participated in the study. In addition, 31 PLWH were contacted while they were utilizing some HIV-related services (e.g. CD4 test) and 25 (80.6%) of them joined the study. The overall response rates, defined as the number of participants completed the questionnaire divided by the number of participants invited to take part in the study, were 71.4 % in Shenzhen and 75.4% in Hengyang.

Respondents were briefed about the purpose of the study and assured that confidentiality would be maintained. After providing written informed consent, study participants were interviewed face-to-face in a private room within the local CDCs or the hospitals/clinics. The Hengyang participants were interviewed by the first author and two other well-trained doctors from the local CDC, whilst the Shenzhen participants were interviewed by the first author and a doctor from the local CDC. No personal information was recorded in the questionnaire and a monetary incentive of 50 Yuan (US$6.25) was offered to the participants for giving up their time to take part in the interview. Approval was obtained from the ethics committee of the Chinese University of Hong Kong.

3.3.3. Measurements

Background characteristics

Information was collected about participants' background characteristics (age, gender,

educational level, marital status, income, employment). Participants were also asked how they thought HIV had been transmitted in their case, whether they were on antiretroviral treatment, and how long they had been diagnosed with HIV.

The perceived stress scale among People Living with HIV/AIDS in China

A 35-item PSSHIV (with eight subscales) has recently been developed and fully validated among HIV-infected persons in China [240]. The item responses are rated using a 5-point Likert scale from not at all stressful (1) to extremely stressful (5). It exhibits good internal consistency (Cronbach's alpha =0.76 to 0.94 for the overall scale and the 8 subscales) and construct validity. In this study, the Cronbach's alpha for the overall scale and the 8 subscales were 0.81 to 0.94.

The Perceived Social Support Scale (PSSS)

The PSSS is a validated 12-item instrument, assessing perceived support arising from three 'factor groups' (namely family, friends, and significant others) [241]. The item responses are rated using a 7-point Likert scale from very strongly disagree (1) to very strongly agree (7). The scores range from 12 to 84, with a higher score indicating a higher level of perceived support. The Chinese version of the PSSS was validated in a study conducted some years ago, and showed good internal reliability (Cronbach's alpha =0.89) [242]. In this study, the Cronbach's alpha value was 0.89.

The Chinese version of the revised Life Orientation Test (CLOT-R)

Optimism was measured by the Chinese version of the revised Life Orientation Test (CLOT-R) [243, 244]. It consists of three positively worded items (e.g. 'I am always optimistic about my future') and three negatively worded items (e.g. 'I hardly expect things to go my way'). The item responses are rated using a 5-point Likert scale from strongly disagree (0) to

strongly agree (4). It has shown to be a reliable and valid index of optimism [244, 245]. In this study, Cronbach's alpha was 0.54.

Perceived Discrimination Scale for PLWH (PDSHIV)

The PDSHIV was constructed for this study. Based on literature review [246, 247] and discussion with PLWH, six items were generated: 'Family members are unwilling to live with PLWH', 'Health care workers would refuse to provide services to you or would provide services to you at a lower quality', 'Friends are reluctant to be affiliated with PLWH', 'PLWH would be fired if the employer knew of their HIV status', 'Most people would discriminate against PLWH', 'Family members of PLWH are looked down upon by their relatives and neighbors'. Item responses are rated using a 4-point Likert scale from not true at all (0) to absolutely true (3). A higher score indicates a higher level of perceived discrimination. Based on the six items, only one factor was generated from an exploratory factor analysis, explaining 41.9% of the total variance. The composite scale had an alpha value of 0.70.

Brief COPE

The strategies adopted by PLWH to cope with stress in the prior 3 months were assessed by the 28-item Brief COPE, which has 14 two-item subscales. The Cronbach's alpha for the original subscales ranged from 0.50 (Venting) to 0.90 (Substance Use) [248]. Item responses of the Chinese Brief COPE [249] are rated using a 4-point Likert scale from not doing it at all (1) to doing it a lot (4).

The Chinese version of Beck Depression Inventory (C-BDI-II)

The Chinese version of the Beck Depression Inventory II (C-BDI-II) was used to assess depression. BDI-II [232] is a self-report instrument for measuring the severity of clinical

depression in adolescents and adults. Each of its 21 items is scored from 0 (absent) to 3 (severe), and total scores can range from 0 to 63. BDI-II has been widely used among PLWH for measuring levels of depression among them [250-252]. The C-BDI-II was authorized for use in this study by the Chinese Behavioral Sciences Society. The manual of the C-BDI-II suggests the cut-off value of '0-13' as normal, '14-19' as mild, '20-28' as medium and '29-63' as severe. It has been proved to have good reliability (Cronbach's alpha=0.86) and factorial structure [253, 254]. In this study, the Cronbach's alpha was 0.93.

Health distress subscale of Medical Outcomes Study HIV Health Survey (MOS-HIV)

MOS-HIV is one of the most widely used instruments to assess the Quality of Life (QoL) among HIV-infected people [255]. The MOS-HIV measures 10 domains, namely General Health, Physical Function, Role Function, Social Function, Cognitive Function, Pain, Mental Health, Energy/Fatigue, Health Distress, and Quality of Life. MOS-HIV had been used to investigate effectiveness of treatments and programs, and factors predicting well-being of PLWH [234, 236]. A Chinese version (35 items) of MOS-HIV was validated and the Cronbach's alpha of the health distress subscale was 0.90 [237]. In this study, the health distress subscale of MOS-HIV was used to measure the mental health aspect of quality of life. Item responses of the health distress subscale are rated using a 6-point Likert scale from all of the time (1) to none of the time (6). In this study, the Cronbach's alpha of health distress subscale of MOS-HIV is 0.89.

3.3.4 Statistics

Univariate and multivariate analysis were performed to investigate the determinants of perceived stress and psychological outcomes. A series of CFA and EFA were performed to explore the structure of Brief COPE using the current data. The relationship of stress, coping and psychological well-being variables was examined using linear regression models. Details of statistics are elaborated in the corresponding chapters.

Chapter 4 Development of the perceived stress scale for People Living with HIV in China

4.1 Background

Psychological stress is defined as a relationship between the person and the environment that is being appraised by the person as taxing or exceeding his or her resources and hence endangering his or her well-being [135]. AIDS, a chronic disease in the age of highly active antiretroviral therapy (HAART), is associated with both emotional and physiological stress [256]. Stressors frequently encountered by PLWH include uncertainty about one's future, health and financial problems, social isolation and stigmatization etc. [257-259]. Perceived stress among PLWH was associated with poorer stress management skills, inappropriate coping mechanisms and depression [89, 196, 260, 261]. It could also drive PLWH to practice unhealthy behaviors, such as the use of alcohol or tobacco [257].

The number of PLWH in China is estimated to be 0.7 million [262]. Problems faced by PLWH in China include financial stress (44.1%), unemployment and low self-esteem (22.8%), being discriminated against or rejected by peers (16.8%) or being discriminated against by family members (9.9%) [263]. Physical health and social discrimination are two 'most difficult aspects of life' faced by PLWH in Hong Kong [264]. Non-availability of or high cost of medical treatments are also important problems faced by PLWH in China [15, 265, 266].

Only one validated HIV-specific perceived stress scale is currently available; its development was based on a homosexual/bisexual sample and did not assess medication-related stress [205]. The modified version of the Perceived Stress Scale (PSS) has been applied to some PLWH populations [195-197]; it, however, assesses severity of global

stress, which is not specific to HIV/AIDS [185]. A few other life-event scales are specific to HIV/AIDS but they have not been formally validated [81, 152].

4.2 Objectives

The present study develops and validates a new Perceived Stress Scale for People Living with HIV/AIDS (PSSHIV) in China. Based on some checklists of problems and stressors that are relevant to PLWH [81, 132], some initial domains of perceived stress were identified by the authors. These domains were then modified by the PLWH participants of this study, who further generated question items with respect to these domains. The generation of question items from the study participants, rather than from the test developers, is a preferred test construction process and the resulting constructs are expected to have better psychometric validity [267].

There is a dearth of data on stress-related research among Chinese PLWH [268]. The underdevelopment might be attributed to the non-availability of validated scales measuring perceived stress among PLWH. Such scales are potentially useful in service provision and evaluation of interventions. The translation of the PSSHIV into other languages is also feasible and potentially beneficial.

It was hypothesized that the PSSHIV subscales would be positively correlated with other psychological scales measuring stress, depression and anxiety, and negatively correlated with quality of life.

4.3 Study design

The PSSHIV was developed by a four-stage item-generation study (Study 1) and a validation study (Study 2) (See Figure 4.1).

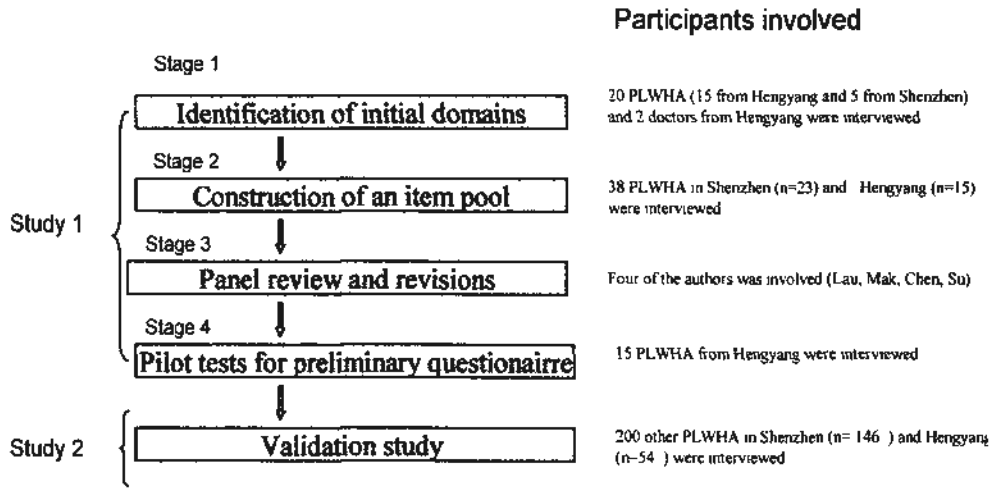


Fig. 4.1 Summary of the research design

4.3.1 Study 1. The item generation study

Stage 1. Identification of initial domains

A total of ten domains of HIV-related stress that may be faced by PLWH were identified by the authors, using three approaches: a thorough literature review on research that mentioned stressors and problems frequently faced by PLWH [81, 147, 185, 196, 205], in-depth interviews with 20 PLWH and two local doctors managing PLWH and a panel discussion participated by four study members (Lau, Mak, Chen, and Su). These 10 domains included stress related to medical care, financial problems, employment problems, family problems, worries about transmitting HIV to others, stigmatization and discrimination, stressful social relationships, emotional and mental health issues, sexual problems, and physical problems.

Questions for HIV infected cases for the in-depth interviews to identify the initial domains:

Introduction: I will now ask you some questions that PLWH might confront; all information in this interview is anonymous and confidential; you can refuse to reply when you feel reluctant or unwilling to tell.

i. Did you confront any stress after you knew about your HIV infection? If yes, in what aspects?

ii. What's the most stressful thing you are concerned about at present?

iii. What are your considerations for the future?

iv. How was your mood after you knew about your HIV infection? (at the beginning and at present)? How did you adjust your mood?

v. How about your consideration in regard to your family? (parents and partner)

vi. How was your sexual life after you knew about your HIV infection?

vii. Did you tell others about your HIV infection?

viii. How is your work and financial status now?

ix. What do you think about the effect of HIV infection on your physical health?

x. How did you deal with your relationships with others?

xi. What do others think about your HIV infection?

xii. What do you think about your HIV infection?

Questions for doctors for the in-depth interviews to identify the initial domain

i. What's the greatest concern or stressor confronted by your patients?

ii. What are the normal reactions when your patients know about their HIV infection?

iii. What were the patients' attitudes towards ARV therapy?

Stage 2. Construction of the item pool

A total of 38 participants (17 intravenous drug users, 5 heterosexual males, 9 heterosexual females, 6 men who have sex with men, 1 former blood donor), 15 of whom were currently receiving anti-viral therapy, participated in this part of the study. They were asked by the author of the present study to suggest up to five items of HIV-related perceived

stress that they perceived themselves to have experienced in the past month, and to rate such items according to the level of stress experienced and the relevance to oneself (10-point scale). In addition, they were asked to provide up to three items for each of the aforementioned 10 domains of perceived HIV-related stress, according to their experience in the last month. A total of 453 raw categories were hence collected, which were grouped into 78 items by two of the study members (Lau, Su).

Stage 3. Item review and revision

The 78 items were then independently reviewed by a panel (Lau, Mak, Chen and Su), considering their clarity, potential redundancy, number of participants mentioning the item and the ratings attached to the items. After two rounds of panel discussion, a pool of 44 items was selected for pilot testing (see Appendix4.1).

Stage 4. Pilot testing for the preliminary questionnaire

The 44-item questionnaire was pilot-tested by interviewing 15 participants in Hengyang, to assess the extent of perceived stress experienced by them in the last month (1= absolutely not stressful, 5 = extremely stressful). Qualitative feedback was obtained about the appropriateness of these items and some revisions were subsequently made.

4.3.2 Study 2. The validation study

Participants

A total of 200 PLWH from Shenzhen (n=146) and Hengyang (n=54) participated in Study 2 (MSM: 14.1%, IDU: 36.9%, heterosexual transmission: 43.4%). A random sub-sample (n= 31) was interviewed twice (2 to 3 weeks apart) to establish test-retest reliability.

Measures

Information about participants' background characteristics (i.e., age, gender, educational level, marital status, employment status, mode of HIV transmission, CD4 count, medical treatment status, time of HIV diagnosis, and relationship with family members) was collected. In addition, the validated Chinese version (Cronbach's alpha =0.78) of the Perceived Stress Scale (PSS) was used in this study [199]; it consists of 14 items (never = 0 to very often = 4) [185]. The validated Chinese version of the 35-item Medical Outcomes Study HIV Health Survey (MOS-HIV) was also used to assess quality of life (Cronbach's alpha of the Subscales ranged from 0.78 to 0.90) [237]. The scale has 10 domains (namely general health, physical function, role function, social function, cognitive function, pain, mental health, energy/fatigue, health distress, and quality of life) and a single item of health transition. It has been used to evaluate the effectiveness of interventions and to investigate factors predicting well-being of PLWH [235, 236]. The Chinese brief version of the Depression, Anxiety, and Stress Scale (DASS-21) was also used to measure psychological distress [239]. It consists of three self-reported subscales (each with 7 items), measuring depression, anxiety, and stress [238]. Participants gave item ratings according to their experience over the past week on a 4-point Likert rating scale.

4.4 Data analysis

Descriptive statistics were presented. Missing values were imputed by using the item mean. Exploratory factor analysis, using principal component and varimax rotation methods, was performed to uncover the underlying dimensions of the items. Subscale scores were constructed by summing up the item scores of individual factors, while an overall score was constructed by summing up the scores of all individual items. Item-total correlation coefficients, split-half correlation coefficients and Cronbach's alpha values were derived to

measure internal consistency. Weighted Kappa coefficients with quadratic weights and intra-class correlation coefficients (ICC) were used to assess test-retest reliability [269, 270]. Pearson correlation coefficients among the overall scale and the eight subscales were also calculated. The associations between the overall scale and the subscales of the PSSHIV and other relevant measurement instruments (PSS, MOS-HIV and DASS) were evaluated by Pearson correlation coefficients to establish concurrent validity. One-Way ANOVA was applied to examine the associations between some HIV-related variables and the overall scale and subscales of the PSSHIV. SPSS of Windows (Version 14.0) was used for statistical analyses and a p-value of <0.05 was taken as statistically significant.

4.5. Results of the validation study

4.5.1 Background characteristics of respondents

Of the respondents, 63% were male; 53.3% were 30 to 39 years old; 51% completed senior high school; 50% were currently married; 64.1% were unemployed; 43.4% were infected via heterosexual behaviors; 31.0% and 31.5% had a CD4 count ≥ 200 and <200, respectively; 40.5% were currently receiving HAART; 27.1% admitted they had a worsened family relationship after being diagnosed HIV positive (Table 4.1).

4.5.2 Item selection by consideration of psychometric properties

For individual items, the percentages of respondents responding with '1'(floor effect) and '5' (ceiling effect) respectively ranged from 6.5% to 47.5% and 12.0 to 47.0%. An item is considered non-responsive if its floor or ceiling effects exceed 70% [271]. None of the items falls into this category, though respectively 8.6% and 8.9% of the items exhibited a floor effect or a ceiling effect exceeding 40% (data not tabulated).

An exploratory factor analysis (EFA) was performed on the 44 items, yielding nine factors with eigenvalue > 1.0. Three items (Items 14, 27, 36) with their factor loadings smaller than 0.45 were removed from subsequent analysis, according to some researchers' suggestion [104, 272]; two other items with cross-loadings (>.40) on multiple factors (Items 43, 44) were also removed from subsequent analysis [273]. A second round of EFA was conducted and four more items were removed due to the two aforementioned reasons (Items 4, 13, 15, and 40).

4.5.3 Psychometric properties of the PSSHIV

Construct validity

Another round of EFA was applied to the remaining pool of 35 items and 8 factors were identified (explaining 71.47% of the total variance; KMO=0.905; Table 4.2). The communities of the 35 items ranged from 0.51 to 0.86 (most of them > 0.60). These 8 factors assess respondents' level of perceived HIV-related stress with respect to: 1) social/psychological problems, 2) sexual relationship, 3) functional problems, 4) social acceptance/rejection, 5) work-related issues, 6) family/offspring concerns, 7) accessibility to medical treatments, and 8) concerns about medical treatment outcomes (Table 4.3). Eight subscales were hence formed. The overall score is formed by summing up all item scores.

Internal Consistency

The internal consistency reliability of the overall scale and the eight subscales of PSSHIV were high (Cronbach's alpha= 0.76 to 0.94, Table 4.3). The item-total Pearson correlation coefficients of the items ranged from 0.31 to 0.74; the item-subscale Pearson correlation coefficients ranged from 0.53 to 0.83 (data not tabulated), these figures are considered to be acceptable [274, 275].

Correlations among the Subscales of PSSHIV

The Pearson correlation coefficients among the PSSHIV Subscales ranged from 0.21 (Family/offspring issues and Functional problems) to 0.70 (Social/psychological problems and Functional problems) (ps<0.01, Table 4. 4).

Test-retest reliability

The Kappa (κ) statistic was used to assess the items' test–retest consistency. The weighted Kappa values of the 35 items ranged from 0.41 (moderate agreement) to 0.88 (excellent agreement) [276, 277](data not tabulated). The ICC of the overall scale and the other subscales ranged from 0.73 to 0.92 (Table 4. 3).

Concurrent validity measures

The overall scale, the Social/Psychological Problems and Functional Problems subscales of the PSSHIV were significantly correlated with the PSS, DASS and all domains of the MOS-HIV (*r*s =0.50 to 0.71 for positive correlations, and -0.73 to -0.21 for negative correlations; *p*s <0.05). The other 6 PSSHIV subscales were all significantly correlated with the PSS, the stress subscale of the DASS and the Health Distress subscale of the MOS-HIV; and were also correlated with some other subscales of the DASS and the MOS-HIV (*r*s =0.16 to 0.39 for positive correlations, -0.58 to -0.15 for negative correlations, *p*s <0.05, Table 4.5).

The overall scale, the Social/Psychological Problems subscale, the Functional Problems subscale and the Accessibility to Treatment subscale were correlated with almost all external variables that were used to establish external validity (subscales of the DASS, PSS, MOS-HIV etc). It was found that the Social/Psychological Problems subscale yielded stronger correlation coefficients with variables that are related to stress, anxiety, health

distress and mental health (*r*s=0.58 to 0 .73) than with measures that are related to physical conditions (e.g., physical function, health transition, pain etc.; *r*s=-0.29 to -0.43) and cognitive function or role function (*r*s=-0.47 and -0.39). It was also observed that QOL measures on social function, role function and physical function were significantly correlated with the Functional Problem subscale (besides the Social/Psychological Problem subscale and the Accessibility to Treatment subscale), but not with the Sexual Relationship subscale, Family/Offspring Issues subscale. The Sexual Relationship subscale and the Social Acceptance/Rejection subscale were more likely to be significantly correlated with some psychological variables (e.g., stress, health distress, depression and anxiety) than with variables that are related to physical conditions (e.g., pain, energy/fatigue, overall health, and physical function), role and social functions (*p*s <0.05, Table 4.5).

Relationship between PSSHIV scores and HIV-related variables

The results showed that only the Functional subscale (but not the other seven subscales) was associated with mode of HIV transmission – higher scores were reported among those reporting IDU as a mode of transmission as compared to those reporting other modes of transmission (One-way ANOVA and Scheffe's test, $p<.05$, data not tabulated). Those who paid for their antiretroviral therapy expenses had lower scores in the Social Acceptance/Rejection subscale, as compared to those who were not under antiretroviral treatment. (One Way ANOVA, Scheffe's test, $p<0.05$, data not tabulated)

4.6 Discussion

The multi-stage PSSHIV construction process made use of information obtained from the literature review, information generated from PLWH and expert panel discussion. Both qualitative and quantitative methods were used and a reasonably large sample of PLWH was involved. This method of collecting items from the study subjects has been advocated by

some researchers [267]. The constructed scale possesses satisfactory psychometric properties. The face and content validity of the PSSHIV were ensured by the detailed item-generation process. The factors generated by the final EFA agree very well with the initial domains identified in Study 1. The Cronbach's alpha values of the Overall Scale and the Subscales all exceeded the acceptable criterion of 0.70 [278]. Other reliability statistics such as ICC coefficients (all above 0.70), and item-subscale correlation coefficients were also acceptable. In the EFA, the communities of all items exceeded 0.50 and, with such values, a sample size of 150 to 200 is likely to be adequate [279]. Concurrent validity was demonstrated by the significant correlations between the PSSHIV overall scale and its subscales and other relevant measures such as PSS, DASS and MOS-HIV.

Some degree of converging and diverging validity has been demonstrated by the significance or non-significance of the correlations between the PSS-HIV subscales and external variables such as subscales of DASS, PSS and MOS-HIV. For instance, the Social Psychological subscale of the PSS-HIV correlated better with psychological variables (stress, depression etc.), as compared to physical variables or cognitive function and role function variables. External variables related to functioning were also significantly correlated with the Functional Problem subscale but not with Sexual Relationship or Family Offspring Issue subscales etc.

Participants who were IDU reported higher perceived stress in the Functional Stress subscale, as compared to the MSM and heterosexual transmission groups. These observations may be partially explained by the medical complication of prevalent infectious diseases due to frequent septic parenteral insults among IDU, which causes functional issues among IDU [280]. One study indicated that among AIDS patients with moderate to severe immune suppression, IDUs were more likely than homosexual men to report symptoms such

as fatigue, weight loss, diarrhea, and shortness of breath. Such differences may be due to co-morbidities associated with injection drug use [281].

The WHO recommends attention should be given to the psychosocial needs of PLWH, as an integral part of care programs [214]. A number of researchers had conducted studies on mental health issues of PLWH in China [138, 282]. These studies, however, did not explore specific types of stress that are confronted by PLWH and did not assess the impact of these various types of stress on the psychosocial adjustment process among PLWH [138, 282]. A fully validated and comprehensive measurement instrument such as PSSHIV would allow researchers and doctors to improve the quality of development and provision of support services. The PSSHIV can also serve as an outcome measure in evaluating stress reduction programs targeting PLWH.

This new scale includes stress related to accessibility to treatment and treatment outcomes, which were significantly associated with depression, anxiety and quality of life. Similar findings were reported [283, 284]. Until recently, PLWH living in many developing countries have had limited access to antiretroviral therapy [285]. The cost of antiretroviral drugs in developing countries has reduced substantially over the last few years [286]. Stress was related to poor antiretroviral medical adherence among PLWH[287]. In December 2003, the Chinese government announced the "Four Free and One Care" policy, which entails free antiretroviral therapy to uninsured rural residents and uninsured urban residents [288]. Although the number of patients receiving antiretroviral therapy in China has been increasing [286], accessibility remains a serious concern in China [289]. Meanwhile, discrimination against PLWH in health care settings was also prevalent in China, especially in settings where health care workers are less well-trained and where preventive measures for HIV infection are inadequate [128]. Another study among the general rural residents in rural China documented that HIV/AIDS knowledge was related to HIV-related public stigma

(possible reactions held by the general population to individuals infected with HIV) [130]. It is hence important to provide HIV-related knowledge and training to health care workers and the general population in order to alleviate stress among PLWH in China.

In this study, perceived stress due to concerns about family/offspring was associated with health distress. Continuity of the family tree is essential in traditional Chinese culture [225]. Under the one-child policy [226], the family line might be discontinued if the PLWH were not going to have a child due to HIV-related considerations, or if the child were vertically infected. Scaling up professional counseling services and provision of prophylaxis to pregnant HIV women during perinatal stage are greatly warranted.

This newly validated PSSHIV addresses some of the limitations of the previous developed HIV stress scales [81, 205]. It is one of the first HIV-specific measurement instruments that has been developed via rigorous item generation and validity procedures. PLWH living in different countries may share some similar constructs related to HIV-specific perceived stress [132]. The PSSHIV should therefore have a wide range of applications. Further research to translate and to validate PSSHIV in other cultures will extend our understanding on general issues related to stress faced by PLWH. Most of the HIV-related instruments were created in Western countries and then validated in Eastern countries. The reverse should also be feasible and beneficial.

Appendix3.1: Items that were generated by in-depth interviews and a panel discussion.

The following items are related to stress that may result from HIV/AIDS infection. Please assess the extent of perceived stress related to these items experienced by you in the last month, 1= Absolutely not stressful, 2=A bit stressful, 3=Moderately stressful, 4=Quite stressful, 5 = Extremely stressful. There are no right or wrong answers. Feel free to tick in the pane in front of the exact answer you select.

Items

1. I'm afraid I cannot obtain free ART from the government

2. I'm afraid I cannot obtain free ART from the government regularly.

3. I feel it is difficult to afford medical expenses.

4. Attitude of health care workers to HIV-infected people makes me feel uncomfortable.

5. I worry about the side effects triggered by ART.

6. I'm afraid that the treatment effectiveness is not good enough.

7. I'm afraid I can't get the optimal ART regimen when I need to change the prescription.

8. Because of my health status, I can't cope with a heavy work load.

9. I'm afraid that my work would be affected by medical visits.

10. I'm afraid that my HIV status will be known in my work place.

11. I'm afraid of losing my job due to HIV infection.

12. I'm afraid of being subjected to a health check-up in a new job.

13. I have found it difficult to find a new job due to HIV infection

14. I worry about my worsening health due to HIV infection.

15 I'm afraid that a simple disease will cause HIV related complications.

16. HIV/AIDS decreases my capacity for thought and memory.

17. HIV/AIDS decreases my physical strength.

18. I feel tense during sex encounters.

19. I feel disturbed to avoid sexual encounter due to HIV infection.

20. I have fear of disclosing my HIV status to my sex partner.

21. I have fear of transmitting HIV to a sex partner.

22. HIV has decreased my chances of finding a sex partner.

23. I feel guilty towards sex partner about having HIV/AIDS

24. I feel low self-esteem due to HIV.

25. I feel nervous when people mention HIV.

26. I often feel lonely.

27. I'm always suffering from insomnia due to HIV infection.

28. I feel depressed due to HIV infection.

29. I always blame myself for contracting HIV.

30. I always feel self-loathing due to HIV.

31. I have familial pressure to have offspring.

32. I plan not to have children.

33. I have a fear of infecting a newborn baby.

34. I'm afraid my family is stigmatized because of my HIV infection.

35. Family does not accept me due to HIV infection.

36. I feel sorry to my family due to HIV infection.

37. I try to avoid social interactions with others.

38. I feel difficultly in confiding in other people about my HIV infection

39. I feel incapable of participating in social activity

40. Others worry about my transmission to them.

41. I'm afraid I'm rejected by family and friends.

42. I'm looked down upon by others.

43. I'm especially concerned about others' attitude to me due to HIV infection

44. I'm disturbed by others' attitude after they know my HIV infection.

*** The items highlighted in bold text remained in the final version of the PSSHIV.**

The paper of stress scale development has been published: Su, X. Y., Lau, J. T. F., Mak, W. W. S., Chen, L., Feng, T. J., Chen, X., Liu, C. L., Liu, J., Liu, D., and Cheng, J. Q. (2008). Development of the Perceived Stress Scale for People Living with HIV/AIDS in China. AIDS Patient Care and STDs 22, 989-998.

Table 4.1 Background characteristics of the respondents (n=200)

		n	%
Gender	Male	126	63 0
	Female	74	37 0
Age (years)	29 or below	65	33 0
	30-39	105	53 3
	40 or above	27	13 7
Education level	Primary or below	24	12 0
	Junior high	74	37 0
	Senior high/technical secondary school	70	35 0
	Junior College or above	32	16
Marital status	Currently married	100	50
	Currently not married	100	50
Place of residence	Hengyang	64	32
	Shenzhen	136	78
Employment status	Unemployed	125	64 1
	Part time	9	4 6
	Full time	61	31 3
Probable mode of HIV transmission	MSM behavior	28	14 1
	Blood transfusion/donation	11	5 5
	Heterosexual behavior	86	43 4
	IDU	73	36 9
Receiving antiretroviral therapy	No	119	59 5
	Yes, self paid	11	5 5
	Yes, government paid	70	35 0
Year confirmed of HIV status	2005 or before	69	35 4
	2006 or after	126	64 6
Relationship with family members after HIV diagnosis being made	Worse than before	54	27 1
	Same as before	114	57 3
	Better than before	31	15 6

Table 4.2 Factor Loadings of the Perceived Stress Scale among PLWH (PSSHIV)

Perceived stress (abbreviated items)	Factors							
	1	2	3	4	5	6	7	8
30 Self-loathing due to HIV	**.852**	.110	.085	.125	.082	.108	.168	109
28 Depression due to HIV	**.774**	.064	.250	.161	.032	.045	.085	119
29 Blame myself for contracting HIV	**.771**	124	.090	.013	.033	129	.145	.138
24 Low self-esteem due to HIV	**.716**	.218	.260	236	.157	-.017	.095	119
26 Loneliness	**.716**	.164	.192	.244	.158	-.002	.109	099
25 Feel nervous when people mention HIV	**.703**	.307	.093	.160	.145	.156	.108	.171
37 Avoid social interactions	**.624**	.131	.323	.180	.240	-.067	.192	.019
39 Feel incapable of participating in social activity	**.622**	.085	.397	.183	.135	.053	.086	.128
38 Feel difficultly in confiding in other people about my HIV infection	**.514**	.267	.199	.242	.180	.125	.153	.013
21 Fear of transmitting HIV to a sex partner	-.020	**.806**	.049	.201	.107	.126	.077	.060
20 Fear of disclosing HIV status to sex partner	.138	**.795**	.092	.110	.106	.027	.058	.022
22 HIV has decreased my chances of finding a sex partner	.078	**.713**	.028	.065	.136	.094	.154	.036
23 Feel guilty towards sex partner about having HIV/AIDS	.207	**.711**	-.016	.173	.094	.084	.020	.146
18 Feel tense during sex encounters	317	**.706**	.228	.123	.059	.129	-.026	.093
19 Avoid sexual encounters	.290	**.706**	.142	.037	.140	.169	-.074	.079
8 Difficult to cope with heavy work load	.310	-.019	**.775**	.141	.130	-.098	.067	099
9 Worried that work would be affected by medical visits	.331	.112	**.670**	.161	.314	.037	.157	.090
16 Decreased capacity for thought and memory	.320	.233	**.666**	.148	-.004	132	.077	.194
17 Decreasing physical strength	.374	.263	**.634**	.087	-.043	.148	.159	.222
41 Rejected by family and friends	.217	**.161**	.262	**.791**	.121	.069	.117	.069
35 Family does not accept me	.187	.193	.058	**.759**	.132	.126	.180	.032
34 Family is stigmatized	.248	.157	.096	**.694**	.193	.097	-.076	.235
42 Looked down upon by others	.373	.234	.113	**.643**	.062	.083	.151	.065
10 Fear of my HIV status being known in my workplace	.135	.201	.058	.085	**.857**	.178	.017	**.094**
11 Fear of losing my job	.204	.206	.188	.114	**.834**	.128	.075	**.093**
12 Fear of being subjected to a health check-up in a new job	.216	.176	.060	.264	**.745**	.075	108	**.151**
32 Plan not to have children	.119	.210	.041	.057	.110	**.861**	.087	.035
33 Fear of passing the virus to newborn baby	.006	.088	-.004	157	.101	**.847**	.018	-.005
31 Societal/familial pressure for not having offspring	.152	.179	.059	.055	.113	**.816**	.126	.153
1 Cannot obtain free antiretroviral therapy (ART)	.271	.048	-.027	.101	-.014	.123	**.847**	.102
2 Cannot obtain free ART regularly	.198	.103	.113	.155	.083	.129	**.845**	.177
3 Difficulty affording medical expenses	.188	.052	.358	.053	.144	-.010	**.658**	.044
6 Effectiveness of treatment	.198	.071	.101	.051	.080	.013	.116	**.818**
5 Experiencing ART side effects	.160	.115	.116	.064	.022	.091	.033	**.803**
7 Accessibility of second line regimen of ART	.105	.114	.158	.176	.227	.061	.154	**.666**
Eigenvalue	5.83	4.11	2.80	2.78	2.56	2.47	2.28	2.19
Cumulative % of Variance explained	16.65	28.41	36.41	44.35	51.66	58.70	65.20	71.47

Exploratory factor analysis, using principal component analyses for factor extraction (with Varimax rotation). Factor 1-8 addressed stress due to Social/Psychological Problems, Sexual Relationship, Functional Problems, Social Acceptance/Rejection Issues, Work- related Issues, Family/Offspring Issues, Accessibility to Treatment, Treatment Outcomes, respectively.

Table 4.3 Reliability coefficients for the Perceived Stress Scale among PLWH (PSSHIV)

Overall scale/Subscales	No of items	Internal consistency		Test-retest reliability	
		Cronbach's alpha	Split-half coefficient	Intraclass correlation coefficient	*p* value
Overall Scale	35	0 94	0 89	0 89	0 000
Subscales					
Social/psychological problems	9	0 93	0 88	0 83	0 000
Sexual relationship	6	0 88	0 83	0 92	0 000
Functional problems	4	0 85	0 75	0 86	0 000
Social acceptance/rejection issues	4	0 85	0 86	0 77	0 000
Work related issues	3	0 89	0 75	0 72	0 000
Family/offspring issues	3	0 86	0 86	0 92	0 000
Accessibility to treatment	3	0 82	0 57	0 83	0 000
Treatment outcomes	3	0 76	0 62	0 73	0 000

Table 4.4 Pearson correlation coefficients among PSSHIV Subscales

	1	2	3	4	5	6	7	8
1 Social/psychological problems	1	48**	70**	60**	46**	28**	49**	42**
2 Sexual relationship	48**	1	40**	47**	43**	36**	24**	31**
3 Functional problems	70**	40**	1	50**	41**	21**	42**	43**
4 Social acceptance/rejection issues	60**	47**	50**	1	46**	31**	37**	36**
5 Work related issues	46**	43**	41**	46**	1	33**	28**	34**
6 Family/offspring issues	28**	36**	21**	31**	33**	1	25**	22**
7 Accessibility to treatment	49**	24**	42**	37**	28**	25**	1	34**
8 Treatment outcomes	42**	31**	43**	36**	34**	22**	34**	1

** $p < 0.01$

Table 4.5 Pearson correlation coefficients between the PSSHIV and other external validity measures

	Perceived Stress Scale among PLWH (PSSHIV)								
Other measures	Overall Scale	Social/ Psychological Problems Subscale	Sexual Relationship Subscale	Functional Problems Subscale	Social Acceptance /Rejection Subscale	Work related Issues Subscale	Family/ Offspring Issues Subscale	Accessibility to Treatment Subscale	Treatment Outcome Subscale
Perceived Stress Scale	.50**	.58**	.22**	.53**	.31**	.18**	.22**	.32**	.26**
DASS_stress	.58**	.66**	.38**	.63**	.38**	.20**	.16*	.32**	.24**
MOS_health distress	-.62**	-.73**	-.37**	-.58**	-.38**	-.28**	-.20**	-.34**	-.24**
DASS_depression	.59**	.71**	.32**	.64**	.39**	.20**	12	.36**	.25**
DASS_anxiety	.52**	.59**	.31**	.60**	.35**	12	14	.34**	.22**
MOS_cognitive function	-.43**	-.47**	-.23**	-.54**	-.24**	-.14*	- 11	-.26**	-.25**
MOS_mental health	-.55**	-.66**	-.30**	-.58**	-.37**	-.18*	- 12	-.36**	-.25**
MOS_quality of life	-.41**	-.50**	-.17*	-.47**	-.26**	- 13	- 10	-.35**	-.19**
MOS_health transition	-.31**	-.31**	-.24**	-.26**	-.22**	-.16*	- 04	-.26**	-.20**
MOS_social function	-.23**	-.30**	01	-.46**	- 10	- 11	01	-.16*	-.15*
MOS_pain	-.33**	-.43**	- 07	-.50**	-.15*	- 06	- 07	-.29**	-.16*
MOS_energy/fatigue	-.38**	-.51**	-.17*	-.57**	- 14	- 06	- 06	-.29**	- 13
MOS_overall health	-.33**	-.44**	- 09	-.56**	- 13	- 03	- 06	-.19**	-.15*
MOS_role function	-.28**	-.39**	- 07	-.46**	- 14	- 06	- 01	-.15*	- 13
MOS_physical function	-.21**	-.29**	- 03	-.40**	- 10	01	- 02	- 13	- 13

* $p < 0\ 05$, ** $p < 0\ 01$

Chapter 5. Validation of the Brief COPE instrument for assessing coping strategies among PLWH in China

5.1 Background

Coping is defined as constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person [135]. It may significantly amplify or diminish the effects of stress or adverse events [290] as different types of coping strategies can have protective or harmful effects on individuals' health and well-being [291-293].

People Living with HIV (PLWH) face challenges such as stigma [294, 295], poor antiretroviral adherence [296] and depression [297]. Thus, there is a strong need to identify protective and risk factors and effective coping strategies in association with mental health problems and to develop relevant evidence-based prevention programs [298] targeting PLWH. Research on PLWH found that appropriate coping strategies are associated with better mental health and quality of life [299], decreased depressive symptoms [300], effective stress management of stress, and better drug adherence [301].

The COPE Inventory was developed to assess a broad range of coping responses. Its development was based on the coping model developed by Lazarus and Folkman [135], and the behavioral self-regulation model developed by Carver and Scheier [302, 303]. It has 60 items, making up 15 subscales (4 items per scale), each with a specific conceptual focus. Good psychometric properties including high values of Cronbach's alpha, test-retest reliability and significant correlations with external variables have been reported [304]. There is no fully validated Chinese version of the COPE Inventory.

The Brief COPE [248] is the abbreviated version of the COPE Inventory and assesses dispositional as well as situational coping efforts [304]. The 28-item Brief COPE (including 14 subscales with two items each: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame) has acceptable psychometric properties and has been used extensively to examine the relationship between various coping strategies and psychological outcomes in PLWH [305-307] and in other populations [308]. Its constructs, however, had not been subjected to thorough factor validation. Though the Chinese version of the Brief COPE was translated into Chinese and back-translated into English, test for internal consistency and factor analysis had not been performed [249]. The estimated number of PLWH in China is 700,000, and few psychological support services exist, despite the highly stressful and discriminating social environment [309]. The investigation of their coping responses to stressors within the cultural context is absolutely critical. There is, however, a dearth of such data in China, possibly due to the lack of fully validated Chinese instruments assessing coping strategies.

PLWH of different countries may use coping strategies differently. Prior studies advocated culturally sensitive approach to ensure that the impact of interventions is optimized to benefit the individuals recovering from a stressful event [310]. In addition to social prejudices, Chinese PLWH encounter difficulties due to HIV/AIDS-related symptoms and complications, low socio-economic status, conservative social environment [309], and lack of social support [311].

5.2 Objectives

This study investigated the psychometric properties of the Chinese version of the Brief

COPE among PLWH in China. Two previously specified conceptual structures of the Brief COPE were tested by using confirmatory factor analysis (CFA). The two measurement models [170, 308] are presented in Figure 5.1 and Figure 5.2. The first model grouped the 14 subscales of the Brief COPE into three categories: problem-focused, emotion-focused, and dysfunctional coping (Fig.1) [308, 312]. Dysfunctional coping correlated with depressive symptoms, while mixed findings have been reported on the relationship between problem-focused and emotion-focused coping strategies and psychological outcomes [170, 308]. The second model grouped the 14 subscales under adaptive coping (included all the subscales of problem-focused and emotion-focused coping in the first model) and maladaptive coping strategies (included all the subscales of dysfunctional coping in the first model) (Fig.2) [170]. Adaptive coping strategies tend to be associated with desirable outcomes and maladaptive coping strategies tend to be associated with undesirable outcomes [158, 170].

Previous studies on Brief COPE have used either the combined subscales (e.g. adaptive versus maladaptive coping) [167, 170, 308] or the separate subscales [249, 313-315]. In this study, confirmatory factor analysis was first used to test the two aforementioned models. Upon poor fit of previous models, exploratory factor analysis (EFA) was performed to investigate the structure of the Brief COPE.

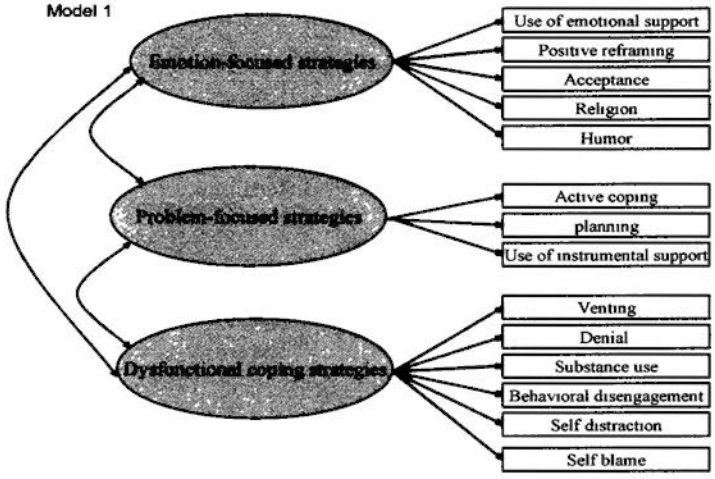


Fig. 5.1 Brief COPE structure utilized by Cooper etc., 2006

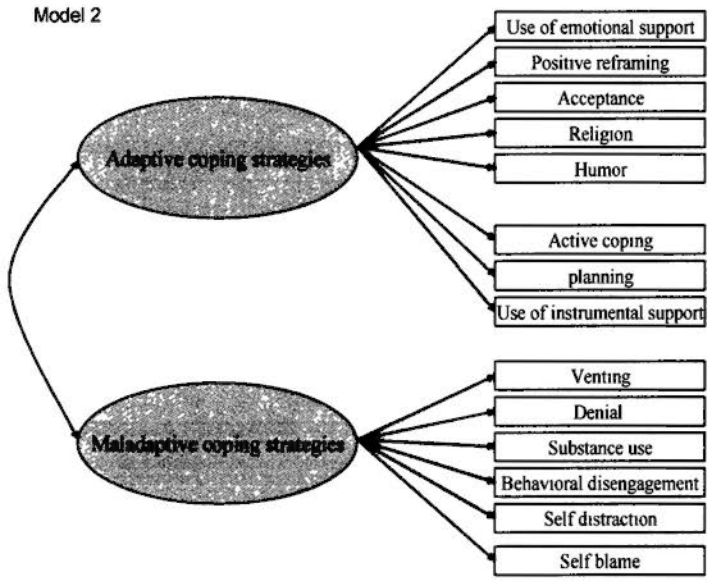


Fig. 5.2 Brief COPE structure utilized by Meyer etc., 2001

5.3 Statistical Analysis

Descriptive statistics were presented. Cronbach's alphas of each subscale of Brief COPE were calculated. The two models of the Brief COPE described in Figure 5.1 and Figure 5.2 were specified and estimated by maximum likelihood using LISREL 8.5. Relative chi-square ($\chi 2$) was calculated to indicate the model fit. The appropriateness of each latent

construct was evaluated in terms of the comparative fit index (CFI), the root mean square error of approximation (RMSEA), normed fit index (NFI), non-normed fit index (NNFI) and goodness of fit index (GFI). An acceptable relative $\chi 2$ fit index is usually set at a 3:1 ratio, while some researchers consider a high ratio of around 5:1. CFI, GFI, NFI and NNFI values of 0.90 or greater [316] and RMSEA values of 0.08 or less [201], are indicative of a good model fit, with RMSEA values of 0.05 or less considered to be a near-perfect fit [317].

EFA was applied to the 28 items. The number of factors was determined by eigenvalues [318] and factor loadings [319, 320]. The Kaisor-Meyer-Olkin (KMO) and Bartlett's sphericity tests were used to measure sampling adequacy. Subscales scores were derived by summing up the item scores of individual factors. Item-subscale correlation coefficients were derived and Cronbach's alpha coefficients [321] were estimated. Spearman correlation coefficients among different subscale scores of the Brief COPE and CLOT-R (measures optimism), PSSS (measures social support) and PDSHIV (measures perceived discrimination) were derived.

5.4 Results

5.4.1 Background characteristics of respondents

Of the respondents, 73.6% were male. 53.1% were 30 to 39 years old. 41.5% were currently married. 51.6% had attained a junior high education level. 47.7% had no income. Respectively, 29.6%, 58.3% and 12.2% were infected via heterosexual, IDU and MSM behaviors. 43.8% were receiving ARV treatment (Table 5.1).

5.4.2 Internal reliability of the original subscales of the Brief COPE

The Cronbach's alpha of the subscales ranged from 0.37 to 0.88, all being greater than 0.50 except four subscales had values less than 0.50 (Acceptance, Humor, Venting, and

Self-distraction, see Table 5.2).

5.4.3 Results of confirmatory factor analysis

For Model 1 and Model 2, the relative χ^2 index, the test of absolute model fit, was respectively 6.81 and 6.60, clearly indicating poor absolute fit of the models with the data. The comparative model fit (represented by RMSEA, NFI, NNFI), the CFI and GFI were also poor (Table 5.3).

5.4.4 Results of exploratory factor analysis

The KMO value was 0.84, and the result of the Bartlett's sphericity test was statistically significant ($\chi^2 = 2572.21$, $df = 378$, $p < 0.000$), meeting the criteria (the value in which KMO should be 0.60 or higher to proceed to factor analysis; the significant chi square value obtained from the Bartlett's sphericity test indicates a non-random correlation matrix for factor analysis) [322]. The varimax rotation yielded six factors using the criterion of eigenvalue larger than 1, explaining 56.13% of the total variance. The minimum item loading was 0.40 and there was only one item with cross-loadings >0.40 ('I've been turning to work or other activities to take my mind off things', see Table 5.4); the construct validity was hence satisfactory [104, 272, 279]. The six factors were named 'Problem-solving and Acceptance', 'Negative Venting and Avoidance', 'Support Seeking', 'Self-blame and Denial', 'Reliance on Spirituality', and 'Humor and Self-distraction'.

5.4.4.1 Inter-item correlations and internal consistency of the subscales that were identified from the EFA

The item-total correlation coefficients of the six factors ranged respectively from 0.31 to 0.58, 0.42 to 0.66, 0.48 to 0.64, 0.54 to 0.59, 0.62, and 0.31 to 0.46. These figures are

acceptable [274, 275]. Cronbach's alpha coefficients of the six subscales ranged from 0.61 to 0.80 (Table 5.4).

5.4.4.2 Concurrent validity of the structure identified from the EFA

Table 5.5 shows that the 'Support Seeking' subscale was positively correlated with the PSSS (r=0.30, p<0.05) and negatively correlated with the PDSHIV(r= -0.12, p<0.05). The 'Problem-solving and Acceptance' subscale score correlated positively with the CLOT-R (r=0.19, p<0.05) and the PSSS (r=0.24, p<0.05). The 'Negative Venting and Avoidance' (r= -0.20, p<0.05) and 'Self-blame and Denial' subscales (r= -0.16, p<0.05) correlated negatively with the CLOT-R. The 'Humor and Self-distraction' subscale positively correlated with the PSSS (r=0.171, p<0.05) (see Table 5.5).

5.5 Discussion

In recent years, the literature on coping for stress related to chronic diseases, life-threatening illness and natural disasters has grown substantially [323-325]. The COPE inventory and the Brief COPE, have also been used in a number of HIV-related studies [326, 327]. Amongst PLWH, coping strategies such as behavioral disengagement and denial are associated with disease progression and worse psychological status, whereas the coping strategy of acceptance is associated with a lower level of distress [328, 329]. There was, however, no unanimous conclusion about the effect of higher-order coping strategies (e.g. problem-focused and emotion-focused coping) on psychosocial outcomes as the results were mixed [158, 167, 308, 312].

Our CFA results supported neither the grouping of the subscales into the 'emotion-focused, problem-focused and dysfunctional coping strategies', nor into the

'adaptive and maladaptive coping strategies' [170, 308]. Carver, the author of COPE and Brief COPE also did not recommend combining sub-scales into 'problem-focused' and 'emotion-focused' indices, or to form an 'overall' index. He suggested to use separate subscales or factors obtained from EFA when investigating associations with other variables [248].

Two of the six coping factors ('Humor and Self-distraction' and 'Problem-solving and Acceptance') that were generated by the EFA of this study reflected the resilience nature of the traditional Chinese culture. As seen from some popular ancient Chinese proverbs, such as 'Ku Zhong Qiu Le' (苦中求樂, 'pursue happiness while one is suffering') and 'Sui Yu Er An' (隨遇而安, 'following what you would encounter with a peaceful mind'), Chinese culture is highly resilient to cope with harsh conditions.

'Negative Venting and Avoidance' (such as use alcohol and other drugs) and 'Self-blame and Denial' were two of the identified factors. PLWH have been known to frequently use such coping strategies after they were informed about their HIV status [330 331]. Some PLWH may hope that spirituality would result in better disease outcomes [331]. Some other PLWH sought help from their family members, relatives, or close friends to alleviate their stress [332]. These findings are in agreement with the factor 'Support Seeking', which was identified both in this study and in a prior study conducted by Carver[248, 304]. In this study, 'Reliance on Spirituality' was also identified as a factor, this is consistent with the emerging effect of religiosity in China [333]. Therefore, it's not surprising that the PLWH will seek religious support to alleviate their stress.

In this study, some psychometric properties of the original 14 subscales (e.g. Cronbach's alpha values) were less than satisfactory. Low alpha values had been reported for

some of the 14 subscales of the original Brief Cope instrument [170]. The psychometric properties associated with the new six-factor structure identified in this study were, however, acceptable (e.g. KMO, Bartlett's sphericity test and Cronbach's alphas of the factors). Therefore, the new structure of the Brief COPE should be applicable in present data and related others.

Some of our validation results are consistent with those obtained from other studies. As expected, optimism correlated positively with the 'Problem-solving and Acceptance', and negatively correlated with the 'Negative Venting and Avoidance' and 'Self-blame and Denial' subscales. This is consistent with the result of Carver's validation study of the COPE, in which optimism was positively correlated with 'active coping strategy and seeking instrumental support' and was negatively associated with 'ventilation of emotions' [304, 334]. Social support was found to predict problem-focused coping [335] and adaptive coping strategies by other researchers[336]. In this study, social support positively correlated with the 'Problem-solving and Acceptance' and 'Humor and Self-distraction'. The results were hence consistent with those obtained from previous studies.

In addition, our data showed that 'Support Seeking' correlated negatively with perceived discrimination. Discrimination against PLWH exists in health service settings, including refusals to provide treatments and involuntary disclosure of patients' HIV status [123, 128, 337, 338]. Avoidance of using AIDS-related services has been used by PLWH as a strategy for protecting themselves and their families from stigmatization and discrimination [130, 339]. In this study, 'Support seeking' correlated positively with perceived social support. The aforementioned findings were consistent with those obtained from some previous studies targeting Chinese PLWH [123, 340].

In summary, the psychometric evaluation proposed a six-factor structure for the Chinese version of the Brief COPE. The factor structure is different from those of the original version and previous empirical studies. It, however, has good psychological properties and the factors carry explicit interpretations. Validation of the Brief COPE in other Chinese populations is warranted.

Table 5.1 Background characteristics of the respondents (n=258)

		% (n=258)
Demographic variables		
Gender	Male	73 6
	Female	26 4
Age (years)	29 or below	22 9
	30-39	53 1
	40 or above	24 0
Local resident	Yes	72 9
	No	27 1
Marital status	Currently married	41 5
	Currently not married	58 5
Whether having kid(s)	Yes	47 3
	No	52 7
SES variables		
Education level	Primary or below	12 0
	Junior high	51 6
	Senior high/technical secondary school	27 5
	Junior College or above	8 9
Employment status	Employed	25 2
	Unemployed	67 1
Individual monthly income	No income	47 7
	<=500 yuan	15 5
	500 to 1000 yuan	10 5
	1000 to 2000 yuan	11 2
	>2000 yuan/month	12 8
Whether have health insurance	Yes	21 7
	No	77 5
HIV related variables		
Probable mode of HIV transmission	MSM behavior	12 2
	Heterosexual behavior	29 6
	IDU	58 3
Year confirmation of HIV status	1997 to 2005	26 7
	2006 to 2008	72 5
Currently receiving ARV therapy	Yes	43 8
	No	56 2

Table 5.2 Internal consistency of the 14 subscales of Brief COPE

Coping strategies	Cronbach's alpha
Active coping	0.53
Planning	0.612
Use of instrumental support	0.72
Use of emotional support	0.57
Positive reframing	0.56
Acceptance	0.42
Religion	0.76
Humor	0.49
Venting	0.42
Denial	0.69
Substance use	0.88
Behavior disengagement	0.54
Self-distraction	0.37
Self-blame	0.77

Table 5.3 Indices of CFA for Model 1 and Model 2

Model	No. of factors	χ^2(d.f.)	Relative χ^2 fit index	RMSEA	NFI	NNFI	CFI	GFI
Model 1	3	2382.16(350)	6.81	0.15	0.71	0.72	0.74	0.60
Model 2	2	2315.62(351)	6.60	0.15	0.71	0.72	0.74	0.61

RMSEA=root mean square of approximation; NFI=normed fit index; NNFI=non-normed fit index; CFI=comparative fit index; GFI=goodness of fit index.

Table 5.4 Factor loadings of 28 items of Brief COPE

Items of Brief COPE	Factors					
	1	2	3	4	5	6
14 I've been trying to come up with a strategy about what to do	**0.70**	-0 06	0 12	0 29	0 04	0 01
12 I've been trying to see it in a different light, to make it seem more positive	**0.68**	0 10	0 13	-0 12	-0 01	0 24
25 I've been thinking hard about what steps to take	**0.66**	0 04	0 25	0 10	0 02	0 11
2 I've been concentrating my efforts on doing something about the situation I'm in	**0.66**	-0 02	0 04	0 13	0 07	0 10
7 I've been taking action to try to make the situation better	**0.65**	0 13	0 01	0 13	0 01	0 10
17 I've been looking for something good in what is happening	**0.60**	-0 10	0 23	-0 01	0 27	0 04
24 I've been learning to live with it	**0.53**	0 02	0 20	0 00	0 19	0 21
20 I've been accepting the reality of the fact that it has happened	**0.42**	0 29	0 03	-0 37	0 39	-0 22
11 I've been using alcohol or other drugs to help me get through it	-0 09	**0.88**	0 07	0 07	0 05	0 04
4 I've been using alcohol or other drugs to make myself feel better	-0 01	**0.68**	0 09	0 10	0 01	-0 02
16 I've been giving up the attempt to cope	0 11	**0.55**	0 21	0 22	0 08	0 08
21 I've been expressing my negative feelings	0 15	**0.50**	0 09	0 17	0 16	0 33
6 I've been giving up trying to deal with it	0 09	**0.40**	-0 00	0 28	0 25	0 35
10 I've been getting help and advice from other people	0 22	0 11	**0.77**	0 08	0 06	-0 12
23 I've been trying to get advice or help from other people about what to do	0 21	0 12	**0.76**	-0 05	0 23	-0 01
15 I've been getting comfort and understanding from someone	0 12	-0 01	**0.67**	-0 05	0 08	0 32
5 I've been getting emotional support from others	0 01	0 12	**0.64**	0 09	-0 05	0 31
9 I've been saying things to let my unpleasant feelings escape	0 38	0 26	**0.54**	0 22	0 10	-0 03
3 I've been saying to myself "this isn't real "	0 11	0 11	-0 09	**0.72**	0 02	0 18
8 I've been refusing to believe that it has happened	0 23	0 17	0 08	**0.71**	-0 04	0 04
26 I've been blaming myself for things that happened	0 03	12	0 11	**0.68**	0 41	-0 07
13 I've been criticizing myself	0 09	0 29	0 13	**0.61**	0 36	-0 06
22 I've been trying to find comfort in my religion or spiritual beliefs	0 13	0 12	0 12	0 12	**0.78**	0 19
27 I've been praying or meditating	0 10	0 07	0 14	0 38	**0.66**	0 22
19 I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping	0 21	-0 06	0 15	0 04	0 05	**0.67**
28 I've been making fun of the situation	0 16	0 27	0 08	0 07	0 31	**0.48**
18 I've been making jokes about it	0 30	0 20	0 22	-0 12	0 29	**0.46**
1 I've been turning to work or other activities to take my mind off things	**0.45**	0 17	-0 04	0 23	-0 01	**0.45**
Cronbach's alpha	0 80	0 76	0 78	0 76	0 76	0 61
Item-subscale correlation coefficients	0 31 - 0 58	0 42 - 0 66	0 48 - 0 64	0 54 - 0 59	0 62	0 31 - 0 4
Variance explained	13 07%	9 81%	9 75%	9 28%	7 01%	6 61%

Table 5.5 Correlation coefficients between the 6 subscales and other psychological variables

	CLOT-R	PSSS	PDSHIV
Problem-solving and Acceptance	**0.19****	**0.24****	-0 08
Negative Venting and Avoidance	**-0.20****	-0 03	0 11
Support Seeking	0 12	**0.30****	**-0.12***
Self-blame and Denial	**-0.16***	-0 12	0 11
Reliance on Spirituality	-0 06	0 02	0 04
Humor and Self-distraction	0 10	**0.17****	-0 06

CLOT-R Chinese version of the revised Life Orientation Test, PSSHIV The Perceived Stress Scale for People Living with HIV/AIDS, PDSHIV Perceived Discrimination Scale for PLWH * p<0 05, ** p<0 01

The paper of Validation of the Brief COPE has been submitted: Su, X. Y., Lau, J. T. F., Mak, W. W. S., Choi KC, Feng, T. J., Chen, X., Liu, C. L., Liu, J., Liu, D., Chen, L., Song J.M., Zhang Y., Zhao G. L. and Cheng, J. Q. (2009) Validation of the Brief COPE instrument for assessing coping strategies among People Living with HIV in China. AIDS Care (under review).

Chapter 6 Identifying clusters of PLWH with similar profile of stress characteristics

6.1 Background

In the previous chapter, the development of Perceived Stress Scale for People Living with HIV/AIDS (PSSHIV) in China was described. PSSHIV consists of 35 items in eight domains: social/psychological problems, sexual relationships, functional problems, social acceptance/rejection issues, work related issues, family/offspring issues, accessibility to treatment, and treatment outcomes [240]. Since PLWH vary in their eight perceived stress domains, cluster analysis may be able to group the PLWH together based on their perceived stress level in each domain of PSSHIV. Cluster analysis has been used in previous studies to gain a better understanding of variation to perceptions[341], diseases distribution characteristics, and symptoms assembling of diseases [342].

6.2 Objectives

In this chapter we firstly applied cluster analysis to identify groups (clusters) of PLWH with similar stress characteristics. The hypothesis is that there would be subgroups of PLWH characterized by different combination of stress subscales. Secondly, characteristics of PLWH belonging to different identified groups (clusters) were compared. The compared characteristics include background characteristics, individual characteristics (coping strategies adopted and optimism), relationship variables (perceived discrimination, social support) and psychological status (depression and health distress).

6.3 Statistical analysis

Data were analyzed using SPSS (Statistical Package for the Social Sciences; SPSS, Inc.,

Chicago), version 16.0. To determine the patterns of the stress levels among the individuals, we clustered participants on the basis of their eight stress domains of PSSHIV. For the purpose of clustering, mean scores of each stress domain (total scores of the subscales of PSSHIV divided by the number of the items in each subscale) were computed, in order to more clearly represent the relative levels of each stress domain that were experienced by the members of each cluster. In cluster analysis, cases are grouped according to their similarity on the clustering variable (in this case, the eight stress subscales of PSSHIV) [343]. The Ward's method, an agglomerative hierarchical method was used, which considers each stress subscale as a cluster size of one; it then joins similar clusters together until all clusters are merged into a single cluster [344]. This method has been found to have a number of desirable properties and to maximize within group homogeneity [231]. The number of clusters to be merged from the data was determined with a bar chart, whether cases in the different clusters differed from each other on the cluster variables and the interpretability of the cluster solution [231]. To understand the nature of the clusters, t-test analyses were conducted to examine possible differences among clusters on the stress level in each cluster.

6.4 Results

6.4.1 Identification of clusters with respect of subscale scores of PSSHIV

Among the 258 PLWH in the sample, Ward's method was used to explore the possible clusters on the basis of the similarity of their individual stress profiles across the eight stress domains. Cluster memberships of 2 to 4 were explored respectively (Fig 6.1 to 6.3). Based on the figures of the mean stress profile, interpretation of clusters and compactness (how similar to one another the elements of a cluster are) and distinctness (how different one cluster is from its closest neighbor) of the dendrogram, examination of the resulting clustering solution

suggested the existence of two distinct clusters, and the two clusters differed reliably in terms of scores of all eight stress domains (all *p*s <0.001, Table 6.1). This result is not particularly surprising because the clusters were formed in a way designed to maximize the differences in the profiles across the groups. The two clusters of stress were especially remarkable in terms of levels of perceived stress from Figure 6.1, and were labeled as high stress group (n=124) and low stress group (n=134). These two clusters were retained for further analysis. Figure 6.1 presents the results of the cluster analysis, including the number of individuals in each cluster and the average stress scores.

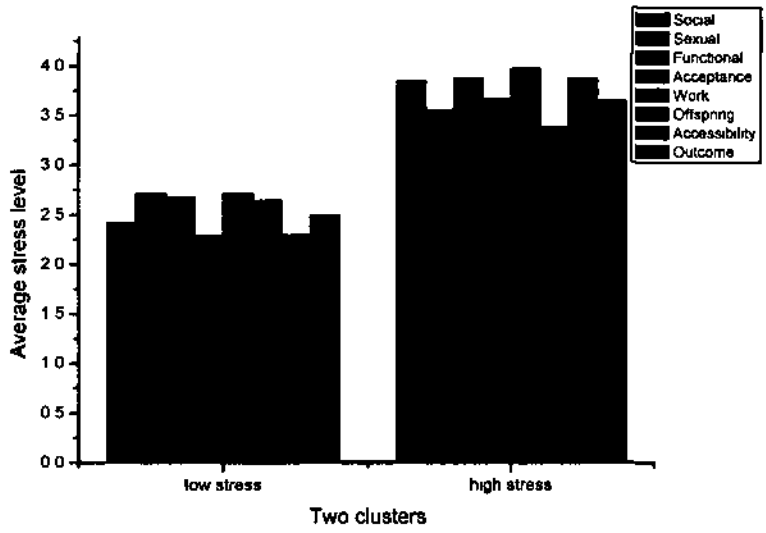


Fig. 6.1 Two clusters of stress—low stress level and high stress level
Cases of clusters: low stress, 134, high stress 124

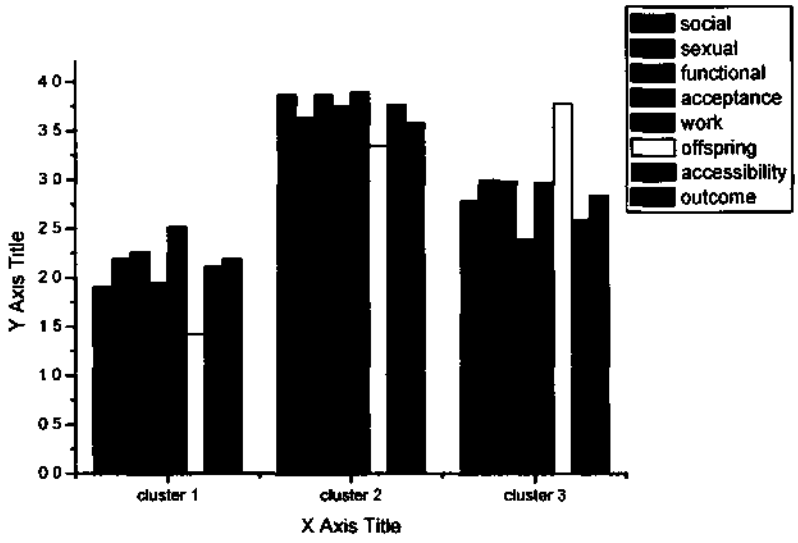


Fig. 6.2 Three clusters of stress
Case of clusters: 63, 126, 69

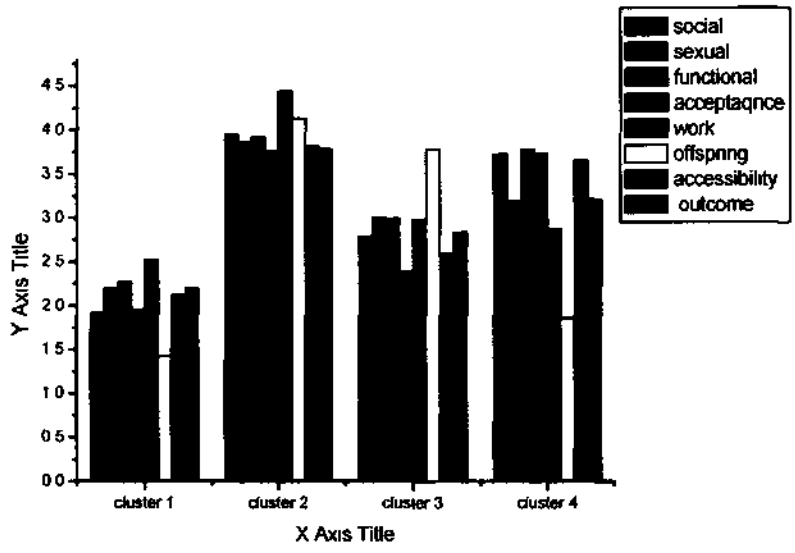


Fig. 6.3 Four clusters of stress
Cases of clusters: 63, 83, 69, 43

6.4.2 Characteristics across the two groups with similar stress profiles

Background variables were cross-tabulated with clustering variables (high stress and low stress), to describe their characteristics across the two profiles. The chi-square test statistics indicated that the stress levels were significantly different across the SES variables. Those with higher education level, higher income, having a job and health insurance have a higher percentage of low stress and lower percentage of high stress (Table 6.2, *ps* < 0.05). The finding is consistent with the prior findings of the factors of perceived stress using multiple regression models.

Optimism and coping strategies were conceptualized as individual characteristics in this study, since they are all related to dispositional manners when confronting difficulties. The comparison of the two profiles found that the high stress group had a lower level of optimism compared to the lower stress group (mean overall stress=11.36 vs. 12.40). Among the coping strategies, the high stress group was more likely to adopt five of the six coping strategies, except the 'Humor and self-distraction' with no significant difference between the two groups (Table 6.1, *ps*<0.05).

The comparisons of the relationship characteristics of social support and perceived discrimination, and psychological status, were in the expected direction. The high stress group reported statistically lower social support and higher perceived discrimination; and the high stress group also possessed higher levels of depression and lower quality of life. (Table 6.1, *ps*<0.01)

6.5 Summary

We used cluster analysis to empirically identify subgroups of individuals with different

stress levels. Compared to the three-cluster solution and four-cluster solution (could not be interpreted clearly, the two-cluster solution is of certain theoretical interest because it managed to discriminate individuals on the basis of their overall stress level and across different SES status (people with higher SES status have lower stress levels). Individual characteristics like optimism were higher in the low stress group; while higher stress will lead the PLWH to adopt more coping strategies to cope with the difficulties they are confronted with. Meanwhile, the levels of social support and perceived discrimination were significantly different between the two groups, indicating the buffering effect of social support and the predicting effect of perceived discrimination to perceived stress, that is, a worse relationship predicts higher stress among PLWH. This was in the predicted direction as the literature suggested [309, 345]. The determinant effect of stress on psychological outcomes also indicated that higher stress may predict a worse psychological status [346]. Based on the finding in this study, suggestions for interventions will be provided to PLWH, with a focus on observed patterns of perceived stress.

Table 6.1 Comparison on the mean scores of subscales of PSSHIV and other characteristics across different clusters

	Overall low stress profile (n=134)		Overall high stress profile (n=124)		t-test
	Mean	SD	Mean	SD	p
Profile defining					
Social/Psychological stress	2 42	0 79	3 84	0 73	**0.000****
Sexual relationship	2 71	1 10	3 55	1 04	**0.000****
Functional problems	2 67	0 88	3 87	0 92	**0.000****
Acceptance/rejection issues	2 29	0 89	3 66	0 91	**0.000****
Work related issues	2 71	1 29	3 97	1 18	**0.000****
Offspring issues	2 64	1 52	3 38	1 57	**0.000****
Accessibility to treatment	2 29	0 95	3 87	0 98	**0.000****
Treatment outcomes	2 49	0 89	3 65	1 00	**0.000****
Individual characteristics					
Optimism	12 40	3 29	11 36	3 44	**0.014***
Coping strategies					
Problem-solving and acceptance	17 40	4 66	18 67	3 99	**0.020***
Negative venting and avoidance	8 23	2 50	9 19	3 03	**0.006****
Support-seeking	8 41	2 49	9 24	3 02	**0.017***
Self-blame and denial	7 66	2 51	9 71	2 87	**0.000****
Reliance on spirituality	2 76	1 14	3 41	1 48	**0.000****
Humor and self-distraction	8 05	2 12	8 49	2 34	**0.114**
Relationship					
Social support	53 71	16 77	46 44	17 46	**0.001****
Perceived discrimination	12 11	3 34	13 72	3 64	**0.000****
Psychological status					
Depression	17 93	12 19	29 13	13 49	**0.000****
Health distress (QOL)	18 19	4 20	13 18	4 33	**0.000****

Table 6.2 Compare the distribution of socio-economic variables across different clusters

	% (n=258)	Low stress (n=134)	High stress (n=124)	*p* (Chi-square)
Demographic variables				
Gender	Male (73 6)	103(54 2%)	87(45 8%)	0 222
	Female (26 4)	31(45 6%)	37(54 4)	
Age (years)	29 or below (22 9)	32(54 2%)	27(45 8%)	0 896
	30-39 (53 1)	71(51 8%)	66(48 2%)	
	40 or above (24 0)	31(50 0%	31(50 0%)	
Local resident	Yes (72 9)	97(51 6%)	91(48 4%)	0 857
	No (27 1)	37(52 9%)	33(47 1%)	
Marital status	Currently married (41 5)	74(49 0%)	77(51 0%)	0 263
	Currently not married (58 5)	60(56 1%)	47(43 9%)	
Whether having kid(s)	Yes (47 3)	59(48 4%)	63(51 6%)	0 276
	No(52 7)	75(55 1%)	61(44 9%)	
SES variables				
Education level	Primary or below (12 0)	12(38 7%)	19(61 3%)	**0.024**
	Junior high (51 6)	62(46 6%)	71(53 4%)	
	Senior high/technical secondary school (27 5)	44(62 0%)	27(38 0%)	
	Junior College or above (8 9)	16(69 6%)	7(30 4%)	
Employment status	Employed (25 2)	43(66 2%)	22(33 8%)	**0.007**
	Unemployed (67 1)	90(46 9%)	102(53 1%)	
Individual monthly income	No income (47 7)	52(42 3%)	71(57 7%)	**0.033**
	<=500 yuan (15 5)	21(52 5%)	19(47 5%)	
	500 to 1000 yuan (10 5)	17(63 0%)	10(37 0%)	
	1000 to 2000 yuan (11 2)	18(62 1%)	11(37 9%)	
	>2000 yuan/month (12 8)	26(66 7%)	13(33 3%)	
Whether have health insurance	Yes (21 7)	39(69 6%)	17(30 4%)	**0.003**
	No (77 5)	95(47 5%)	105(52 5%)	
HIV related variables				
Probable mode of HIV transmission	Non-IDU (48 1)	65(52 4%)	59(47 6%)	0 882
	IDU (51 9)	69(51 5%)	65(48 5%)	
Currently receiving ARV	Yes (43 8)	59(52 2%)	54(47 8%)	0 938
	No (56 2)	75(51 7%)	70(48 3%)	

Chapter 7 Descriptive statistics of key variables by background characteristics

7.1 Background

Depression is the most commonly occurring and under-treated psychiatric disorder among PLWH [208]. The lifetime prevalence of depression in patients infected with HIV has been estimated at 22-45% [208]. Depressive symptoms in PLWH are associated with disease progression, lower CD4 cell count, and higher baseline viral load levels [47]. Depressive symptoms seem also to be associated with lower levels of adherence to medication regimens, development of drug resistance HIV and failure of treatment [56, 57]. Furthermore, depression has been found to affect both people's sexual behavior, which includes engaging in unsafe sex, and self-medication with alcohol or drugs [80-83].

However, most of the psychological data on HIV/AIDS is derived from Western populations, so it is not necessarily generalizable to the Chinese PLWH. To date, there is a limited number of studies examining depression among the Chinese PLWH and the rate of depression differs depending on the measures used and the population studied. A study in mainland China showed that 92% of HIV infected mainland rural former blood donors (FBD) had moderate to severe depression based on cutoffs of the Beck Depression Inventory [116]. By contrast, a study conducted in Hong Kong demonstrated a 17.7% depression rate among HIV/AIDS people, using the Profile of Mood States assessment [118].

Impaired quality of life (QoL) is frequently observed with depression in patients suffering from HIV-infection [109]. Factors like fear of death, concern about expensive treatment costs, feelings of guilt towards their family, loneliness, difficulty with adherence to rigid medication regimens, and physical and psychological discomfort associated with the

infection and HAART treatment [110-113], all have contributed to the deterioration of patients' psychological well-being. Perceived discrimination, coping resources (optimism and social support) and coping strategies are most frequently studied factors that are related to psychological well-being of PLWH, apart from the perceived stress. Therefore, distinction of population who perceived less discrimination, with better resources, more adaptive coping resources, is of our interest, as well as identifying those with worse psychological well-being.

Coping is viewed as a response to perceived stress [347]. Coping styles are likely to differ among individuals, even when they are faced with a similar stressful situation. These differences may be accounted for by different appraisals of the situation or by preferences for different coping styles. Evidence suggests that preferred coping style is influenced by situational [348] and dispositional factors [197, 304]. The experience of being diagnosed with HIV infection or AIDS is extremely stressful, including abandonment, pain, death, and the exposure of their non-heterosexual orientation, drug use, prostitution, or unsafe sexual activity [347]. However, little research to date has examined how individuals cope with these stressors and whether different groups of PLWH are prone to use different coping strategies.

Categorization of coping style in this study differs from the prior study, such as problem-focused versus emotion-focused coping, or active versus avoidance coping. We have derived a six-factor model from the Brief COPE in Chapter 5 and the six factors are Problem-solving and acceptance, Negative venting and avoidance, Support seeking, Self-blame and denial, Reliance on spirituality, Humor and self-distraction.

7.2 Objectives

The chapter reported here has two objectives. The first was to estimate the prevalence of depressive disorder in PLWH in China; the second was to examine the differences in perceived discrimination, coping resources, coping strategies and psychological well-being according to individual's background characteristics (e.g., gender, education level, income).

7.3 Data analysis

Prevalence of depression was calculated using the cut-off values of BDI-II provided by the Chinese Behavioral Sciences Society [232]. Measures of central tendency and variability were used to describe the levels of perceived discrimination, coping resources, coping strategies and psychological well-being variables across different background groups. Bivariate correlation was performed to investigate the relationship between depression and quality of life among the present sample. Student's *t*-test and one-way ANOVA were employed to compare the differences of the above variables across groups with different background characteristics. The significant variables in univariate analysis were put in the subsequent linear regression as independent variables to identify the significant background variables of perceived discrimination, coping resources and coping strategies in multivariate analysis.

7.4. Results

7.4.1 Prevalence of depression among overall sample and subgroups

Mean scores on C-BDI-II among participants were segmented into categories of normal, mild, moderate and severe depression according to the cut-off values provided by the manual of Chinese BDI-II [232]. The overall prevalence of depression (the proportion of those with mild to severe depression) was 70.9% and the proportion of individuals with moderate

to severe depression is 63.3% (Table 7.1).

In univariate analysis, participants with older age, lower education level and income, unemployed, and with HIV transmitted by IDU behavior were more likely to have higher rate of moderate to severe depression. In multivariate analysis, only individuals without income were shown more likely to have higher rate of moderate to severe depression (Table 7.1, $p<0.05$).

7.4.2 Relationship between background variables and depression

The mean and SD of C-BDI-II were calculated and compared among subsets defined by different background characteristics. The mean score of total BDI-II (23.31±13.98, range 0–58) was in the moderate range of depression (20-28) [349]. In multivariate analysis, the score of depressive symptoms was significantly higher among individuals of lower education, lower income and with IDU-transmitted HIV than in other groups. (Table 7.2, $p<0.05$)

7.4.3 Relationship between background variables and QoL

Quality of life as measured by the Health Distress subscale of MOS-HIV (15.78±4.94, range 6-24) demonstrated no significantly differences among individuals with different background characteristics, though individuals with some certain background characteristics were more likely to have better QoL in univariate analysis (Table 7.3, $p<0.05$).

7.4.4 Correlation between depression and QoL among PLWH

The association between depression and quality of life showed a negatively significant correlation ($r= -0.66$, $p<0.05$) (Data not tabulated).

7.4.5 Optimism, social support and perceived discrimination by background variables

Only 0.8% of the participants never perceived any discrimination in terms of HIV infection (data not tabulated). In multivariate analysis, no significant differences were found in optimism and perceived discrimination across groups with different background characteristics. In respect of social support, PLWH with symptomatic stage and AIDS were more likely to perceive a higher support compared to those with asymptomatic stage (Table 7.4, $p<0.05$).

7.4.6 Coping strategies by individual characteristics

Among the overall sample, 'Problem-solving and Acceptance' (mean = 2.25) and 'Self-blame and Denial' (mean = 2.16) were commonly used coping strategies (mean scores were generated by dividing subscales scores by the number of items, data not tabulated). Descriptive statistics for coping strategies across the background variables were shown in Table 7.5. In multivariate analysis, no background characteristics were significantly related to 'Self-blame and denial' and 'Reliance on spirituality' (Table 7.5, $p<0.05$).

Problem-solving and acceptance

In multivariate analysis, currently unmarried individuals at the time of interview were more likely to adopt 'Problem-solving and acceptance' as coping strategies comparing to those who were currently married (mean=18.65 vs. 17.56) (Table 7.5, $p<0.05$).

Negative venting and avoidant

In multivariate analysis, those with lower income and contracted HIV via IDU behavior were more likely to use 'Negative venting and avoidance' as coping strategy (Table 7.5, $p<0.05$).

Support seeking

In multivariate analysis, those currently receiving ARV therapy were more likely to adopt 'Support seeking' as their coping strategy (mean=9.29 vs. 8.43) (Table 7.5, $p<0.05$).

Humor and self-distraction

In multivariate analysis, those currently receiving ARV therapy were more likely to adopt 'Humor and self-distraction' as their coping strategy (mean=8.77 vs. 7.87) (Table 7.5, $p<0.05$).

7.5 Summary

This cross-sectional study was undertaken to assess the prevalence of depression and characteristics associated with depressive symptoms and health distress. Among the PLWH who completed the survey, 60.3% of those screened had moderate to severe depressive symptoms within the two weeks prior to the survey. This figure was consistent with the findings of previous studies on the prevalence of depression among PLWH in China, and was much higher than the average rate of depression (22-45%) reported among PLWH worldwide [208]. Previous study indicated that low social economic status (SES) was a significant predictor of depression among PLWH [350]. In this study, income as one of the most important SES variables was also shown significantly related to depression, which is consistent with the prior funding that PLWH with lower SES are more likely to have depressive disorder [350]. Since 63.2% of the study participants have income lower than 500 yuan in this study, it's not surprising that the rate of depressive symptoms in this study were found much higher than previous study.

The findings of a number of previous studies indicate that depressive symptoms are associated with increased AIDS-related mortality [65], rapid disease progression [47] and poor adherence to HAART [51, 72, 351]. In developed countries, mental health care has in many cases

been integrated into the HIV-related care system because individuals living with HIV often experience varying ranges of psychological distress over the course of their lives following an HIV diagnosis [352, 353]. Researchers have documented that participation in mental health care was related to enhanced medication adherence, increased maintenance of lower-risk sexual behaviors, increased disclosure of HIV serostatus to sex partners and improved overall quality of life [354-356]. In China, although mental health issues were increasingly being recognized by the government and health care workers, financial resources allocated were still very scarce, and China has grossly inadequate human resources and infrastructure to promote mental health, as in other developing countries [28]. Accordingly, allocation on mental health care of PLWH was also insufficient.

Depression among PLWH is typically first seen and treated in the community by non-mental health professionals who are primarily general practitioners (GPs) [357]. Despite the reported high prevalence of depression in this and previous studies, there is ongoing concern that depression remains under-recognized and under-treated in primary care [358, 359] which may have a significant negative impact on the course of HIV. Primary health-care workers need to be trained in recognition and evidence-based treatment of mental disorders, and given suitable supervision and support [360]. Screening of depressive disorders, provision of appropriate treatment for the HIV-infected individuals and identification of psychosocial factors linked to depression among HIV/AIDS population are prerequisites for effective prevention and intervention measures that will improve the quality of life of PLWH.

Following the awareness of HIV infection, PLWH confronted with various hardships, such as reduction in financial resources, a need for external support, and a deteriorating health condition. This truly represents stress, defined as "a relationship between the person and the environment that is appraised by the person as taxing or exceeding personal

resources and as endangering his or her well-being" (p 839) [361]. It is not surprising that those with symptomatic stage perceived more social support than those with asymptomatic stage. PLWH with more advanced disease progression are more likely to disclose their HIV infection status to family or friends and hence use the care and support services, no matter voluntarily or passively [362].

Problem-focused coping and emotion-focused coping are two frequently identified styles of coping. They represent attempts at altering the problem in the environment that is causing the tension (problem-focused coping, e.g. confrontation), or attempts at managing one's emotional reaction (emotion-focused coping, e.g. escape or avoidance) [304, 361]. However, emotion-reduction and problem-solving are not mutually exclusive; in fact they are complementary, both being aimed at the same goal of inner tension reduction [363]. In recent years, the conceptualization of coping as responses to stress was suggested by many researchers to involve volition and conscious effort by the individual and the responses that are automatized and not under conscious control [290, 364-366]. This distinction avoids an overly broad and imprecise definition of coping in which coping include everything that individuals do in response to stress [135, 364].

In the present study, those with lower SES (represented by having lower income) were more likely to use 'negative venting and avoidance' as coping strategies. The same, individuals transmitted HIV by IDU behaviors were more likely to use 'negative venting and avoidance' compared to those non-IDU transmitted. There are studies reported that community-dwelling drug users, especially those of low socioeconomic status, relied more on emotion-reduction strategies compared to non-users [367]. Previous research also found IDUs were more likely to be depressed and use the avoidant coping [368, 369].

Besides, in the present sample, compared to non-IDU transmitted individuals, individuals infected via IDU behaviors were mostly have no job (91.0% vs. 56.9%), no income (63.4% vs. 30.6%) and lower education (73.9% vs. 52.4% have a junior high or below education) (data not presented). In other words, IDU-transmitted individuals are mostly in low SES. In sum, PLWH with lower SES were more likely to use involuntary coping strategies ('negative venting and avoidance') and more prone to seek emotional support from others during their adjustment to the stress of HIV infection.

In conclusion, the findings of the present study revealed the severity of the mental health status, and the related background factors through which they affect psychological well-being among PLWH. More human resources and infrastructure should be allocated to promote mental health of PLWH in China. Intervention programs focusing on lower SES PLHW are warranted to promote them use the more active and problem solving coping strategies, and hence improve their psychological well-being. Further multivariate analysis to investigate the role of coping strategies on psychological well-being during the psychological adjustment considering factors in stress and coping model will be introduced in the following Chapters.

Su, X. Y., Lau, J. T. F., and Mak, W. W. S. (2009). Prevalence and determinants of depression among People Living with HIV/AIDS in China. *In* "9th International Congress on AIDS in Asia and the Pacific (ICAAP) ", Bali, Indonesia, 9-13 August (Oral presentation). Abstract Code: 4560-ON-AB-A.

Table 7.1 Prevalence of depression among overall sample and subgroups based on C-BDI-II cut-offs

	Normal	Mild	Moderate	Severe	Moderate to Severe	ORu (*p*) (Moderate to severe)	ORm (*p*) (Moderate to severe)
Overall sample	75(29 1%)	30(11 6%)	62(24%)	91(36 3%)	153(60 3%)		
Gender							
Male*	54(28 4%)	21(11 1%)	51(26 8%)	64(33 7%)	115(60 5%)	1	---
Female	21(30 9%)	9(13 2%)	11(16 2%)	27(39 7%)	38(55 9%)	0 83(0 504)	---
Age							
29 or below*	23(39 0%)	6(10 2%)	15(25 4%)	15(25 4%)	30(50 8%)	1	---
30-39	37(27 0%)	20(14 6%)	30(21 9%)	50(36 5%)	80(58 4%)	1 36(0 330)	---
40 or above	15(24 2%)	4(6 5%)	17(27 4%)	26(41 9%)	43(69 3%)	**2.19(0.004)**	---
Marital status							
Currently married*	41(27 2%)	19(12 6%)	38(25 2%)	53(35 1%)	91(60 3%)	1	---
Currently not married	34(31 8%)	11(10 3%)	24(22 4%)	38(35 5%)	62(57 9%)	0 99(0 709)	---
Education level							
Junior College or above*	12(52 2%)	5(21 7%)	4(17 4%)	2(8 7%)	6(26 1%)	1	---
Senior high/technical secondary school	24(33 8%)	9(12 7%)	18(25 4%)	2(28 2%)	20(53 6%)	**3.26(0.026)**	---
Junior high	33(24 8%)	14(10 5%)	35(26 3%)	51(38 3%)	86(64 6%)	**5.18(0.001)**	---
Primary or below	6(19 4%)	2(6 5%)	5(16 1%)	18(58 1%)	23(74 2%)	**8.15(0.001)**	---
Employment status							
Employed*	35(53 8%)	8(12 3%)	14(21 5%)	8(12 3%)	22(33 8%)	1	---
Unemployed	39(20 3%)	22(11 5%)	48(25 0%)	83(43 2%)	131(68 2)	**4.20(0.000)**	---
Individual monthly income							
>2000 yuan/month*	22(56 4%)	7(17 9%)	8(20 5%)	2(5 1%)	10(25 6)	1	1
1000 to 2000 yuan/month	13(44 8%)	3(10 3%)	8(27 6%)	5(17 2)	13(44 8%)	2 36(0 101)	---
500 to 1000 yuan/month	10(37 0%)	3(11 1%)	6(22 2%)	8(29 6%)	14(51 8%)	**3.12(0.032)**	---
<=500 yuan/month	11(27 5%)	4(10 0%)	10(25 0%)	15(37 5%)	25(62 5%)	**4.83(0.001)**	---
No income	19(15 4%)	13(10 6%)	30(24 4%)	61(49 6%)	81(74 0%)	**8.25(0.000)**	**3.65(0.018)**
Probable mode of HIV transmission							
IDU*	24(17 9%)	14(10 4%)	32(23 9%)	64(47 8%)	96(71 7%)	1	---
Non-IDU	51(41 1%)	16(12 9%)	30(24 2%)	27(21 8%)	57(46 0%)	**0.34(0.000)**	---
Receiving ARV therapy							
Yes*	31(27 4%)	12(10 6%)	23(20 4%)	47(41 6%)	70(62 0%)	1	---
No	44(30 3%)	18(12 4%)	39(26 9%)	44(30 3%)	83(57 2%)	0 822(0 445)	---

ORu odds ratio in univariate analysis, ORm: odds ratio in multivariate analysis

Table 7.2 levels of depression and their relationship with background characteristics

	Depression (C-BDI-II,alpha=0 93)			
	Mean(0-58)	SD	*p(u)**	*p(m)**
Overall sample	23.31	13.98		
Gender			0 644	0.178
Male	23 07	13.55		
Female	23.99	15.21		
Age			**0.048**	0.268
29 or below	19 69	13.72		
30-39	23.74	13.88		
40 or above	25 81	13.97		
Marital status			0 919	0.756
Currently married	23 39	13.63		
Currently not married	23.21	14.52		
Education level			**0.000**	**0.028**
Primary or below	29.74	15.55		
Junior high	24.84	17.23		
Senior high/technical secondary school	20.36	12.94		
Junior College or above	14.96	10.8		
Employment status			**0.000**	0.219
Employed	15.06	12.41		
Unemployed	26.22	13.32		
Individual monthly income			**0.000**	**0.007**
No income/month	28 36	13.68		
<=500 yuan/month	23 83	12.62		
500 to 1000 yuan/month	21 63	14.79		
1000 to 2000 yuan	17 38	11.04		
>2000 yuan/month	12 44	9.2		
Probable mode of HIV transmission			**0.000**	**0.018**
Non-IDU	18.68	12.80		
IDU	27.6	13.7		
Receiving ARV therapy			0.454	0.542
Yes	24.72	14.28		
No	22.22	13.69		

C-BDI-II The Chinese version of Beck Depression Inventory *p(u)* p value in univariate analysis*
p(m) p value in multivariate analysis*

Table 7.3 levels of QoL and their relationship with background characteristics

	QoL (Health Distress of MOS_HIV alpha=0 89)			
	Mean(6-24)	SD	*p(u)**	*p(m)**
Overall sample	15.78	4.94		
Gender			0.633	0 885
Male	15.69	4.89		
Female	16.03	5.1		
Age	16.68	5.09	0 221	0.418
29 or below	15.69	4.96		
30-39	15.15	4.71		
40 or above	15.78	4.94		
Marital status			0.487	0.440
Currently married	15.6	5		
Currently not married	16.03	4.87		
Education level			0.127	0 402
Primary or below	14.52	5.01		
Junior high	15.45	4.85		
Senior high/technical secondary school	16.72	4.93		
Junior College or above	16.52	5.14		
Employment status			**0.001**	0.386
Employed	17.54	4.89		
Unemployed	15.15	4 81		
Individual monthly income			**0.002**	0.153
No income/month	14 7	4.66		
<=500 yuan/month	16 08	5.31		
500 to 1000 yuan/month	15.3	4.79		
1000 to 2000 yuan	17.59	4.52		
>2000 yuan/month	18.87	4.96		
Probable mode of HIV transmission			**0.004**	0 361
Non-IDU	16.71	4.50		
IDU	14.93	4.75		
Receiving ARV therapy			0.219	0.478
Yes	15.35	4.72		
No	16.12	5.1		

QoL Health distress subscale of MOS-HIV *p(u)* p value in univariate analysis*

p(m) p value in multivariate analysis*

Table 7.4 Coping resources and perceived discrimination among background characteristics

	optimism			social support			perceived discrimination		
	Mean±SD	*p(u)**	*p(m)**	Mean±SD	*p(u)**	*p(m)**	Mean±SD	*p(u)**	*p(m)**
Gender		0 870	0 742		0 465	0 366		0 127	0 127
Female	11 84±3 96			48 87±17 29			11 46±3 27		
Male	11 92±3 18			50 69±17 53			12 68±3 66		
Age		0 171	0 069		**0.000**	0 091		0 052	0 534
29 or below	12 24±3 65			48 12±15 31			13 28±2 99		
30-39	12 07±3 48			53 42±17 27			12 383± 86		
40 or above	11 20 ±2 88			45 11±18 48			13 61±3 29		
Marital status		0 665	0 469		0 857	0 559		0 731	0 780
Currently married	11 82±3 34			50 04±16 68			12 82±3 63		
Currently not married	12 00±3 49			50 46±18 57			12 97± 3 51		
Education level		0 190	0 079		0 421	0 053		0 182	0 637
Primary or below	11 74±2 68			45 58±16 99			13 94±2 76		
Junior high	11 59±3 46			50 28±18 29			12 59±3 69		
Senior high	12 13±3 33			51 52±15 85			12 72±3 74		
junior college or above	13 19±3 90			52 04±17 89			13 67±3 12		
Employment		0 789	0 087		0 543	0 700		0 697	0 253
Employed	11 81±3 81			49 12±16 33			12 73±3 00		
Unemployed	11 94±3 26			50 65±17 86			12 94±3 44		
Income		0 813	0 244		0 212	0 509		0 283	0 095
No income	11 74±3 22			51 20±16 52			13 31±3 16		
<500/month	11 83±3 56			47 15±21 35			13 10±3 47		
500 to 1000/month	11 63±3 68			56 11±15 81			12 19±4 54		
1000 to 2000/month	12 45±3 70			47 59±15 36			12 17±4 67		
>2000/month	12 24±3 60			48 13±18 00			12 88±3 57		
Transmission categories		0 872	0 952		0 300	0 433		0 206	0 191
Non-IDU	11 62±4 11			46 32±15 23			13 41±2 76		
IDU	11 81±3 16			51 33±17 60			13 22±3 15		
Disease stage		0 424	0 536		**0.038**	**0.024**		0 941	0 510
Asymptomatic stage	11 71±3 31			47 69±17 37			12 90±3 83		
Symptomatic stage and AIDS	12 05±3 47			52 31±17 31			12 87±3 36		

p(u)* p value in univariate analysis *p*(m)* p value in multivariate analysis

Table 7.5 Levels of coping strategies among background characteristics (*p(m)* p value in multivariate analysis)*

	Problem-solving and acceptance		Negative venting and avoidance		Support seeking		Self-blame and denial		Reliance on spirituality		Humor and self-distraction	
	M(SD)	*p(m)**	M(SD)	*p(m)**	M(SD)	*p(m)**	M(SD)	*p(m)**	M(SD)	*p(m)**	M(SD)	*p(m)**
Gender		0 126		0 144		0 111		0 232		0 466		0 572
Male	18 21(4 41)		8 93(2 96)		8 97(2 76)		8 56(2 84)		3 04(1 32)		8 31(2 23)	
Female	17 47(4 32)		8 04(2 19)		8 35(2 81)		8 90(2 96)		3 16(1 44)		8 13(2 25)	
Age (years)		0 092		0 815		0 279		0 997		0 322		0 225
29 or below	17 80(4 87)		8 14(2 89)		8 44(2 98)		8 54(3 13)		3 10(1 48)		7 92(2 28)	
30-39	18 45(4 11)		8 86(2 79)		9 06(2 62)		8 62(2 81)		3 09(1 36)		8 58(2 26)	
40 or above	17 24(4 46)		8 85(2 72)		8 61(2 92)		8 79(2 79)		3 00(1 21)		7 90(2 05)	
Marital status		**0.021**		0 780		0 204		0 343		0 485		0 138
Currently married	17 56(4 41)		8 81(2 89)		8 66(2 62)		8 47(2 98)		3 01(1 25)		8 09(2 21)	
Currently not married	18 65(4 30)		8 53(2 67)		9 02(3 00)		8 89(2 71)		3 16(1 48)		8 50(2 26)	
Education level		0 126		0 743		0 734		0 395		0 404		0 647
Primary or below	17 71(4 08)		8 90(2 95)		9 03(2 34)		9 13(3 19)		3 32(1 60)		8 68(2 14)	
Junior high	17 83(4 37)		8 89(2 84)		8 92(2 97)		8 75(2 91)		3 14(1 38)		8 21(2 19)	
Senior high/technical secondary school	18 44(4 49)		8 73(2 75)		8 90(2 67)		8 50(2 78)		2 89(1 19)		8 49(2 28)	
Junior College or above	18 17(4 77)		7 17(2 17)		7 61(2 39)		7 87(2 47)		2 96(1 33)		7 30(2 32)	
Employment status		0 347		0 800		0 257		0 909		0 222		0 09
Employed	17 55(4 73)		7 75(3 01)		8 02(2 72)		8 19(2 99)		2 80(1 31)		7 83(2 47)	
Unemployed	18 22(4 22)		9 03(2 65)		9 10(2 75)		8 82(2 82)		3 17(1 36)		8 43(2 13)	
Individual monthly income		0 555		**0.044**		0 315		0 719		0 813		0 445
No income	18 13(4 41)		9 25(2 75)		9 22(3 04)		8 78(2 95)		3 24(1 42)		8 34(2 16)	
<=500 yuan	18 30(4 19)		8 90(2 39)		8 95(1 99)		8 98(2 82)		2 98(1 14)		8 88(2 22)	
500 to 1000 yuan	18 33(3 61)		9 30(3 21)		8 67(2 37)		9 63(2 65)		2 82(1 14)		8 59(1 82)	
1000 to 2000 yuan	17 93(3 76)		7 48(2 23)		7 90(2 06)		8 18(2 70)		3 00(1 31)		8 07(2 27)	
>2000 yuan/month	17 18(5 43)		7 21(2 74)		8 15(3 18)		7 54(2 71)		2 90(1 48)		7 31(2 47)	
Transmission route		0 941		**0.000**		0 624		0 068		0 410		0 343
IDU	18 19(4 25)		9 61(2 80)		9 16(2 61)		9 05(2 82)		3 19(1 38)		8 53(2 10)	
Non-IDU	17 82(4 54)		7 70(2 45)		8 43(2 92)		8 20(2 88)		2 95(1 32)		7 98(2 34)	
Currently receiving ARV therapy		0 554		0 533		**0.038**		0 647		0 130		**0.004**
Yes	18 68(4 09)		8 95(2 37)		9 29(2 70)		8 81(2 85)		3 23(1 41)		8 77(2 06)	
No	17 49(4 55)		8 50(3 09)		8 43(2 79)		8 52(2 89)		8 52(2 89)		7 87(2 29)	

Chapter 8 Determinants of perceived stress among PLWH

8.1 Background

Problems faced by PLWH in China include physical health, financial stress, unemployment, low self-esteem, discrimination by peers or family members, and inaccessibility and high cost of medical treatments [263, 370]. In the present study, we developed a perceived stress scale for Chinese PLWH and identified eight domains of perceived stress: social/psychological problems, sexual relationship, functional problems, social acceptance/rejection issues, work-related issues, family/offspring issues, accessibility to treatment, and treatment outcomes [240]. Exploring how each of these domains manifests in Chinese PLWH will be critical for finding the most appropriates means to alleviate their perceived stress.

Stigma is defined as any characteristic, real or perceived, that conveys a negative social identity [371]. Since populations infected by HIV are often believed to be high risk groups (such as IDU, FSW etc.) [309], widespread discrimination toward PLWH was documented among the general public [372] and health care workers [337]. Prevalence of stigmatization toward HIV is higher than that related to other chronic diseases [373]. Perceived HIV-related discrimination increases vulnerability to stress-related emotional and mental health disorders [374-376], and decreases the number of visits to health care organizations [377]. Stigma and discrimination are the greatest barriers against delivery of HIV prevention and care services [378].

Despite the direct effects of stigma towards HIV/AIDS, some PLWH remain unaffected by this negative influence and, in fact, they thrive in this adverse situation. Their sense of

optimism may act as a buffer to help them from internalizing the stigma from the public. Optimism is defined as the generalized expectation of favorable outcomes [153]. It is associated with better adjustment to HIV/AIDS via the mitigation of the negative effects of adaptive demands [156, 379, 380]. Optimism attenuates the effect of discrimination on stress responses among cardiovascular patients [381].

Another buffer is social support, which is defined as the 'psychological and material resources available to individuals through their interpersonal relationships [social network]' (p 582) [233]. Numerous studies have identified associations between higher levels of social support and better adjustment to HIV/AIDS [68, 133, 299]. Failure to obtain social support is a major source of stress for HIV-infected individuals [112]. Moreover, perceived discrimination is associated with a lower level of social support [382, 383]. Currently, whether social support moderates the impact of perceived discrimination onto perceived stress is unknown.

8.2 Objectives

This study investigated: 1) the levels of perceived discrimination, optimism, social support and perceived stress among PLHW in China, and associations between background variables (demographic, socio-economic and HIV-related variables) and perceived stress; 2) whether perceived discrimination was a risk factor of perceived stress, whilst optimism and social support were protective factors of perceived stress; 3) whether social support and optimism would moderate the association between HIV-related perceived discrimination and perceived stress among PLWH. Such multiplicative interaction effects have not been reported in the literature.

8.3 Statistical Analysis

Background characteristics including demographic, SES and HIV-related status were listed. Levels of subscales of PSSHIV were calculated (Objective 1). Bivariate and multivariate analysis between the background variables and the Overall Scale/subscales of the PSSHIV were applied, using Spearman correlation coefficients and a series of stepwise linear regression models. Pearson correlation and partial correlation controlling for the significant background variables were derived between Overall Stress/Subscales of PSSHIV and PDSHIV/PSSS/ CLOT-R (Objective 2). Variables (PSSHIV, CLOT-R, PSSS and PDSHIV) were mean centered by subtracting the mean score from each participant's score prior to the computation of interaction terms (PDSHIV X CLOT-R and PDSHIV X PSSS) to reduce multicollinearity [384, 385]. A series of multiple regression models were conducted to explore the main effect of PDSHIV/PSSS/CLOT-R and effect of interaction terms on Overall stress/subscales of PSSHIV (Objective 3). Data were analyzed with SPSS for Windows (version 14.0).

8.4 Results

8.4.1 Level of perceived stress

The mean score of subscales of PSSHIV ranged from 8.99 (Offspring Issue Subscale) and 27.92 (Social/Psychological Problems Subscale) (Table 8.1). After dividing subscale scores by the number of items in each subscale, Functional Problem Subscale and Work Related Issues Subscales have the highest mean score (3.25 and 3.31, data not tabulated). The Cronbach's alphas of the subscales ranged from 0.81 to 0.91(Table 8.1)

8.4.2 Associations between background variables and the overall scale and the subscales of PSSHIV

In the bivariate analysis, those of older age, who have children, and who are not married were more likely than others to have lower Family/Offspring Issues subscale scores. Lower age was also associated with higher Work-related Issues subscale scores. Local residents were associated with higher stress on functional problems and lower stress on work-related issues. Variables indicating SES were associated with the overall scale and some other subscales of the PSSHIV (e.g. Social/Psychological Problems, Functional Problems, Family/Offspring issues and Accessibility to Treatment subscales). Education and employment were also associated with other subscale scores (Social Acceptance/Rejection, Work-related Issues and Treatment Outcome subscales). The three HIV-related variables (transmission via IDU, receiving ARV therapy and having HIV status confirmed before 2005) were associated with higher scores on the Functional Problems Subscale (Table 8.2, $p<0.05$).

The background variables that were bivariately correlated with the overall scale or other subscales of the PSSHIV were used as candidates of respective multivariate stepwise regression models. The results are summarized in Table 8.2.

8.4.3 Correlation coefficients between the overall and subscale scores of the PSSHIV and perceived discrimination

Controlling for those significant background variables that were associated with the Overall Scale score or respective subscales of the PSSHIV (see Table 8.2), the PDSHIV score correlated positively with the Overall scale and all except two subscales of the PSSHIV (Work-related Issues Subscale and Sexual Relationship Subscale) (partial r=0.15 to 0.35; Table 8.3, $p<0.05$).

8.4.4 Correlation coefficients between the overall and subscale scores of the PSSHIV and coping resources (optimism and social support)

Controlling for those significant background variables that were associated with the Overall Scale score or respective subscales of the PSSHIV (see Table 8.2), Partial r coefficients suggested that the PSSS scores correlated negatively with the Social Acceptance/Rejection, Social Psychological Problems and Accessibility to Treatment subscale scores (partial r= -0.13 to -0.37). Similar adjusted partial r values suggest that the CLOT-R was correlated with the overall stress scale, the Social Acceptance/Rejection, and Social Psychological Problems subscales (partial r= -0.16 to -0.24; Table 8.3, $p<0.05$).

In addition, the CLOT-R correlated positively with the PSSS (r=0.30) and the PDSHIV correlated negatively with the CLOT-R and PSSS (r= -0.18 and -0.22, respectively) (Data not tabulated, $p<0.05$).

8.4.5 Multiple linear regression analysis

A series of multivariate linear regression models were performed with Overall score and each subscale score of PSSHIV as dependent variables. The independent variables included: 1) background variables that were significant with dependent variables in bivariate correlation (showed in table 8.2); 2) PSSS and CLOT-R; 3) interaction terms (PSSS X PDSHIV and CLOT-R X PDSHIV).

PDSHIV was a significant predictor of the Overall Stress and all subscale scores of the PSSHIV (β= 0.14 to 0.30, $p<0.05$). Moreover, higher CLOT-R scores predicted lower Overall Stress, Social/Psychological Problems, and Functional Problems subscales scores of the PSSHIV (β= -0.12 to -0.17, $p<0.05$). Higher PSSS scores predicted higher Sexual

Relationship Subscale scores (β = 0.21, p<0.05) and lower Social Acceptance/Rejection Subscale scores (β = -0.30, p<0.05) of the PSSHIV. The two interaction terms (PDSHIV X CLOT-R and PDSHIV X PSSS) were not significant in all relevant models (Table 8.4). The final model of determinants of perceived stress was shown in Figure 8.1.

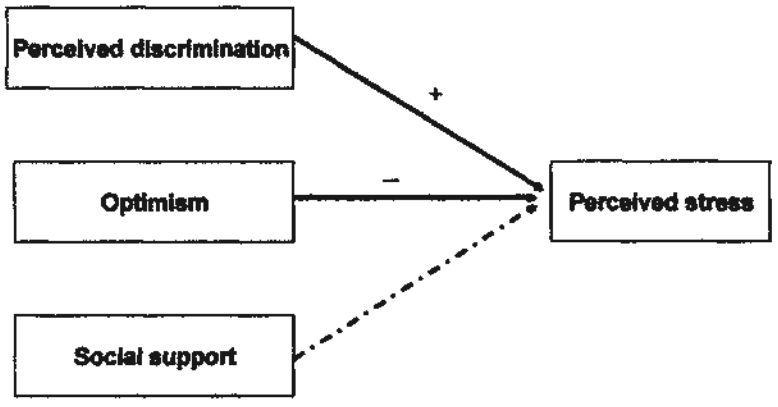


Fig.8.1 Determinants of the overall perceived stress. A solid arrow indicates a correlation. A dotted arrow indicates no correlation

8.5 Discussion

The effect of socioeconomic status (SES) on health is of critical importance to PLWH. Income, education and work status play a role in whether PLWH use health resources, such as having health insurance and obtaining medical care, that contribute to good health [299, 386, 387]. The SES variables (education, employment, income and health insurance) in the present study also significantly predicted perceived stress measured by PSSHIV, which would lead to more severe mental health problems like depression or lower quality of life [89]. Higher SES was also proved to be associated with lower perceived discrimination [388], which was a significant predictor of all PSSHIV domains in the present study.

A previous study has proved the existence of an 'educational income gap' between those well-educated and those with lower levels of education [389]. As SES indicators, income and employment status play an important role in obtaining adequate health care. People with work and with higher income unsurprisingly have less concern about accessing more updated treatment regimens and timely physical checkups, because they can more easily afford the relevant costs [390]. Consistent with the prior findings, better education level, employed status and higher income predicted less perceived stress scores in this study. The Chinese government promised to provide free ARV therapy for PLWH in need; however, eligibility for receiving free ARV therapy depends on the severity of disease, whether they have a local identity, and the availability of the medication. Further, second-line regimen, medication for opportunistic infection, and tests for viral load are not covered by government payment [262]. A broad-based strategy to improve PLWH's health should include investments in skills building, targeted employment and career counseling to alleviate perceived stress of PLWH. Adequate coverage of affordable medical care services should be provided to PLWH by the government.

Perceived discrimination proved to be a major source of perceived stress in this study, which is consistent with the previous study of Chinese PLWH. PLWH who report experiencing discrimination have worse physical and psychological health outcomes [103, 391, 392]. In China, prejudice against PLWH is prevalent because HIV infection is believed to be a consequence of homosexuality, commercial sex, or illicit drug abuse [114]. Prejudice against PLWH together with the perceived contagiousness of the disease are attributed to the widespread discrimination toward PLWH in China among general public and health care professionals [337, 338]. Despite the biomedical characteristics of HIV/AIDS, the contagiousness of HIV/AIDS is often exaggerated by others (e.g. family members, friends

and health workers) when they are interacting with PLWH, which, in turn, enhances the latter's nervousness about their "contagious" bodies [121]. Programs and interventions to alleviate the stress faced by PLWH need to incorporate strategies that could effectively change health professionals' and public attitudes towards PLWH. Even in a broader sense, these interventions must also address people's core perceptions about HIV/AIDS and values of respect toward other people, rather than limiting programs to presenting factual information about HIV/AIDS.

High levels of optimism are associated with better abilities to adapt in PLWH and in other populations [379, 380, 393]. In PLWH, optimists were found to have higher proactive behavior, less avoidant coping, less depression and even slower disease progression [394, 395]. Consistent with prior studies, we found significant relations between optimism and perceived stress (for Overall Stress, Social/Psychological Problems and Functional Problems Subscales). Previous empirical study found that encouraging people to be more proactive, helping them to be less avoidant, could contribute to some of optimism's protective effects [394]. Our results suggest that having a positive, optimistic attitude toward HIV infection may be helpful because of its relation with perceived stress. Stress management interventions that offer strategies to promote problem-solving skills and utilize optimistic explanation style are hence warranted, which have been demonstrated effective in preventing psychological distress in previous empirical study [396].

Social support has been proved to be one of the significant elements that can improve mental health and quality of life in stress-management interventions for HIV positive adults [397]. Social support was negatively related to stress on Social Acceptance/Rejection in this study. If PLWH are better supported and cared for, their negative psychosocial consequences might be prevented or at least reduced [398]. More attention should be paid to the social

environment of individuals diagnosed with HIV [399]. Although many PLWH keep their HIV status secret from family and community members, and are reluctant to seek help from relatives or friends, they seek assistance from the health care system and express their considerable trust in their health care providers [400]. If sufficient training is provided to health staff, they can become a key source of support for PLWH.

From the result of this study, though optimism and social support were both associated with perceived stress directly, the buffering hypothesis of optimism and social support on the effect of perceived discrimination to perceived stress was not supported as expected [381, 382]. Obviously perceived discrimination is an issue that should be paid much attention among Chinese PLWH. To gain a better understanding of discrimination from the perspective of HIV-infected individuals and to find the solution of diminishing perceived discrimination is of particular importance for alleviating the perceived stress among PLWH.

Despite medical advances in the prevention of mother-to-child transmission (PMTCT) [401], making the decision about having children is still not easy for PLWH [402]. In this study, those of a younger age, who are married and who have no children had significantly higher perceived stress on Family/Offspring Issues, which further indicated the worry of PLWH about this issue. A number of social factors including stigma, isolation, limited support from family and community, and uncertainty regarding the future may create an unsupportive environment for PLWH who desire to have children [402, 403]. Health staff should provide careful counseling and in-depth knowledge on prevention of mother-to-child transmission to those who intend to have children, while at the same time respect PLWH's reproductive choices and help them to be successful with their choices [400].

The present study revealed the importance of mitigation and elimination of perceived

discrimination during stress management intervention among PLWH. Psychological interventions aimed at reducing stress perceived by PLWH should focus on the source and details of perceived discrimination among PLWH. Health care systems must do a better job addressing the special needs of those who have low SES for improving the long-term mental and physical status of PLWH. Programs that offer strategies to promote social support and optimistic explanation skills to facilitate the regulation of emotion and improve coping with stress are recommended. Stress management interventions may involve education programs that provide detailed information about possible transmission routes, accessibility of services and disease processes.

Table 8.1 Descriptive Statistics for subscales of PSSHIV

	All	
PSSHIV	Mean (SD)	Cronbach's alpha coefficient
Overall Scale	108.58(28.43)	0.94
Social/Psychological Problems Subscale	27.92(9.39)	0.91
Sexual Relationship Subscale	18.69(6.90)	0.84
Functional Problem Subscale	12.98(4.32)	0.86
Acceptance/Rejection Issues Subscale	11.79(4.54)	0.81
Work Related Issues Subscale	9.94(4.16)	0.82
Offspring Issues Subscale	8.99(4.76)	0.88
Accessibility to Treatment Subscale	9.15(3.74)	0.84
Treatment Outcomes Subscale	9.13(3.32)	0.83

Table 8.2 Results of bivariate correlation and stepwise regression models between the background variables and Overall/Subscales of PSSHIV

	Overall Scale		Social/ Psychological Problems Subscale		Sexual Relationship Subscale		Functional Problems Subscale		Social Acceptance /Rejection Subscale		Work related Issues Subscale		Family/ Offspring Issues Subscale		Accessibility to Treatment Subscale		Treatment Outcome Subscale	
	r	β	r	β	r	β	r	β	r	β	r	β	r	β	r	β	r	β
Demographics																		
Age	--	--	--	--	--	--	--	--	--	--	**-.18****	BS	**-0.29****	**-0.19****	--	--	--	--
Local resident	--	--	--	--	--	--	**0.20****	BS	--	--	**-0.16****	BS	--	--	--	--	--	--
Marital status	--	--	--	--	--	--	--	--	--	--	--	--	**0.20****	BS	--	--	--	--
Whether have kids	--	--	--	--	--	--	--	--	--	--	--	--	**-0.50****	**-0.46****	--	--	--	--
SES																		
Education level	**-0.22****	**-0.16****	**-0.20****	BS	--	--	**-0.23****	**-0.17****	**-0.13***	**-0.13****	--	--	**-0.16****	**-0.16****	**-0.19****	BS	--	--
Employment status	**-0.17****	BS	**-0.20****	BS	--	--	**-0.33****	BS	--	--	**0.16****	BS	--	--	**-0.22****	BS	**-0.14***	**-0.13****
Income level	**-0.22****	**-0.14****	**-0.25****	**-0.25****	--	--	**0.33****	**-0.31****	--	--	--	--	**-0.16***	**-0.13****	**-0.29****	**-0.22****	--	--
Health insurance	**-0.18****	BS	**-0.13***	BS	--	--	**-0.16***	BS	--	--	--	--	**-0.15***	BS	**-0.15***	BS	--	--
HIV variables																		
Whether transmitted via IDU	--	--	--	--	--	--	**0.25****	BS	--	--	**-0.22****	BS	--	--	--	--	--	--
Whether receiving ARV	--	--	**0.13***	BS	--	--	**0.13***	BS	--	--	--	--	--	--	--	--	--	--
Whether Confirmed before 2005	**0.16***	BS	--	--	--	--	**0.18****	BS	--	--	--	--	--	--	**0.21****	**0.16****	--	-
R^2	0.06		0.06				0.16		0.01		0.04		0.32		0.11		0.01	

r: bivariate correlation coefficient; β: Standardized regression coefficients of multiple stepwise regression model; '--': 'not significant in bivariate spearman correlation'. 'BS': 'significant in bivariate Spearman correlation but not selected by the multiple stepwise regression'. Coding of the background Age: 1= <29, 2= 30-39, 3= 40 or above; Local residents: 0= no, 1= yes; Marital status: 0=currently not married, 1=currently married; Whether having kids: 0=no, 1=yes; Education level: 1=primary school or below, 2=junior high, 3=senior high/technical secondary school, 4=junior college or above; Employment status: 0=unemployed, 1=employed; Income: 1=no income, 2=<500, 3=500-1000, 4=1000-2000, 5=>2000; Health insurance: 0=no, 1=yes; Transmission route: 0=MSM or heterosexual transmitted, 1=IDU; Disease stage: 0=asymptomatic stage, 1= Symptomatic stage and AIDS; Receiving ARV therapy: 0=no, 1=yes, Confirm time: 0: 2006 or after, 1: 2005 or before. ** $p<0.01$; * $p<0.05$.

Table 8.3 Bivariate correlation coefficient, and Partial r for the correlation between Overall/Subscales of PSSHIV, discrimination, support and optimism

	Overall Scale	Social Acceptance /Rejection Subscale	Social/ Psychological Problems Subscale	Accessibility to Treatment Subscale	Functional Problems Subscale	Family/ Offspring Issues Subscale	Treatment Outcome Subscale	Work related Issues Subscale	Sexual Relationship Subscale
Discrimination									
r	0.33**	0.35**	0.34**	0.18**	0.27**	--	0.19**	0.17**	--
Partial r	0.32**	0.35**	0.32**	0.15*	0.26**	0.15*	0.19**	N/A	N/A
Support									
r	--	-0.37**	-0.18**	--	--	--	--	--	0.16*
Partial r	--	-0.37**	-0.20**	-0.13*	--	--	--	N/A	N/A
Optimism									
r	-0.19**	-0.17**	-0.25**	--	-0.14*	--	--	--	--
Partial r	-0.17**	-0.16**	-0.24**	--	--	--	--	N/A	N/A

r: bivariate correlation coefficient; partial r: correlation coefficient after controlling significant background variables in partial correlation (listed in Table 2), N/A: no significant background variables; Part R: increment in R^2 when the variable (e.g. Perceived discrimination) was added to the model controlling for significant background variables; --: not significant; ** $p<0.01$; * $p<0.05$.

Table 8.4 Multivariate linear regression models to identify determinants of Overall/Subscales of PSSHIV

	Overall Scale		Social/ Psychological Problems Subscale		Sexual Relationship Subscale		Functional Problems Subscale		Social Acceptance /Rejection Subscale		Work related Issues Subscale		Family/ Offspring Issues Subscale		Accessibility to Treatment Subscale		Treatment Outcome Subscale	
	β	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*
Discrimination	**0.30**	**.000**	**0.26**	**.000**	**0.14**	**.035**	**0.26**	**.000**	**0.27**	**.000**	**0.15**	**.026**	**0.14**	**.010**	**0.14**	**.027**	**0.18**	**.006**
Support	0.01	.864	-0.08	.207	**0.21**	**.001**	0.08	.190	**-0.30**	**.000**	-0.01	.933	0.07	.185	-0.09	.154	0.02	.819
Optimism	**-0.13**	**.036**	-0.17	**.004**	-0.10	.135	**-0.12**	**.045**	-0.05	.422	-0 08	254	-0.08	.175	0.01	.869	-0 05	.481
Support X Discrimination	0.02	.686	0 08	.154	-0 01	.935	0.04	.436	0.01	.921	-0.02	779	0.03	.602	-0.06	321	-0.03	.585
Optimism X Discrimination	0 07	.256	0.04	.448	0.03	.609	0.082	.149	0.06	.280	0.07	.260	0 00	.993	0.01	.884	0.03	.615
	R^2=0. 15		R^2=0. 18		R^2=0. 04		R^2=0. 22		R^2=0. 20		R^2=0. 02		R^2=0. 32		R^2=0. 12		R^2=0. 020	

β Standardized regression coefficients Overall/Subscales of PSSHIV, Optimism, Social support and Perceived discrimination in the table were mean centered and the interaction terms were computed using mean-centered variables ** p<0 01 , * p<0 05

Su, X. Y., Lau, J. T. F., and Mak, W. W. S. (2009). Perceived discrimination and perceived stress among People Living with HIV/AIDS. *In* "9th International Congress on AIDS in Asia and the Pacific (ICAAP)", Bali, Indonesia, 9-13 August (Poster presentation). Abstract Code: 4275-ON-AB-A.

Chapter 9 Determinants and buffers of psychological well-being of PLWH

9.1 Background

Given the high prevalence of depression and low quality of life among PLWH, it is important to examine and understand the role of psychosocial factors during the process of adjustment to HIV infection. By identifying key psychosocial factors that are amenable to change, governmental and health care organizations can enhance clinical interventions to promote health and wellness of PLWH. Perceived discrimination, perceived stress, coping resources and coping strategies have received the most attention among factors that are purported to be related to mental health outcomes in recent years [112, 287, 376, 379].

AIDS is associated with both emotional and physiological stress [256]. Stressors that have been frequently encountered by PLWH include uncertainty about one's future health and financial problems, social isolation, and stigmatization [257-259]. Perceived stress among PLWH has been associated with poorer stress management skills, inappropriate coping mechanisms and depression [89, 196, 260, 261].

Reviews of the previous studies suggest that PLWH reporting perceived HIV discrimination had great levels of perceived stress and depressive symptoms [404, 405]. Perceived discrimination could significantly predict perceived stress among Chinese PLWH [406]. Meanwhile, stress has been showed to predict worse psychological well-being during the process of adjustment among both the general population [407] and among PLWH [81, 205]. Hence, it is possible that PLWH who perceived more discrimination will have more perceived stress, which leads to worse psychological well-being.

While perceived stress and perceived discrimination predict worse psychological

well-being of PLWH, social support and optimism as coping resources have often been shown to be important protective factors in the mental health of PLWH. Social support is broadly defined as the "psychological and material resources available to individuals through their interpersonal relationships [social network]" [233]. Numerous studies have found an association between higher levels of quantitative and qualitative social support and better adjustment to HIV/AIDS [68, 133, 299]. Optimism, a sense of personal control, and the ability to find meaning in one's life experiences, is a valuable psychological resource long demonstrated to be associated with mental health [408, 409]. Several studies have found higher levels of optimism to be related to better adjustment to HIV/AIDS via the mitigation of the negative effects of adaptive demands [156, 379, 380]. These findings support the evidence that coping resources have psychologically adaptive function through reducing overriding fears and lessening AIDS-related concerns [202].

Evidence suggests that optimism and social support may predict psychological well-being both directly and as moderators of stress. Optimism has been found to be related to distress [154], and moderates the impact of stress on psychological well-being among men with HIV [147]. Social support has both a direct impact and moderating effects with stress on psychological well-being of patients with rheumatoid arthritis [410] and a direct impact on depression among PLWH [147]. However, no evidence has so far been found for a stress-buffering effect of social support among PLWH [411, 412].

A person with HIV infection may engage in a variety of coping responses in order to deal with disease-related stressors, such as social stigma, HIV-related symptoms, and financial burden of treatment [136]. Some PLWH might face high levels of stress while maintaining better psychological well-being, as long as they adopt appropriate coping strategies. The use of particular coping strategies has been found to affect the level of stress

and adaptation differentially. For example, coping by means of denial has been shown to be associated with a more rapid progression to AIDS and higher levels of depression [71], whereas problem-focused coping has been found to be associated with less depressive symptoms and a higher quality of life for PLWH [172]. Significant interactions between stress and coping on psychological well-being also have been noted [174-176].

9.2 Objectives

The present chapter had three major aims. The first aim was to examine the bivariate correlation between perceived discrimination, perceived stress, coping resources, coping strategies and psychological well-being. The second aim was to test hypothesis concerning the determinants of psychological well-being (represented by depression and health distress domain of quality of life). A model containing socio-demographic variables was fit (Model 1), and Model 2 and Model 3 added two independent variables of perceived discrimination (stressor) and perceived stress to Model 1 (Model 3 was named stressor-stress model). Other variables were then sequentially (hierarchically) added to see whether these variables will improve model fitness. Coping resources and interaction terms between coping resources and perceived stress were added stepwisely to Model 4 (Model 5 and 6). Variables regarding the 6 coping strategies and their interaction terms with perceived stress were added to Model 6 to form Model 7 and 8. The modeling strategy was summarized in Table 9.2.

The hypotheses being tested included 1) whether the stressor and stress have independent effects on psychological well-being, 2) whether coping resources have independent and additional effects to those of stressor-stress model on psychological well-being, 3) whether coping resources interact with stress to determine psychological well-being, 4) whether coping strategies have independent and additional effects to the

model containing the stressor, stress, coping resource variables and, 5) whether coping strategies interact with stress to determine psychological well-being.

9.3 Statistical analysis

Pearson correlations were generated to test associations between perceived discrimination, perceived stress, optimism, social support and coping strategies, and psychological well-being variables (depression and QoL). Hierarchical multiple linear regression models were fit to test the aforementioned sets of nested hypotheses. The continuous variables were mean centered by subtracting the mean score from each participant's score prior to the computation of interaction terms between perceived stress and social support (PSSHIV X PSSS), perceived stress and optimism (PSSHIV X CLOT-R), perceived stress and each coping strategies, to reduce multicollinearity [384, 385]. Student's T-test and ANOVA were conducted (in chapter 7) to determine if demographic factors and HIV-related background variables were significantly related to psychological well-being variables, in which case they were included as control variables in hierarchical regression analyses into Model 1. F−test was used to compare nested models (the two considered models both contain the same terms and one has at least one additional term) according to Neyman-Pearson's hypothesis [413]. Each regression model was compared with the model having one more block. The model fitness was determined by the p value of the F-test at the chosen significance level of $p < 0.05$.

9.4 Results

9.4.1 Univariate relationships between the psychosocial factors (perceived discrimination, perceived stress, coping resources and coping strategies) and psychological well-being

As expected, perceived discrimination and perceived stress were positively correlated with depression and negatively correlated with QoL. Social support and optimism were negatively correlated with depression and positively correlated with QoL. Depression was positively correlated with 5 out of 6 coping strategies besides 'Problem-solving and acceptance' (r=0.144 to 0.483, $p<0.05$). QoL was negatively correlated with all coping strategies (r= -0.173 to -0.531) (Table 9.1, $p<0.05$).

Pearson correlations were also performed to examine the extent to which each stress subscale was related to psychological well-being at bivariate level. Table 9.1 shows correlations between psychological well-being and subscales of PSSHIV. As expected, better adjustment was related to fewer perceived stress, except that depression is not related to work-related stress.

9.4.2 The stressor-stress models --- Perceived stress and perceived discrimination as determinants of psychological well-being (adjusting for socio-demographic variables)

The socio-demographic variables explained 21.7% of the total variance (R-square) in depression (Model 1 in Table 9.3, $p<0.05$). Perceived discrimination explained an additional 1.3% of the variance in depression (Model 2 of Table 9.3, $p<0.05$). Perceived stress explained additional 14.4% of the variance in depression (Model 3 of Table 9.3, $p<0.05$). A separate analysis showed that adjusted for socio-demographic, perceived discrimination has a positive relationship with perceived stress ($\beta=0.324$, $p<0.01$; data not tabulated). In Model

2 of Table 9.3, perceived discrimination has a positive relationship with depression (β=0.153, p<0.01). In Model 3 of Table 9.3, perceived stress has a positive effect on depression (β=0.418; p<0.01), whereas perceived discrimination that was statistically significant in the Model 2, became non-significant after adjusting for perceived stress. The Sobel test [414] showed a significant reduction in the regression coefficients between perceived discrimination and depression after perceived stress was introduced (z=2.77, p <0.05; data not tabulated), supporting the conclusion that perceived stress mediated the link between perceived discrimination and depression as recommended by Baron and Kenny [415]. Taken together, this pattern of results indicated that the relationship between the perceived discrimination and depression was fully mediated by perceived stress (Table 9.3, p<0.05, Fig. 9.1)

The socio-demographic variables explained 6.6% of the total variance (R-square) in QoL (Model 1 in Table 9.4, p<0.05). Perceived discrimination explained an additional 3.8% of the variance in QoL (Model 2 of Table 9.4, p<0.05). Perceived stress explained additional 32.0% of the variance in depression and QoL (Model 3 of Table 9.4, p<0.05). In the same way as depression, the relationship between the perceived discrimination and QoL was also fully mediated by perceived stress (Table 9.4, z=3.58, p<0.05, Fig. 9.2).

The stressor-stress models in predicting depression and QoL were summarized in Figure 9.1 and Figure 9.2.

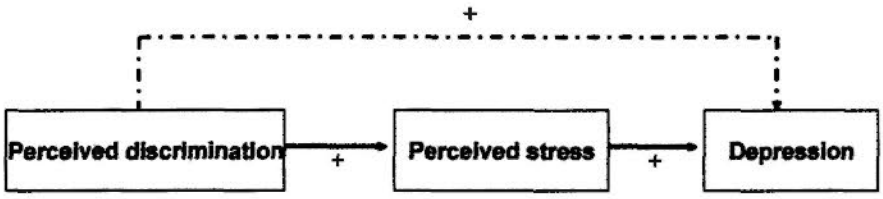


Fig 9.1 The stressor-stress model: Effect of perceived discrimination and perceived stress on depression. A solid arrow indicates a correlation. A dotted arrow indicates a correlation that weakens or disappears when the other risk factor is considered (ref: Kraemer, 2001).

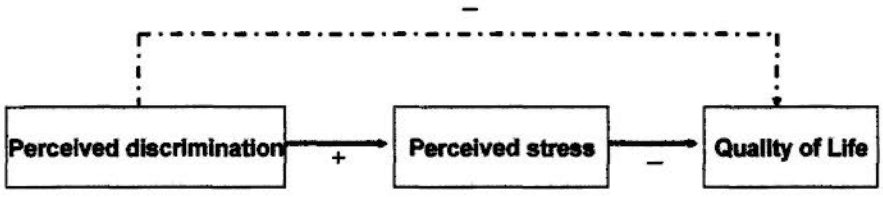


Fig 9.2 The stressor-stress model: Effect of perceived discrimination and perceived stress on QoL. A solid arrow indicates a correlation. A dotted arrow indicates a correlation that weakens or disappears when the other risk factor is considered (ref: Kraemer, 2001).

9.4.3 The stressor-stress-resource models --- Adding coping resources and their interaction terms with perceived stress to the stressor-stress models (adjusting for socio-demographic variables)

When variables on coping resources (social support and optimism) were added to Model 3, they explained an additional 4.6% of the variance in depression (Model 4 and 5, $p<0.05$, Table 9.3). In Model 6, interaction terms between coping resources and perceived stress explained only additional 1.3% variance in depression, which were proved an non-significant increase compare to Model 5 (Table 9.3, F=2.86(2, 246)). In Model 4 of Table 9.3, social support had a negative effect on depression (β= -0.13; $p<0.05$). On the other hand, although the regression coefficient of social support was statistically significant in Model 4, it diminished and became non-significant when optimism was added to Model 4

(Model 5). Since social support and optimism were correlated with each other (r=0.30, $p<0.05$, data not tabulated), the effect of social support on depression was indicated to be mediated by optimism. While the interaction term between perceived stress and social support (PSSHIV X PSSS) significantly predicted depression in Model 6, the model without interaction (Model 5) and the model with interaction (Model 6) did not differ significantly from the F-test of the two nested model (F=2.86(2, 246)). The model added coping resources to stressor-stress model in predicting depression was shown as Fig 9.3.

In table 9.4, when variables on coping resources (social support and optimism) were added to Model 3, they explained an additional 2.6% of the variance in QoL (Model 4 and 5, $p<0.05$, Table 9.4). In Model 6, interaction terms between coping resources and perceived stress explained only additional 0.5% variance in QoL, which were proved an non-significant increase compare to Model 5 (Table 9.4, F=1.14 (2, 248), $p>0.05$). Similarly, PLWH with higher optimism reported better QoL than those with lower optimism. Though marginally significant between social support and QoL ($p=0.08$), the effect of social support on QoL was indicated to be mediated by optimism. Interaction terms PSSHIV X PSSS and PSSHIV X CLOT-R explained only 0.5% of the total variance in Model 6, which was showed an non-significant increase compared to model 5 using F-test for nested models (Table 9.4). The model added coping resources to the stressor-stress model in predicting QoL was shown as Fig 9.4.

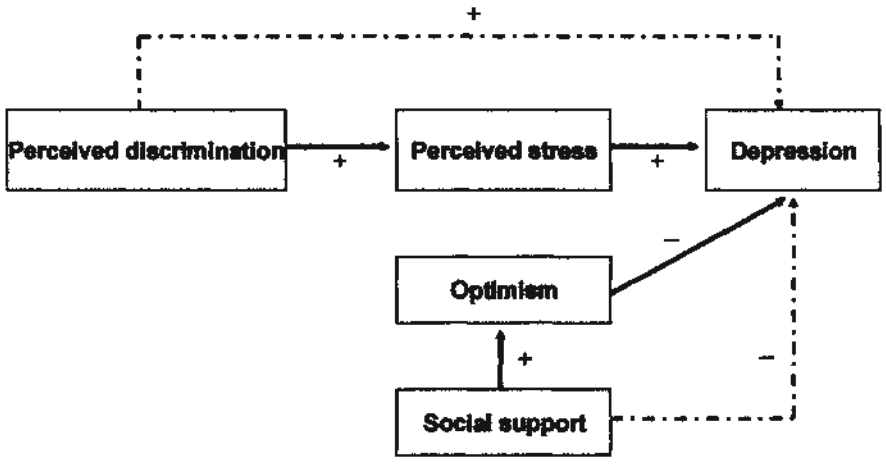


Fig.9.3 The stressor-stress-resource model -Model added coping resources to stressor-stress model in predicting depression. A solid arrow indicates a correlation. A dotted arrow indicates a correlation that weakens or disappears when the other risk factor is considered (ref: Kraemer, 2001).

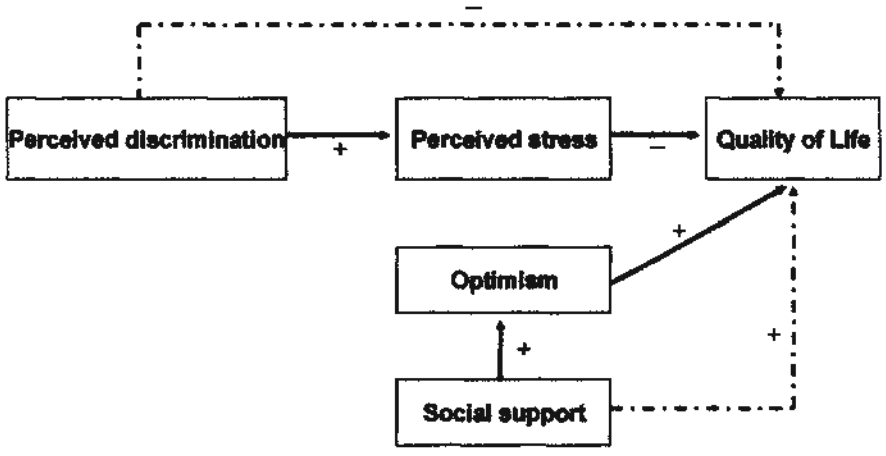


Fig.9.4 The stressor-stress-resource model -Model added coping resources to stressor-stress model in predicting QoL. A solid arrow indicates a correlation. A dotted arrow indicates a correlation that weakens or disappears when the other risk factor is considered (ref: Kraemer, 2001).

9.4.4 The stressor-stress-resource-coping models---Adding coping strategies and their interaction terms with perceived stress to the stressor-stress-resource models (adjusting for socio-demographic variables)

Six coping strategies explained a further 6.9% of the total variance in depression, as

compared to Model 6 (Model 7, Table 9.3, $p<0.05$). Moderating effect between coping strategies and perceived stress on depression were showed non-significant in Model 8 (Table 9.3, $p>0.05$). In Table 9.3, Model 7 (without interaction terms of stress and coping strategies) and model 8 (with interaction terms of stress and coping strategies) were showed not to differ significantly using F-test for comparing nested models (F=0.24, $p>0.05$). Therefore, Model 7 was determined to be a better model than Model 6 and Model 8 in predicting depression. The overall Model 7 accounted for 51.1% of the variance in depression of the PLWH. PLWH using more 'Problem-solving and Acceptance' as a coping strategy showed fewer depressive symptoms; while those using more 'Negative Venting and Avoidance' and 'Self-blame and Denial' as coping strategies showed more depressive symptoms (Table 9.3). The stressor-stress-resource-coping model for depression was shown as Fig. 9.5.

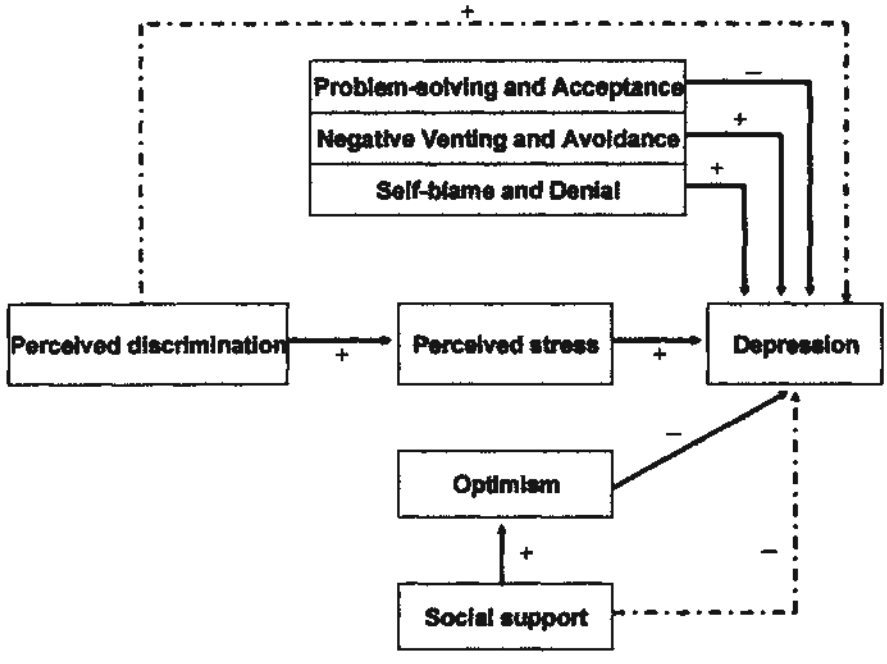


Fig.9.5 The stressor-stress-resource-coping model for depression. A solid arrow indicates a correlation. A dotted arrow indicates a correlation that weakens or disappears when the other risk factor is considered (ref: Kraemer, 2001).

For QoL, six coping strategies explained a further 9.9% of the total variance in QoL, as compared to Model 6 (Model 7, Table 9.4, $p<0.05$). Moderating effect between coping strategies and perceived stress on QoL were showed non-significant in Model 8 (Table 9.4, $p>0.05$). Similar in Table 9.4, the interaction effects between perceived stress and coping strategies were proved non-significant. The overall Model 7 accounted for 55.5% of the variance in QoL of the PLWH. PLWH using more 'Self-blame and Denial' and 'Reliance on Spirituality' as coping strategies showed worse QoL (Table 9.4). The stressor-stress-resource-coping model for QoL was shown as Fig. 9.6.

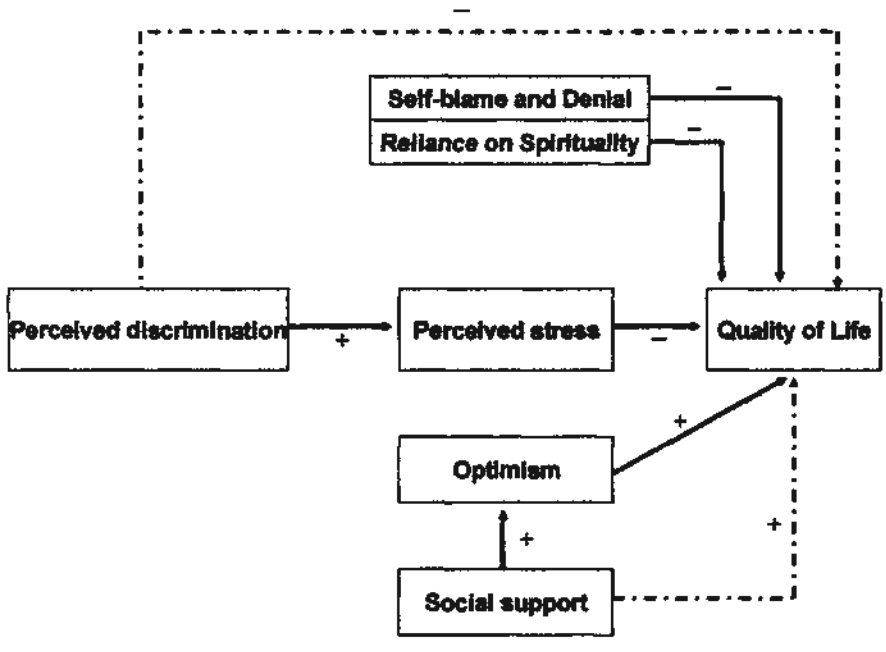


Fig.9.6 The stressor-stress-resource-coping model for QoL. A dotted arrow indicates a correlation that weakens or disappears when the other risk factor is considered (ref: Kraemer, 2001).

9.5 Discussion

9.5.1 Perceived discrimination and perceived stress

Investigation into factors associated with psychological well-being indicated that in this study cohort, psychosocial variables were linked to depression and QoL among PLWH. Perceived stress was demonstrated to be associated with higher depression scores and lower QoL scores, which is consistent with prior studies [89, 196, 260, 261]. As expected, almost every subscale of PSSHIV contributed to the worse psychological well-being of PLWH. This compels us to earn more recognization and pay more attention to the stress aspects, and find out those with higher level of certain kind of stress. Based on this, we can offer tailor-made interventions to the target vulnerable population and improve their psychological well-being prominently.

Furthermore, perceived stress was also a mediator for the effects of perceived discrimination on psychological well-being. That is, perceived discrimination increased perceived stress, which in its turn aggravated depression and QoL. This finding has significant implications for prevention programs targeting the psychological well-being of PLWH, and suggests that perceived discrimination is an important source of perceived stress and should be a critical focus for future prevention work involving the management of perceived stress. PLWH may benefit from learning skills on stress management through alleviating perceived discrimination and thereby potentially improve their psychological well-being.

9.5.2 Social support and optimism

The finding that optimism mediated the relationship between social support and

psychological well-being is in line with the previous findings that social support can enhance positive expectations of the future [416-418]. This indicates that, despite the arguments that optimism is considered as relatively stable disposition [419, 420], it is possible that attempts to strengthen patients' perception of social support may increase their optimistic appraisals. Unsurprisingly, when PLWH have more social support, they are more likely to hold positive and optimistic views in terms of the threat and challenges they are facing, and hence have greater psychological well-being. Since optimistic individuals would be more likely to seek opportunities to alter their illness experiences and thrive under adverse conditions [421], the stress reduction program facilitating an increase in the quality and quantity of PLWH's social support is warranted to be included in the stress management intervention.

Social support has been shown to be a significant element in improving mental health and quality of life in stress-management interventions for HIV positive adults [397]. If PLWH are better supported and cared for, their negative psychosocial consequences might be prevented or, at the very least, reduced [398]. Intervention strategies aimed at encouraging social support may turn out to be useful for increasing the overall psychological well-being of PLWH, and worth considering as complements to stress management strategies [399]. The noteworthy finding in this study was that social support could not predict increases in the mental aspect of quality of life, despite the significant predictive effect on depression. However, the coefficient of social support could be treated as marginally significant, and it still turns notably weak when optimism was added to the model. The mediating effect of optimism hence still existed between social support and QoL, though it is not as strong as between social support and depression. Moreover, although a moderating effect of optimism was not found in this study, optimism was found to be inversely related to depression in this study, which was consistent with the findings of previous studies among PLWH [394, 395].

Encouraging people to be more proactive, helping them to be less avoidant, and screening and treating them for depression could contribute to some of the protective effects of optimism [394].

9.5.3 Coping strategies

Coping responses have been previously established as strong correlates and predictors of psychological distress among PLWH [173]. Active coping appeared to serve a protective function in that emotional distress decreased with greater use of active coping. In contrast, the use of avoidant coping strategies is consistently associated with increased psychological distress, including anxiety and depression, and poor adjustment [131] [422] in studies of HIV-infected individuals [173] [423] [133]. One noteworthy finding of this study is the prominent role of the validated subscales of the coping strategies in psychological well-being. 'Problem-solving and Acceptance' as a form of active coping strategy, in particular, was identified as a strong protective correlate of depression, while 'Negative Venting and Avoidance' and 'Self-blame and Denial' as forms of avoidant coping strategies, were proved risk factors in depression and poor QoL. The findings were consistent with the prior studies [249].

In western culture, religion beliefs or behaviors like praying and mediating are very common and have long been playing an important role in influencing human behavior. Though religion beliefs like Buddism and Christianity are also existing in China [333], there are possibly many differences across cultures, namely in religion, that may impact views of Spirituality aspects. Typically, religiosity has been assessed as a helpful stress buffer [424]. More recently, however, the possibility that religion can also exacerbate stress has been considered. For example, in a meta-analysis of 46 empirical studies, religion, broadly

defined, served as a significant stress buffer in 34% of the studies, but it was also found to worsen stress by 4% [425]. Negative religious coping (e.g., reappraisals of God as punishing, negative attitudes toward God, clergy, or church members) was related to poorer physical health, worse quality of life, and greater depression in medically ill adults. In contrast, positive religious coping (e.g., seeking connection with God, seeking support from clergy and church members, etc.) was related to increased mental health and life satisfaction [424].

After discovering HIV infection, PLWH believers might face increased stress as time goes by, such as emerging HIV/AIDS symptoms, discrimination, disclosure issues, etc., and are likely to adopt negative religious coping strategies; this in turn leads to worse psychological well-being. As in other culture settings, pre-existing cultural and religious values and beliefs contributed to the stigmatization of PLWH in China. The pessimism associated with the belief in reincarnation and punitive attitudes of the Buddhist doctrine toward PLWH may have discouraged them from coping better with the disease, as the next life was believed to be the only hope for redemption [217]. In the present study, 'Reliance on spirituality' was showed to predict worse QoL among PLWH. HIV workers hence need to pay more attention about spirituality-related coping adopted by PLWH in China, especially when carrying out intervention projects aiming to improve psychological well-being of this population.

Substance use is prevalent among HIV positive adults and is linked to a number of adverse consequences [426]. Self-medication with alcohol or drugs was an observed influence of depressive symptoms among HIV/AIDS [83]. In this study, 'Negative venting and avoidance' (including two items of substance use) was found predictive of more depressive symptoms. Other studies also found the use of alcohol and other drugs (AOD) to cope with HIV was negatively associated with certain safer sex attitudes and practices, and less

disclosure of their HIV status to their sex partners [330]. AOD use may hence help facilitate HIV transmission among adolescents with HIV. Naturally, interventions which address the use of AOD among those PLWH must be timely to help reduce the likelihood of HIV transmission and improve psychological well-being.

9.5.4 Implications of the current study

The findings provided an understanding of the role of coping in the psychological well-being of PLWH in China, and suggest the possibility of designing interventions for psychological adaptation to the illness. Interventions supportive of attempts to use adaptive coping strategies such as 'Problem-solving and acceptance' could be particularly effective in improving the psychological well-being of PLWH. It is important to identify patients with depressive symptoms and develop psychological interventions that focus on decreasing maladaptive coping strategies (such as 'Negative venting and avoidance' and 'Self-blame and denial'). The challenging aspect of this will be determining how to integrate psychological screenings and deliver psychological interventions within the current health care structure. Meanwhile, greater attention should be given toward improving support, offering stress management services and diminishing discrimination by the appropriate agencies towards people living with HIV/AIDS.

9.5.5 Conclusions

In conclusion, the findings of the present study revealed the role of psychosocial factors and the pathway through which they affect psychological well-being, among PLWH. The study contributes toward a growing appreciation of the importance of addressing stigmatization issues and social support in both HIV/AIDS research and intervention. To develop appropriate stress management strategies catering to PLWH is also warranted. The

present study, along with findings of previous studies, has shown support for adopting and avoiding of specific coping strategies as a potential benefit in improving psychological well-being. Specifically, those seeking religion-related coping should receive appropriate counseling from professional workers, due to the growing influence of religion in China. Future studies should focus on establishing the causal linkage between perceived stress, coping resources, coping strategies and psychological well-being. Such studies can not only enhance our understanding of the mechanism behind psychosocial factors and psychological well-being, but also contribute to the enhancement of psychosocial services for PLWH and the development of effective service models that could benefit both the PLWH and their communities.

Table 9.1 Pearson correlations between perceived stress, coping strategies and psychological well-being

	Depression	QoL
Perceived discrimination	.199**	-.222**
Coping resources		
Social support	-.155*	.135*
Optimism	-.303**	.272**
Coping strategies		
Problem-solving and acceptance	003	-.163**
Negative venting and avoidance	.483**	-.419**
Support seeking	.160**	-.218**
Self-blame and denial	.420**	-.531**
Reliance on spirituality	.261**	-.426**
Humor and self-distraction	.144*	-.173**
PSSHIV	.489**	-.633**
Social/Psychological problems	.604**	-.729**
Sexual relationship	.231**	-.357**
Functional problems	.515**	-.565**
Acceptance/Rejection issues	.290**	-.385**
Work related issues	001	-.200**
Offspring issues	.203**	-.218**

* p<0 05, **p<0 01

Table 9.2 Hierarchical models containing different independent variables

Model 1	Model 2	Model 3	Model 4	Model 5	Model 6	Model 7	Model 8
SD	SD	SD	SD	SD	SD	SD	SD
	PD	PD	PD	PD	PD	PD	PD
		Stress	Stress	Stress	Stress	Stress	Stress
			Support	Support	Support	Support	Support
				Optimism	Optimism	Optimism	Optimism
					Resource X Stress	Resource X Stress	Resource X Stress
						Coping	Coping
							Coping X Stress

SD Socio-demographic variables PD perceived discrimination Resource support and optimism

Table 9.3 Direct and moderating effect of optimism, social support and coping on depression (DV=C-BDI-II)

	Model 1		Model 2		Model 3		Model 4		Model 5		Model 6		Model 7		Model 8	
	β	*p*	β	*p*	β	*p*	β	*p*	β	*p*	β	*p*	β	*p*	β	*p*
Block 1																
Age	052	371	049	390	087	094	076	137	058	251	056	268	051	280	051	291
Education	**-.130**	**.032**	**-.135**	**.024**	- 060	273	- 044	423	- 033	539	- 042	431	- 041	423	- 048	364
Work	- 083	268	- 100	181	- 049	466	- 051	445	- 078	238	- 074	258	- 081	191	- 077	224
Income	**-.245**	**.002**	**-.218**	**.005**	**-.189**	**.007**	**-.202**	**.004**	**-.184**	**.006**	**-.200**	**.003**	**-.173**	**.007**	**-.174**	**.008**
Transmission route	**.137**	**.032**	**.127**	**.044**	**.168**	**.003**	**.179**	**.002**	**.175**	**.002**	**.172**	**.002**	091	093	088	112
Block 2																
PDSHIV	------	------	**153**	007	017	749	- 012	831	- 023	667	- 018	739	- 008	870	- 005	921
Block 3																
PSSHIV	------	------			**.418**	**.000**	**.413**	**.000**	**.385**	**.000**	**.370**	**.000**	**.287**	**.000**	**.279**	**.000**
Block 4																
PSSS	------	------	------	------	------	------	**-.130**	**.012**	- 083	111	- 080	122	- 052	319	- 059	272
Block 5																
CLOT-R	------	------	------	------	------	------	------	------	**-.186**	**.000**	**-.186**	**.000**	**-.124**	**.016**	**-.119**	**.025**
Block 6																
PSSHIV X PSSS	------	------	------	------	------	------	------	------	------	------	**-.120**	**.019**	- 071	149	- 069	188
PSSHIV X CLOT-R	------	------			------	------	------	------	------	------	015	767	- 012	812	- 022	680
Block 7			------	------												
Cope 1	------	------	------	------	------	------	------	------	------	------	------	------	**-.138**	**.023**	**-.139**	**.029**
Cope 2	------	------			------	------	------	------	------	------	------	------	**.212**	**.000**	**.232**	**.000**
Cope 3	------	------	------	------	------	------	------	------	------	------	------	------	042	461	047	435
Cope 4	------	------	------	------	------	------	------	------	------	------	------	------	**.145**	**.011**	**.144**	**.012**
Cope 5	------	------	------	------	------	------	------	------	------	------	------	------	022	692	027	645
Cope 6	------	------	------	------	------	------	------	------	------	------	------	------	- 026	670	- 038	535
Block 8			------	------												
PSSHIV X Cope 1	------	------	------	------	------	------	------	------	------	------	------	------	------	------	- 005	944
PSSHIV X Cope 2	------	------			------	------	------	------	------	------	------	------	------	------	- 069	261
PSSHIV X Cope 3	------	------	------	------	------	------	------	------	------	------	------	------	------	------	014	806
PSSHIV X Cope 4	------	------	------	------	------	------	------	------	------	------	------	------	------	------	002	975
PSSHIV X Cope 5	------	------	------	------	------	------	------	------	------	------	------	------	------	------	- 008	903
PSSHIV X Cope 6	------	------	------	------	------	------	------	------	------	------	------	------	------	------	021	749
R2	217		240		384		399		429		442		511		514	
Adjusted R2	202		222		366		380		408		417		476		466	
R^2 change	217		013		144		016		030		013		069		003	
F-test for nested models	----		(1,251)=7 59		(1,250)=58 44		(1,249)=6 21		(1,248)=13 02		(2,246)=2 86		(6,240)=5 64		(6,234)=0 24	
p-value of F-test	----		**0.006**		**0.000**		**0.002**		**0.000**		0 059		**0.004**		0 787	

PDSHIV Perceived Discrimination scale for PLWH, PSSS The Perceived Social Support Scale, PSSHIV The Perceived Stress Scale for PLWH, C-BDI-II The Chinese version of Beck Depression Inventory, CLOT-R Optimism Cope 1 Problem-solving and Acceptance, Cope 2 Negative Venting and Avoidance, Cope 3 Support Seeking, Cope 4 Self-blame and Denial, Cope 5 Reliance on Spirituality, Cope 6 Humor and Self-distraction F-test for nested models F value comparing the model with the prior model with one block less

Table 9.4 Direct and moderating effect of optimism, social support and coping on QoL (DV=health distress domain of MOS-HIV)

	Model 1		Model 2		Model 3		Model 4		Model 5		Model 6		Model 7		Model 8	
	β	*p*	β	*p*	β	*p*	β	*p*	β	*p*	β	*p*	β	*p*	β	*p*
Block 1																
Work	086	287	108	176	025	695	024	709	041	513	039	536	037	523	044	460
Income	145	078	112	.170	044	498	050	442	035	593	046	477	037	539	036	552
Transmission route	- 080	245	- 066	.324	**-.127**	**.020**	**-.132**	**.015**	**-.127**	**.018**	**-.127**	**.018**	- 061	235	- 059	261
Block 2																
PDSHIV	------	------	**-.198**	**.001**	- 004	943	015	779	023	655	019	719	- 007	886	- 001	981
Block 3																
PSSHIV	------	------	------	------	**-.612**	**.000**	**-.607**	**.000**	**-.585**	**.000**	**-.578**	**.000**	**-.425**	**.000**	**-.422**	**.000**
Block 4																
PSSS	------	------	------	------	------	------	086	083	046	363	044	383	034	487	044	390
Block 5																
CLOT-R	------	------	------	------	------	------	------	------	**.148**	**.004**	**.148**	**.004**	**.111**	**.021**	**.103**	**.040**
Block 6																
PSSHIV X PSSS	------	------	------	------	------	------	------	------	------	------	057	251	013	788	021	666
PSSHIV X CLOT-R	------	------	------	------	------	------	------	------	------	------	034	491	035	451	049	334
Block 7																
Cope 1	------	------	------	------	------	------	------	------	------	------	------	------	007	903	- 003	961
Cope 2	------	------	------	------	------	------	------	------	------	------	------	------	- 092	103	- 096	109
Cope 3	------	------	------	------	------	------	------	------	------	------	------	------	- 053	335	- 046	417
Cope 4	------	------	------	------	------	------	------	------	------	------	------	------	**-.222**	**.000**	**-.220**	**.000**
Cope 5	------	------	------	------	------	------	------	------	------	------	------	------	**-.167**	**.002**	**-.165**	**.003**
Cope 6	------	------	------	------	------	------	------	------	------	------	------	------	096	094	095	105
Block 8																
PSSHIV X Cope 1	------	------	------	------	------	------	------	------	------	------	------	------	------	------	- 036	576
PSSHIV X Cope 2	------	------	------	------	------	------	------	------	------	------	------	------	------	------	- 013	828
PSSHIV X Cope 3	------	------	------	------	------	------	------	------	------	------	------	------	------	------	007	889
PSSHIV X Cope 4	------	------	------	------	------	------	------	------	------	------	------	------	------	------	072	200
PSSHIV X Cope 5	------	------	------	------	------	------	------	------	------	------	------	------	------	------	- 017	779
PSSHIV X Cope 6	------	------	------	------	------	------	------	------	------	------	------	------	------	------	- 008	898
R2	066		104		424		431		450		455		555		558	
Adjusted R2	055		090		413		417		435		436		527		519	
R^2 change	066		038		320		007		019		005		099		003	
F-test for nested models	----		(1,253)=10 73		(1,252)=14 00		(1,251)=3 09		(1,250)=8 64		(2,248)=1 14		(6,242)=9 06		(6,236)=0 27	
p-value of F-test	----		**0.000**		**0.000**		**0.006**		**0.000**		0 322		**0.000**		0 951	

PDSHIV Perceived Discrimination scale for PLWH, PSSS The Perceived Social Support Scale, PSSHIV The Perceived Stress Scale for PLWH, C-BDI-II The Chinese version of Beck Depression Inventory, CLOT-R Optimism Cope 1 Problem-solving and Acceptance, Cope 2 Negative Venting and Avoidance, Cope 3 Support Seeking, Cope 4 Self-blame and Denial, Cope 5 Reliance on Spirituality, Cope 6 Humor and Self-distraction F-test for nested models F value comparing the model with the prior model with one block less

Chapter 10 Concluding chapter

10.1 Summary of key findings

10.1.1 Development of the perceived stress scale for People Living with HIV in China (PSSHIV)

The PSSHIV was developed using qualitative and quantitative methods among PLWH in mainland China. The constructed PSSHIV consists of 35 items covering 8 domains: social/psychological problems; sexual relationships; functional problems; social acceptance/rejection issues; work-related issues; family/offspring issues; accessibility to treatment; and treatment outcomes. Structurally the PSSHIV possesses satisfactory psychometric properties including face validity, content validity and concurrent validity. Internal reliability and test-retest reliability were also demonstrated to be acceptable. The paper on PSSHIV development in this study was published in 2008 [240]. This fully validated perceived stress scale will allow researchers and service providers to provide more appropriate support services to PLWH. The PSSHIV can also serve as an outcome measure in evaluating stress reduction programs targeting PLWH. Further research to translate and validate PSSHIV in other cultures will enhance understanding of stresses faced by PLWH.

10.1.2 Validation of Brief COPE (COPEHIV)

The Brief COPE inventory has been used extensively to examine the relationship between coping strategies and psychological outcomes in PLWH. Previous studies on the Brief COPE have used either the combined subscales (e.g. adaptive versus maladaptive coping) or the fourteen separate subscales of the Brief COPE. In this study, CFA showed a poor fit for the two previous combined models, and Cronbach's alphas of the separate

subscales were also not satisfied. EFA was therefore performed to explore a potential revised structure of the Brief COPE.

The results of EFA demonstrated a six-factor solution, and the six factors were named 'Problem-solving and Acceptance', 'Negative Venting and Avoidance', 'Support Seeking', 'Self-blame and Denial', 'Reliance on Spirituality' and 'Humor and Self-distraction'. This new structure had acceptable psychological characteristics and can be used in future studies on the coping strategies of PLWH. The validated structure was further used in multivariate analysis to investigate the role of coping strategies on psychological well-being in this study.

10.1.3 Stress profiles identified by cluster analysis

On the basis of the similarity of the individual stress profiles across the eight stress domains, the clustering solution suggested two distinct clusters. The two clusters differ reliably in terms of scores of all eight stress domains, and were labeled as high and low stress groups.

Those with higher SES had a higher percentage of low stress and a lower percentage of high stress, as ascertained by chi-square testing. A comparison of the two profiles found that the high stress group had lower levels of optimism and social support and higher levels of perceived discrimination as compared to the lower stress group. This finding is consistent with the findings of the factors of perceived stress using multiple regression models in later chapter. The results of this chapter showed the same findings regarding the determinants of perceived stress, and revealed the impact of stress levels on psychological status. Investigation of the determinants of psychological well-being considering other elements, in addition to the perceived stress in the stress and coping model, was then suggested.

10.1.4 Prevalence of depressive disorders and levels of perceived discrimination, perceived stress and coping strategies

The overall prevalence of depression (the proportion of those with mild to severe depressive symptoms) within the two weeks prior to the survey was 70.9% and the proportion of individuals with moderate to severe depressive symptoms within the two weeks prior to the survey was 63.3%. These figures are consistent with the existing literature on the prevalence of depression among PLWH in China and are much higher than the global average rate of depression (22-45%) among PLWH. The multivariate analysis showed that individuals without income were more likely to have higher rates of moderate to severe depression. Only 0.8% of the participants never perceived any discrimination in terms of HIV infection. 'Functional Problem Subscale' and 'Work Related Issues Subscales' had the highest mean scores in this study. 'Problem-solving and Acceptance' and 'Self-blame and Denial' were commonly used coping strategies.

10.1.5 Determinants of PSSHIV

The investigation of determinants of perceived stress demonstrated that the SES variables and perceived discrimination significantly predicted perceived stress. While optimism and social support were both associated with some domains of the PSSHIV, the buffering hypothesis of optimism and social support on the effect of perceived discrimination to perceived stress were not supported by the study results. Additionally, the result that individuals with IDU-transmitted HIV reported higher perceived stress in the 'Functional Stress' category highlights the necessity of integration of substance use treatment and HIV/AIDS-related medical care.

10.1.6 Determinants of psychological well-being

Overall perceived stress and 7 out of 8 subscales of PSSHIV were shown to be inversely associated with better psychological well-being, which is consistent with prior studies. Perceived discrimination was negatively related to better psychological well-being, while optimism and social support were positively related to better psychological well-being. Furthermore, perceived stress was also a mediator of the effects of perceived discrimination on psychological well-being. Perceived social support influenced psychological well-being through the mediating effect of optimism.

Consistent with the prior studies, the newly developed coping strategies correlated with psychological well-being in the expected direction. 'Problem-solving and Acceptance' was negatively related to depression, while 'Negative Venting and Avoidance' and 'Self-blame and Denial' were positively related to depression and poor QoL. 'Reliance on spirituality' was a predictor of poorer QoL. Though previous studies have indicated that coping resources and coping strategies always play a buffering role in the relationship between stress and psychological well-being, the moderating effects of optimism, social support and six coping strategies developed between stress and psychological well-being were not found in this study.

The model on adjustment of psychological well-being of PLWH in this study was found to be different from the previously existing stress and coping model. Perceived discrimination is a major source of perceived stress. Coping strategies are different among Chinese PLWH than in Western countries. Social support, optimism and coping strategies have independent effects on the psychological well-being of PLWH, but no buffering effect on the relationship between perceived stress and psychological well-being.

10.2 Comparison with international literature

10.2.1 Instrumentation

PSSHIV

The PSSHIV developed in this study is the first perceived stress scale among PLWH in China. Both qualitative and quantitative methods were used on PLWH who had acquired HIV via various routes. The development procedure consists of a four-stage item-generation study and a validation study, which is rigorous and has been advocated by previous researchers [267]. Many prior studies on PLWH applied the Perceived Stress Scale (PSS) [195-197], which is not specific to HIV/AIDS and does not explore specific types of stress experienced by PLWH and does not assess the impact of these various types of stress on the psychosocial adjustment process among PLWH. A few other life-event scales are specific to HIV/AIDS but they have not been formally validated [81, 152]. The only validated HIV-specific perceived stress scale was based on a homosexual/bisexual sample in Australia and did not assess medication-related stress [205]. Therefore, this newly validated PSSHIV addresses many limitations of the previously developed HIV stress scales.

This new scale includes stress related to accessibility to treatment and treatment outcomes. Although the number of patients receiving antiretroviral therapy in China has been increasing [286], accessibility of ARV therapy remains a serious concern in China [289], which is similar with the situation in many developing countries, where have limited access to antiretroviral therapy [285]. In addition, perceived stress due to concerns about family/offspring was indentified as one of the subscales of PSSHIV. Continuity of the family tree is essential in traditional Chinese culture [225]. Under the one-child policy [226], the family line might be discontinued if the PLWH were not going to have a child due to HIV-related

considerations, or if the child were vertically infected. Other studies also indicated more than 50% of women living with HIV/AIDS who obtain access to ART reported the desire to have a child [427]. Therefore, HIV care and family planning programs should be integrated more thoroughly in order to support PLWH's reproductive choices.

Stress on Sexual relationship was identified as one of the domains of perceived stress among PLWH in China. It reflects the problems commonly confronted by PLWH, such as potential of transmitting HIV to partners, disclosure issues and quality of sexual life [428]. This has never been mentioned as a stress domain in previous literature, though addressing the issues of sexual relationship is important in preventing secondary transmission, improving quality of life of PLWH and seeking relevant services among PLWH. Stress on Social Acceptance/Rejection Issues is mainly focus on the concerns of being stigmatized by family and others. The findings of previous studies showed that stigmatization of people living with HIV/AIDS in China is strongly associated with community-level HIV knowledge and fear, even after taking into account HIV knowledge and fear at the individual level. Public-health interventions aimed at eliminating stigmatization of people living with HIV/AIDS will need to pay special attention to social and community influences while continuously working to enhance HIV knowledge and reduce inaccurate beliefs and fear [129].

Stress on Work-related Issues is basically about concerns on getting a new job and losing job due to HIV infection. Researchers consider employers to be a key power group whose practices can significantly impact the adjustment and recovery of people with HIV. Persons with HIV/AIDS often experience discrimination in hiring and employment, which contributes to social isolation and can further exacerbate symptoms of illness and their psychological well-being [429, 430]. In China and even in developed countries such as the United States, this can mean that people with HIV without jobs may have difficulty meeting

their basic needs. In our study, mandatory testing at recruitment, lack of confidentiality, dismissal, and denial of employment were found the major work-related stress among PLWH in China, which is consistent with the findings in other Asia Pacific countries [246]. In addition, in China, a discrepancy between public policies on protecting people with HIV from employment discrimination and local practices of the social policies towards the employment of PLWH has been found [431]. Unsurprisingly, Chinese government has had trouble implementing and enforcing such policies despite such policies has been promoted to prohibit employment discrimination against Chinese PLWH.

In a study conducted previously, comparisons have been conducted on employers' attitudes and hiring practices towards people with HIV across three culturally and linguistically distinct cities: Chicago, Beijing, and Hong Kong [429]. Employers from all three cities showed reluctance to hire people with HIV, but this trend was most pronounced with employers from Beijing and Hong Kong. Concerns about biological contagion were apparent in all three cities. Social contagion, or the belief that people with HIV could morally corrupt those around them, was a particular concern of employers from Beijing and Hong Kong. The concerns about hiring people with HIV in Hong Kong and Beijing may be related to specific cultural dynamics related to loss of 'face', level of contact and knowledge about people with HIV, and the psychological interconnectedness between people in society [429]. Therefore, HIV stigma reduction intervention programs in China should be conducted not only at both institutional level and individual level, and also consider the cultural differences to modify the programs. For example, in China, stigma reduction interventions could be designed to target culturally specific phenomenon, like loss of 'face', or social standing, for people with HIV.

Validated Brief COPE

The 28-item Brief COPE has been used extensively to examine the relationship between various coping strategies and psychological outcomes in PLWH [305-307]. Most studies have used original subscales or combined subscales [170, 308] which have not undergone thorough psychological assessment in culture and population-specific contexts. The method of CFA to test the previously-used models followed by EFA to investigate the structure of the Brief COPE has not been used before. Factors identified through EFA reflected coping strategies adopted by PLWH from a Chinese cultural perspective, stressing the importance of interpersonal relationships in China, and the resilient nature of traditional Chinese culture [223].

10.2.2 Levels and patterns of perceived discrimination, perceived stress, coping resources and coping strategies

The eight factors of PSSHIV developed in this study are 'Social/Psychological Problems', 'Sexual Relationship', 'Functional Problems', 'Social Acceptance/Rejection', 'Work-related Issues', 'Family/Offspring Concerns', 'Accessibility to Treatments', and 'Treatment Outcome'. These factors are much different from the previous perceived stress scale [205] and the stressor checklist [81, 152] among PLWH and truly reflect the status/needs of PLWH in China. The two clusters (with high stress and low stress) identified by the eight domains of the PSSHIV differed reliably and had significant different levels of coping resources and perceived discrimination in expected direction. These results have never been found in previous studies.

The six factors generated from the Brief COPE via EFA were named 'Problem-solving and Acceptance', 'Negative Venting and Avoidance', 'Support Seeking', 'Self-blame and Denial', 'Reliance on Spirituality', and 'Humor and Self-distraction'. These factors have

acceptable psychometric properties compared with the low alpha values of the original 14 subscales of Brief COPE reported in this and previous studies [170]. Also, some factors ('Problem-solving and Acceptance' and 'Humor and Self-distraction') reflected the nature of traditional Chinese culture, while others ('Negative Venting and Avoidance') reflected frequently used strategies by PLWH after finding out they have been infected with HIV. Therefore, the new structure of the Brief COPE contains unique factors that are suitable within the Chinese context and address HIV-related concerns of Chinese PLWH.

Compare to other chronic diseases, such as cancer, multiple sclerosis, PLWH might adopt different patterns of coping strategies due to the characteristics of HIV and its transmission routes (mostly from heterosexual, homosexual and IDU behaviors). Stigma and discrimination are frequently confronted stressors for PLWH after they know their HIV infection [432]. Unsurprisingly, 'Negative Venting and Avoidance' (including substance use) and 'Self-blame and Denial' are utilized as coping strategies by many PLWH [433], which play a persistent role in pursuing unprotected sex with their partners and development of mental health issues [434]. Compare to PLWH, patients with other chronic diseases seldom use of substance use and self-blame as coping strategies, while religious coping and approach coping were frequently used in patients with other chronic diseases such as cancer [435, 436].

10.2.3 Relationships between stressor, stress, resources, coping strategies and mental health outcome

Though perceived discrimination was proved to be a major source of perceived stress in this and previous studies among PLWH [404, 405], the result that the way in which perceived discrimination may lead to worse psychological well-being was mediated through perceived stress has not been reported before. This indicated the pathway through which perceived

discrimination affects psychological well-being and the major source of perceived stress among PLWH.

The risk and protective factors for perceived stress and psychological well-being were systematically investigated among Chinese PLWH based on prior studies. The results of this research demonstrated that coping resources could reduce perceived stress and increase psychological well-being, supporting findings of previous studies [68, 133, 156, 299, 379, 380]. However, some of the findings of this study differ from those of previous studies. Notably, other studies found significant moderating effects of coping resources and coping strategies between perceived stress and psychological well-being among PLWH and other populations [147, 410]. In contrast, this study found no significant moderating effect of coping resources and coping strategies on the effect of perceived stress on psychological well-being. Further, though the finding that optimism mediated the relationship between social support and psychological well-being is in line with previous findings [416-418], the same result has not been demonstrated among PLWH either worldwide or in China before this study.

In this study, Problem-solving and Acceptance' was commonly used coping strategies and it was showed to be negatively related to depression. In Western countries, passive emotional regulation (strategies that do not directly approach the problem) was perceived as the most often used coping strategies, and it was showed to be associated with greater emotional and behavioral problems [437]. Also, 'Reliance on spirituality' was a predictor of poorer QoL among Chinese PLWH in China. Whilst in Western, positive religious coping (e.g., seeking spiritual support) was associated with positive psychological outcomes and spiritual struggle (e.g., anger at God) was associated with negative psychological outcomes [438]. The results of another study among Sub-Saharan African Women Living with HIV/AIDS revealed approximately 85 percent of the women reported that spirituality played some role

in their ability to cope. Among these, 43 percent indicated that spirituality was the most important factor that kept them going. The most widely used spiritual Coping strategies consisted of support from other believers, prayer, and trusting in God [439]. These results have implications for assessing religious coping and designing interventions targeting appropriate spiritual coping strategies in patients with HIV/AIDS in China.

In western culture, religion beliefs or behaviors like praying and mediating are very common and have long been playing an important role in influencing human behavior. Though religion beliefs like Buddism and Christianity are also existing in China [333], there are possibly many differences across cultures, namely in religion, that may impact views of Spirituality aspects. Typically, religiosity has been assessed as a helpful stress buffer [424]. More recently, however, the possibility that religion can also exacerbate stress has been considered [424]. As in other culture settings, pre-existing cultural and religious values and beliefs contributed to the stigmatization of PLWH in China. The pessimism associated with the belief in reincarnation and punitive attitudes of the Buddhist doctrine toward PLWH may have discouraged them from coping better with the disease, as the next life was believed to be the only hope for redemption [217]. In the present study, 'Reliance on spirituality' was showed to predict worse QoL among PLWH. HIV workers hence need to pay more attention about spirituality-related coping adopted by PLWH in China, especially when carrying out intervention projects aiming to improve psychological well-being of this population.

In addition, another study conducted in Canada indicated that seeking social support is the most commonly used coping strategies among HIV-positive women [440]. In developed countries such as Canada, where social welfare is relatively more perfect compare to developing countries like China and less discrimination against PLWH, it is not surprising PLWH will adopt support seeking as their main coping strategies among a variety of coping

strategies.

10.3 Service implications and recommendations

PSSHIV is a comprehensive, culture-specific stress scale developed among Chinese PLWH. This newly-developed scale is able to assess the stress faced by PLWH in a much more differentiated and comprehensive way and more accurately captures the needs of PLWH in China than previous perceived stress scales. Future studies should explore the most prevalent types of stress in different population groups in order to offer relevant services to alleviate their stress. The stress subscales developed can also serve as an evaluation tool for stress management programs.

The effects of the subscales of PSSHIV on psychological well-being were also remarkable. Seven out of eight dimensions of the PSSHIV were associated with more depressive symptoms and poorer QoL. This provides a framework for implementing intervention programs catering to improving psychological well-being of PLWH in China. Based on the contents of the stress subscales that were significantly related to psychological well-being, pragmatic measures such as offering medical and psychological counseling (focusing on social/psychological and functional problems), publicizing the accessibility and effect of ARV therapy (focusing on treatment-related stress), and exploring ways of disseminating knowledge on secondary transmission and PMTCT (focusing on sexual relationship and family/offspring issues), would be effective in relieving the stress of PLWH in different areas, helping to avoid stress developing into depression and thus dampening QoL.

Perceived discrimination was shown to be a distinct source of perceived stress of

PLWH, which led to worse psychological well-being. Perceptions of higher levels of discrimination, which were accepted by PLWH as legitimate (internalized stigma), motivated people to avoid disclosing their HIV status and hence complicate the treatment and care of HIV [441]. Medical practitioners should carry out psychological assessments and care without judgmental attitudes and help PLWH disclose their HIV status to family members. This would help to reduce HIV-related stigma within Chinese culture [125]. Meanwhile, increasing public acceptance and understanding of HIV infection, as well as improving the internal competencies of PLWH through appropriate education, would be beneficial to the health of PLWH, in addition to providing effective and timely medical treatment to PLWH. Improving the capacity of service providers through appropriate training programs and promotion of a comprehensive social environment is also warranted in China.

Further, encouraging PLWH to adopt positive thinking (i.e., optimism) and provide more external support (mentally and physically) is warranted to improve the psychological well-being of PLWH. For example, thinking about joyful and pleasant issues instead of thinking about being HIV-positive, thinking about what steps to take and how to handle being HIV-positive, thoughts of attaching a positive meaning to being HIV-positive, thoughts of playing down the seriousness of being HIV-positive or emphasizing its relativity when compared to other events, would be effective ways of coping with HIV infection and benefit the psychological well-being of PLWH [442]. To achieve this goal, regular theory-based workshops should be provided by qualified psychiatrists to guide the modes of thoughts of PLWH during their adjustment to HIV infection. In addition, support from family members (to be more understanding to and less discriminative against PLWH), health care workers (by providing appropriate counseling, treatment and care) and policy makers (by creating

regulations on meeting the needs of PLWH) would provide factual assistance and benefit the psychological well-being of PLWH.

The findings provide an understanding of the role of coping in the psychological well-being of PLWH in China, and suggest the possibility of designing interventions for psychological adaptation to the illness. Interventions supporting attempts to use adaptive coping strategies such as 'Problem-solving and acceptance' may be particularly effective in improving the mental health and well-being of PLWH. In addition, to assess the religious coping adopted by PLWH in China and guide them to use the positive religious coping is of particular importance with the emerging effect of religious in China in recent years. It is important to identify patients with depressive symptoms and develop psychological interventions that focus on decreasing maladaptive coping strategies (such as 'Negative venting and avoidance' and 'Self-blame and denial'). The challenging aspect of this will be determining how to integrate psychological screening and deliver psychological interventions within the current health care structure. The findings of this research may be especially useful to those who design and organize preventative measures, and for the reduction of stress and improvement of psychological well-being.

Stress management therapy has been proven to be effective among chronically ill patients in reducing stress, facilitating coping strategies, and changing cognitive appraisals of stressful events. This therapy is a form of cognitive behavior intervention and consists of a number of sessions including: Conceptualization of the stress; Cognitive restructuring; Deactivation techniques; Social skills; Personality pattern and its relationship with health; Anger management; Humor and optimism as coping strategies, etc [443].

Coping resources and coping strategies were proved to have main effect on

psychological well-being, but no significant moderating effect between the relationship of perceived stress and psychological well-being was found. This may be in part because the coping strategies and social support variables we used in the study were not perfectly match the specific stress. Given that perceived stress is very specific in this study, specific coping strategies or context-specific strategies and support are necessary for each of the stressful situations. The current measures lack this specificity. Moreover, lack of the moderating effect might also in part because the individual differences in coping resources and coping strategies are not so meaningful in terms of how perceived stress affects subsequent psychological well-being. Educations aiming at reduce the stigma and discrimination toward PLWA and appropriate stress management skills should be the main ways to improve psychological well-being of PLWH, aided by adopting appropriate coping strategies and promoting more coping resources. However, at least we can say that coping resources and coping strategies are helpful for better psychological well-being, but in terms of mitigating the effects of stress on outcome, we need to be more specific in our tactics.

Perceived discrimination has been proved to be a barrier for PLWH to disclose there HIV infection, finding testing and treatment related to HIV infection. Poverty, unstable family relations and unhealthy social environment limit the PLWH to disclose their HIV status. Therefore, PLWH are socially marginalized and face the risk of transmission, re-infection and failure to adhere to medication, and require particular support from the health sector or community groups [432]. In our study, 'Support Seeking' was identified as one of the coping strategies utilized by PLWH, which reflected the needs of social support by PLWH. Also, our data showed that 'Support Seeking' correlated negatively with perceived discrimination.

Substance use is prevalent among HIV positive adults and is linked to a number of

adverse consequences [426]. Self-medication with alcohol or drugs was an observed influence of depressive symptoms among HIV/AIDS [83]. In this study, 'Negative venting and avoidance' (including two items of substance use) was found predictive of more depressive symptoms. Other studies also found the use of alcohol and other drugs (AOD) to cope with HIV was negatively associated with certain safer sex attitudes and practices, and less disclosure of their HIV status to their sex partners [330]. AOD use may hence help facilitate HIV transmission among adolescents with HIV. Naturally, interventions which address the use of AOD among those PLWH must be timely to help reduce the likelihood of HIV transmission and improve psychological well-being.

In summary, apart from the problems found in this study and the relevant suggestion raised, health policies that match the factual needs of PLWH in China should focus on the alleviating stress and discrimination PLWH faced, changing the attitudes of public, monitoring the AOD use among PLWH and providing appropriated support. Appropriate psychological interventions to PLWH are warranted to improve the psychological well-being of PLWH.

10.4 Theoretical implications

The stress and coping model developed by Lazarus and Folkman consists of stressor, appraisal, coping resources, and coping strategies, and describes the stress and coping process that affects adaptational outcomes [135]. In the current study, appraisal was not included due to the lack of validated instruments (evaluative process of an event in terms of threat, challenge and controllability), but developed 'perceived stress', which was tailor-made for PLWH in China. Besides the basic components in the stress and coping model, perceived discrimination was also applied as a stressor in this study due to its

This study used single point rather than long-term or multi-point measurements. It therefore cannot show whether a causal relationship exists between variables such as stress, coping strategies and psychological well-being. Further studies using longitudinal methods are required for this. Findings of this study also suggest that patterns of psychological adjustment among PLWH with different transmission categories and among different countries and cultural contexts need to be investigated.

Various studies have shown positive effects of cognitive-behavioral oriented interventions [444, 445] and coping effectiveness training [446] in improving emotional problems in HIV-infected men [442]. Intervention studies taking into account coping strategies developed in this study might be a useful way in relieving the perceived stress and eventually improving the psychological well-being of PLWH in China.

Furthermore, path analysis or Structural Equation Model involving all related variables and domains of scales could be performed to develop a more holistic model of stress and coping among PLWH in China. A more comprehensive and integrated stress and coping model for Chinese PLWH would benefit PLWH in China and the work of public health practitioners and researchers in this area.

10.6 Major limitations of the dissertation

The study of PSSHIV development has several limitations. First, known group comparison between AIDS and non-AIDS participants was not performed. Data on CD4 counts, which is required for defining AIDS, were not available for one-third of the participants, rendering known group comparison unfeasible. Self-report bias may exist, though there is no clear social desirability bias associated with over-reporting or

under-reporting levels of perceived stress. The weighted Kappa coefficients of 23 out of 35 items indicated only moderate (though acceptable) test-retest reliability. Convenience sampling was used, and although the sample included different types of PLWH, selection of participants by mode of HIV acquisition may have led to an unrepresentative sample.

The validation study of the Brief COPE has several limitations. Besides the limitation of the sampling frame in Survey 2 (which only covered a proportion of all PLWH in the two cities (e.g. those with valid telephone numbers or using particular services) and may not have been representative of the PLWH populations in the 2 cities), the EFA results obtained from this study may be sample dependent. Furthermore, the subscale 'Reliance on Spirituality' only contains two items, so its psychometric properties may not be satisfactory [447]. Moreover, concurrent validity of the Brief Cope was not tested using another instrument due to the length of the questionnaire. Although results for the validation of the Brief COPE indicated good applicability for the population studied, the validity of Brief COPE's structure has not been fully explored, and further psychometric evaluation is warranted. Apart from the above limitations, the results of the present study should be considered in light of the newly developed structure of the Brief COPE. The new structure of the Brief COPE, however, provides specific information about living with HIV/AIDS that would not have been evident if other measures of coping or other structures of Brief COPE had been used.

Self-report bias may exist in the form of social desirability bias associated with the more sensitive questions, such as the level of perceived discrimination. The present study recruited subgroups based on different HIV transmission routes, and this non-random recruitment method limits the generalizability of findings. Moreover, CLOT-R's Cronbach's alpha, a measure of the internal consistency, is relatively low at 0.54. In part, this is based on

indispensable role in the mental health of PLWH in China. Through bottom-up methods and empirical analysis strategies, the two variables (perceived stress and perceived discrimination) were proven to be components that cannot be ignored during psychological adjustment of PLWH within the Chinese cultural context. In addition, although the Brief COPE was employed to measure coping strategies in this study, the actual structure of it was much different from those used in previous empirical studies. Therefore, Western stress and coping studies are culturally specific and cannot be applied across cultural and social contexts, e.g. in China. The findings provide instruments and a preliminary model for further development of more comprehensive models in this area.

Another noteworthy finding of this study is the mediating effect of optimism between social support and psychological, and the identification of the unique pathway by which optimism affects psychological well-being in Chinese PLWH.

This study did not completely follow the previously existing stress and coping model widely utilized among PLWH in Western context. By adding some key variables to the original stress and coping model, this study provided a preliminary psychological model which is unique in Chinese PLWH. Future studies can use the findings of this study to further develop a comprehensive stress and coping model for Chinese PLWH.

10.5 Suggestions for future studies

The PSSHIV and validated Brief COPE developed in this study are the noteworthy findings in this dissertation. Validation of the two scales in different PLWH populations (e.g., HIV positive MSM and IDU) in China and in other countries would be useful and provide instruments for future research in different populations and cultural contexts.

the small number of the items (6 items) of the instrument. However, some researchers regard a Cronbach's alpha of more than 0.50 as acceptable [278].

The cross-sectional design of this study allowed examination of the associations between perceived discrimination, coping resources, perceived stress and psychological well-being among PLWH. However, causality between variables could not be established. Nevertheless, the study's findings suggest that depressed individuals are more likely to perceive stress and discrimination, less likely to sustain or develop social support, and more vulnerable to life stress. Though the medical treatment and management of HIV/AIDS have improved remarkably, the persistence of high rates of depression and low quality of life among PLWH remains an area of concern. The results of this study and others suggest that psychosocial issues play a central role in the development and maintenance of depression and other mental disorders. The exact nature of the relationship between these factors and psychological well-being needs further elucidation through longitudinal research.

10.7 Conclusion

This study has provided useful instruments and information for mental health studies and potential intervention programs among PLWH in China and other cultural contexts. Based on the findings of this study, a comprehensive and integrated stress and coping model could be built in the future and contribute to the health of PLWH and related research.

Appendix 1 Questionnaire for the study of PSSHIV development

Code:_____, Date completed:_____

Health Survey Questionnaire (2006)

Hengyang/Shenzhen CDC

We are from Hengyang/Shenzhen CDC and expect you help us fill out the following questionnaire, which was designed to know more about the health status of People Living with HIV/AIDS. Based upon the analysis of the survey data, more appropriate health service will be provided to you. The questionnaires and related data will be conserved carefully and the confidentiality will be assured (please tick the appropriated answer as "✓")

Part one: ***Basic information***

1. Date of birth (year-month) _____

2. Gender. ☐1 Female ☐2Male

3 Marital status: ☐1Single ☐2 Married ☐3Divorced ☐4 Separated ☐5 Widowed ☐6 Cohabiting ☐7 Others (please give clear indication_____)

4 Education: ☐1 Illiterate ☐2 Primary school ☐3 Junior high school ☐4 senior high/technical secondary school ☐5 Junior College ☐6 University or above

5. Working status: ☐1 Full-time ☐2 Part-time ☐3Retired ☐4 Student ☐5 Job-waiting/lost job ☐6 Others (please give clear indication_____)

6. Whether you are Hengyang/Shenzhen resident (Holding an ID card of the city) ☐1 Yes ☐2 No

7. Nationality: ☐1 Han ☐2 Man ☐3 Hui ☐4 Zhuang ☐5 Miao ☐6 Zang ☐7 Others (please give clear indication_____)

8 What's the route through which you contracted HIV?

☐1 Homosexual behavior ☐2 Blood transfusion/ Using blood products ☐3 Blood selling ☐4 Heterosexual behavior ☐5 Intravenous Drug Use

9. What's your CD4 T-cell counts in your latest CD4 test? ☐1 _____ ☐2 Never tested

10. Are you taking the ARV medication recommended by CDC? ☐1 Yes ☐2 No (please skip the question 10)

11. Who are paying for the ARV meditation? ☐1 Yourself ☐2Government

12. Are you taking other medication besides the ARV regimen? ☐1 Yes ☐2 No

13. Time diagnosed with HIV infection (year-month-date): _____

14. How is the change of the relationship between you and your family after knowing your HIV infection?

☐1 Better ☐2 Same as before ☐3 Worse

Part two:

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each question fairly quickly. That is, don't try to count up the number of times you felt a particular way, but rather indicate the alternative that seems like a reasonable estimate. For each question choose from the following alternatives: 0. never; 1. almost; 2. sometimes; 3. fairly often; 4. very often. (Please tick "✓" in front of the expect answer).

Items	Never	Almost	Some times	Fairly often	Very often
1. How often have you been upset because of something happened unexpectedly?	☐0	☐1	☐2	☐3	☐4
2. How often have you felt that your were unable to control the important things in your life?	☐0	☐1	☐2	☐3	☐4
3. How often have you felt nervous and "stressed"?	☐0	☐1	☐2	☐3	☐4
4. How often have you dealt successfully with irritating life hassles?	☐0	☐1	☐2	☐3	☐4
5 How often have you felt that you were effectively coping with important changes that were occurring in your life?	☐0	☐1	☐2	☐3	☐4
6 How often have you felt confident about your ability to handle your personal problems?	☐0	☐1	☐2	☐3	☐4
7 How often have you felt that things were going your way?	☐0	☐1	☐2	☐3	☐4
8 How often have you found that you could not cope with all the things that you have to do?	☐0	☐1	☐2	☐3	☐4
9 How often have you been able to control irritations in your life?	☐0	☐1	☐2	☐3	☐4
10 How often have you felt that were on top of things?	☐0	☐1	☐2	☐3	☐4
11 How often have you been angered because of things that happened that were outside your control?	☐0	☐1	☐2	☐3	☐4
12 How often have you found yourself thinking about things that you have to accomplish?	☐0	☐1	☐2	☐3	☐4
13 How often have you been able to control the way you spend your time?	☐0	☐1	☐2	☐3	☐4
14. How often have you felt difficulties were piling up so high that you could not overcome them?	☐0	☐1	☐2	☐3	☐4

Part 3:

We would like you to answer some questions about how you are feeling and the kinds of things you are able to do. Please tick "✓" in front of the most appropriate answer. You are asked to check one box for each question. All questions refer to the PAST 4 WEEKS.

	Excellent	Very good	Good	Fair	Poor
1 In general, would you say your health is	☐1	☐2	☐3	☐4	☐5

	None	Very mild	Mild	Moderate	Severe	Very Severe
2 How much bodily pain have you generally had during the past 4 weeks?	☐1	☐2	☐3	☐4	☐5	☐6

	Not at all	A little bit	Moderately	Quite a bit	Extremely
3 During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)	☐1	☐2	☐3	☐4	☐5

4 The following questions are about activities you might do during a typical day Does your health now limit you in these activities? If so, how much?

	Limited a lot	Limited a little	Not limited at all
a The kinds or amounts of vigorous activities you can do, like lifting heavy objects, running or participating in strenuous sports	☐1	☐2	☐3
b The kinds or amounts of moderate activities you can do, like moving a table, carrying groceries or bowling	☐1	☐2	☐3
c Walking uphill or climbing (a few flights of stairs)	☐1	☐2	☐3
d Bending, lifting or stooping	☐1	☐2	☐3
e Walking one block	☐1	☐2	☐3
f Eating, dressing, bathing or using the toilet	☐1	☐2	☐3

	是	否
5 Does your health keep you from working at a job, doing work around the house or going to school?	☐1	☐2
6 Have you been unable to do certain kinds or amounts of work, housework, or schoolwork because of your health?	☐1	☐2

For each of the following questions, please check the box and tick 「✓」 for the one answer that comes closest to the way you have been feeling during the past 4 weeks.

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A little of the Time	None of the Time
7 How much of the time, during the past 4 weeks, has your health limited your social activities (like visiting with friends or close relatives)	□1	□2	□3	□4	□5	□6

8. How much of the time, during the past 4 weeks:	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A little of the Time	None of the Time
a. Have you been a very nervous person?	□1	□2	□3	□4	□5	□6
b. Have you felt calm and peaceful?	□1	□2	□3	□4	□5	□6
c Have you felt downhearted and blue?	□1	□2	□3	□4	□5	□6
d Have you been a happy person?	□1	□2	□3	□4	□5	□6
e. Have you felt so down in the dumps that nothing could cheer you up?	□1	□2	□3	□4	□5	□6

9. How often during the past 4 weeks·	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A little of the Time	None of the Time
a. Did you feel full of pep?	□1	□2	□3	□4	□5	□6
b. Did you feel worn out?	□1	□2	□3	□4	□5	□6
c. Did you feel tired?	□1	□2	□3	□4	□5	□6
d. Did you have enough energy to do the things you wanted to do?	□1	□2	□3	□4	□5	□6
e. Did you feel weighed down by your health problems?	□1	□2	□3	□4	□5	□6
f. Were you discouraged by your health problems?	□1	□2	□3	□4	□5	□6
g. Did you feel despair over your health problems?	□1	□2	□3	□4	□5	□6
h Were you afraid because of your health?	□1	□2	□3	□4	□5	□6

10. How much of the time, during the past 4 weeks:	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A little of the Time	None of the Time

a Did you have difficulty reasoning and solving problems, for example, making plans, making decisions, and learning new things?	□1	□2	□3	□4	□5	□6
b Did you forget things that happened recently, for example, where you put things and when you had appointments?	□1	□2	□3	□4	□5	□6
c Did you have trouble keeping your attention on any activity for long?	□1	□2	□3	□4	□5	□6
d Did you have difficulty doing activities involving concentration and thinking?	□1	□2	□3	□4	□5	□6

11 Please check the box and tick [✓] that best describes whether each of the following statements is true or false for you

	Definitely True	Mostly True	Don't know	Mostly False	Definitely False
a I am somewhat ill	□1	□2	□3	□4	□5
b I am as healthy as anybody I know	□1	□2	□3	□4	□5
c My health is excellent	□1	□2	□3	□4	□5
d I have been feeling bad lately	□1	□2	□3	□4	□5

	Very well	Pretty good	Good and bad parts about equal	Pretty bad	很差 / 非常差
12 How has the quality of your life been during the past 4 weeks? That is, how have things been going for you?	□1	□2	□3	□4	□5

	Much better	A little better	About the same	A little worse	Much worse
13 How would you rate your physical health and emotional condition now compared to 4 weeks ago?	□1	□2	□3	□4	□5

Part 4:

Please read each statement and choose a number 1, 2, 3 and 4 that indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement. The rating scale is as follows:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

	Not apply at all	Some of the degree	Good part of time	Most of the time
1 I found it hard to wind down	☐1	☐2	☐3	☐4
2 I was aware of dryness of my mouth	☐1	☐2	☐3	☐4
3 I couldn't seem to experience any positive feeling at all	☐1	☐2	☐3	☐4
4 I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	☐1	☐2	☐3	☐4
5 I found it difficult to work up the initiative to do things	☐1	☐2	☐3	☐4
6 I tended to over-react to situations	☐1	☐2	☐3	☐4
7 I experienced trembling (eg, in the hands)	☐1	☐2	☐3	☐4
8 I felt that I was using a lot of nervous energy	☐1	☐2	☐3	☐4
9 I was worried about situations in which I might panic and make a fool of myself	☐1	☐2	☐3	☐4
10 I felt that I had nothing to look forward to	☐1	☐2	☐3	☐4
11 I found myself getting agitated	☐1	☐2	☐3	☐4
12 I found it difficult to relax	☐1	☐2	☐3	☐4
13 I felt down-hearted and blue	☐1	☐2	☐3	☐4
14 I was intolerant of anything that kept me from getting on with what I was doing	☐1	☐2	☐3	☐4
15 I felt I was close to panic	☐1	☐2	☐3	☐4
16 I was unable to become enthusiastic about anything	☐1	☐2	☐3	☐4
17 I felt I wasn't worth much as a person	☐1	☐2	☐3	☐4
18 I felt that I was rather touchy	☐1	☐2	☐3	☐4
19 I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	☐1	☐2	☐3	☐4
20 I felt scared without any good reason	☐1	☐2	☐3	☐4
21 I felt that life was meaningless	☐1	☐2	☐3	☐4

Part 5:

The following items are related to stress that may be resulting from HIV/AIDS infection. Please assess the extent of perceived stress related to these items experiencing by you in the last month, 1= Absolutely not stressful, 2=A bit stressful, 3=Moderately stressful, 4=Quite stressful, 5 = Extremely stressful. There are no right or wrong answers. Feel free to tick in the pane in front of the exact answer you selected.

1 I'm afraid I cannot obtain free ART from the government

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

2 I'm afraid I cannot obtain free ART from the government regularly

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

3 I feel it is difficult to afford medical expenses

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

4 Attitude of health care workers to HIV-infected people makes me feel uncomfortable

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

5 I worry about the side effects triggered by ART

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

6 I'm afraid that the treatment effectiveness is not good enough

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

7 I'm afraid I can't get the optimal ART regimen when I need to change the prescription

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

8 Because of my health status, I can't cope with heavy work load

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

9 I'm afraid that my work would be affected by medical visits

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

10 I'm afraid that my HIV status will be known in my work place

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

11 I'm afraid of losing my job due to HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

12 I'm afraid of being subjected to a health check-up in a new job

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

13 I have found it difficult to find a new job due to HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

14 I worry about my worsening health due to HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

15 I'm afraid that simple disease will cause HIV related complications

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

16 HIV/AIDS decreases my capacity for thought and memory

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

17 HIV/AIDS decreases my physical strength

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

18 I feel tense during sex encounters

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

19 I feel disturbed to avoid sexual encounter due to HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

20 I have fear to disclose my HIV status to my sex partner

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

21 I have fear of transmitting HIV to a sex partner

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

22 HIV has decreased my chances of finding a sex partner

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

23 I feel guilty towards sex partner about having HIV/AIDS

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

24 I feel low self-esteem due to HIV

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

25 I feel nervous when people mention HIV

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

26 I often feel lonely

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

27 I'm always suffering from insomnia due to HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

28 I feel depressed due to HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

29 I always blame myself for contracting HIV

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

30 I always feel self-loathing due to HIV

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

31 I have familial pressure to have offspring

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

32 I plan not to have children

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

33 I have fear of infecting newborn baby

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

34 I'm afraid my family is stigmatized because of my HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

35 Family does not accept me due to HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

36 I feel sorry to my family due to HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5

Extremely stressful

37 I try to avoid social interactions with others

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

38 I feel difficult to confide in other people about my HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

39 I feel incapable of participating in social activity

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

40 Others worry about my transmission to them

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

41 I'm afraid I'm rejected by family and friends

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

42 I'm looked down upon by others

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

43 I'm especially concerned about others' attitude to me due to HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

44 I'm disturbed by others' attitude after they know my HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

Signature of the interviewer:

Appendix 2 Questionnaire for the cross-sectional study on stress, coping and psychological well-being

Code _____, Date completed

Health Survey Questionnaire (2007)

Hengyang/Shenzhen CDC

We are from Hengyang/Shenzhen CDC and expect you help us fill out the following questionnaire, which was designed to know more about the health status of People Living with HIV/AIDS. Based upon the analysis of the survey data, more appropriate health service will be provided to you. The questionnaires and related data will be conserved carefully and the confidentiality will be assured (please tick the appropriated answer as "✓")

Part one: ***Basic information***

1 Date of birth (year-month) _____

2 Gender: □1 Female □2Male

3 Marital status

□1Single □2 Married □3Divorced □4 Cohabiting □5 Others (please give clear indication_____)

4 Do you have a kid (kids)? □1 No □2 Yes

5 Education □1 Illiterate □2 Primary school □3 Junior high school □4 senior high/technical secondary school □5 Junior College □6 University or above

6 Working status

□1 Full-time □2 Part-time □3Retired □4 Job-waiting/lost job □5 Others (please give clear indication_____)

7. Time diagnosed with HIV infection (year-month-date) _____

8. Whether you are Hengyang/Shenzhen resident (Holding a ID card of the city) □1 Yes □2 No

9. Are you taking the ARV medication now? □1 Yes □2 No

Part 2:

The following items deal with ways you've been coping with the stress triggered by HIV infection within the past 3 months. We want to know to what extend you've been doing what the item says and How much or

how frequently. Make your answers as true for you as you can. Thanks for your support. 1= I haven't been doing this at all; 2= I've been doing this a little bit; 3= I've been doing this a medium amount; 4= I've been doing this a lot.

1	I've been turning to work or other activities to take my mind off things.	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
2	I've been concentrating my efforts on doing something about the situation I'm in	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
3	I've been saying to myself "this isn't real."	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
4	I've been using alcohol or other drugs to make myself feel better.	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
5	I've been getting emotional support from others.	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
6	I've been giving up trying to deal with it.	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
7	I've been taking action to try to make the situation better.	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
8	I've been refusing to believe that it has happened.	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
9	I've been saying things to let my unpleasant feelings escape.	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
10	I've been getting help and advice from other people.	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
11	I've been using alcohol or other drugs to help me get through it.	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
12	I've been trying to see it in a different light, to make it seem more positive.	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
13	I've been criticizing myself.	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
14	I've been trying to come up with a strategy about what to do.	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
15	I've been getting comfort and understanding from someone.	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
16	I've been giving up the attempt to cope	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
17	I've been looking for something good in what is happening.	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often

18 I've been making jokes about it	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
19 I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
20 I've been accepting the reality of the fact that it has happened	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
21 I've been expressing my negative feelings	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
22 I've been trying to find comfort in my religion or spiritual beliefs	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
23 I've been trying to get advice or help from other people about what to do	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
24 I've been learning to live with it	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
25 I've been thinking hard about what steps to take	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
26 I've been blaming myself for things that happened	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
27 I've been praying or meditating	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often
28 I've been making fun of the situation	☐1 Never	☐2 Some times	☐3 Fairly often	☐4 Very often

Part 3:

We are interested in how you feel about the following statements regarding <u>your family and friends</u>. Read each statement carefully. Indicate how you feel about each statement. Circle the "1" if you <u>Very Strongly Disagree</u>; Circle the "2" if you <u>Strongly Disagree</u>; Circle the "3" if you <u>Mildly Disagree</u>; Circle the "4" if you are <u>Neutral</u>; Circle the "5" if you <u>Mildly Agree</u>; Circle the "6" if you <u>Strongly Agree</u>; Circle the "7" if you <u>Very Strongly Agree</u>.

1 There is a special person who is around when I am in need	1	2	3	4	5	6	7
2 There is a special person with whom I can share my joys and sorrows	1	2	3	4	5	6	7
3 My family really tries to help me	1	2	3	4	5	6	7
4 I get the emotional help and support I need from my family	1	2	3	4	5	6	7
5 I have a special person who is a real source of comfort to me	1	2	3	4	5	6	7
6 My friends really try to help me	1	2	3	4	5	6	7

7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows	1	2	3	4	5	6	7
10. There is a special person in my life who cares about my feelings	1	2	3	4	5	6	7
11. My family is willing to help me make decisions	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.	1	2	3	4	5	6	7

Part 4:

Please indicate the degree you agree or disagree the following sentences. "0" if you strongly disagree; "1" if you disagree; "2" neutral; "3" agree; "4" strongly disagree.

[Strongly disagree (0) ---------- Strongly agree (4)]

1. In uncertain times, I always expect the best. ☐0 ☐1 ☐2 ☐3 ☐4
2. Looking into the future, I do not see any positive scenario. ☐0 ☐1 ☐2 ☐3 ☐4
3. I am always optimistic about my future. ☐0 ☐1 ☐2 ☐3 ☐4
4 I hardly ever expect things to go my way. ☐0 ☐1 ☐2 ☐3 ☐4
5....I rarely count on good things happening to me. ☐0 ☐1 ☐2 ☐3 ☐4
6....Overall, I expect more good things happen to me than bad. ☐0 ☐1 ☐2 ☐3 ☐4

Part 5:

The following items are related to stress that may be resulting from HIV/AIDS infection. Please assess the extent of perceived stress related to these items experiencing by you in the last month, 1= Absolutely not stressful, 2=A bit stressful, 3=Moderately stressful, 4=Quite stressful, 5 = Extremely stressful. There are no right or wrong answers. Feel free to tick in the pane in front of the exact answer you selected.

1. I'm afraid I cannot obtain free ART from the government

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

2. I'm afraid I cannot obtain free ART from the government regularly

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

3. I feel it is difficult to afford medical expenses

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

4. I worry about the side effects triggered by ART

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

5. I'm afraid that the treatment effectiveness is not good enough

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5

Extremely stressful

6 I'm afraid I can't get the optimal ART regimen when I need to change the prescription

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

7 Because of my health status, I can't cope with heavy work load

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

8 I'm afraid that my work would be affected by medical visits

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

9 I'm afraid that my HIV status will be known in my work place

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

10 I'm afraid of losing my job due to HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

11 I'm afraid of being subjected to a health check-up in a new job

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

12 HIV/AIDS decreases my capacity for thought and memory

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

13 HIV/AIDS decreases my physical strength

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

14 I feel tense during sex encounters

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

15 I feel disturbed to avoid sexual encounter due to HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

16 I have fear to disclose my HIV status to my sex partner

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

17 I have fear of transmitting HIV to a sex partner

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

18 HIV has decreased my chances of finding a sex partner

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

19 I feel guilty towards sex partner about having HIV/AIDS

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

20 I feel low self-esteem due to HIV

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

21 I feel nervous when people mention HIV

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

22 I often feel lonely

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

23 I feel depressed due to HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

24 I always blame myself for contracting HIV

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

25 I always feel self-loathing due to HIV

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

26 I have familial pressure to have offspring

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

27 I plan not to have children

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

28 I have fear of infecting newborn baby

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

29 I'm afraid my family is stigmatized because of my HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

30 Family does not accept me due to HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

31 I try to avoid social interactions with others

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

32 I feel difficult to confide in other people about my HIV infection

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

33 I feel incapable of participating in social activity

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

34 I'm afraid I'm rejected by family and friends

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

35 I'm looked down upon by others

☐1 Absolutely not stressful ☐2 A bit stressful ☐3 Moderate stressful ☐4 Quite stressful ☐5 Extremely stressful

Part 6:

How often during the past 4 weeks	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A little of the Time	None of the Time
a Did you feel weighed down by your health problems?	☐1	☐2	☐3	☐4	☐5	☐6
b Were you discouraged by your health problems?	☐1	☐2	☐3	☐4	☐5	☐6
c Did you feel despair over your health problems?	☐1	☐2	☐3	☐4	☐5	☐6
d Were you afraid because of your health?	☐1	☐2	☐3	☐4	☐5	☐6

Part 7: *other information*

1 How much is your monthly income (RMB)?

☐1 No income ☐2 Less than 500 yuan ☐3 500 to 1000 yuan ☐4 1000 to 2000 yuan

☐5 2000 to 5000 yuan ☐6 5000 to 10000 yuan ☐7 more than 10000 yuan

2. Do you always receive financial support from your family and friends ? ☐1 Yes ☐2 No

3 What's the route through which you contracted HIV?

☐1 Homosexual behavior ☐2 Blood transfusion/ using blood products ☐3 Blood selling ☐4 Heterosexual behavior ☐5 Intravenous Drug Use ☐6 Don't know

4 What's your CD4 T-cell account in your latest CD4 test? ☐1 _____ ■Time _____
☐2 Never tested ☐3 don't know

5. Have you disclosed your HIV infection to anybody else besides the doctor (s)

☐1 No answer question 7 ☐2 Yes answer question 6

6. You've told your HIV infection to

☐1 Parents ☐2 Siblings ☐3 Kids ☐4 Spouses/boy(girl friends) ☐5 Friends ☐6 Others

7. You are living with the following person(s) currently:

☐1 Parents ☐2 Siblings ☐3 Spouses/boy(girl friends) ☐4 Friends ☐5 Others ☐6 Self

8 Do you have medical insurance provided by your employer or bought by yourself? ☐1 Yes ☐2 No

Please indicate your opinion to the following items.

9 Most of people discriminate PLWH

☐0 not at all true ☐1 hardly true ☐2 moderately true ☐3 exactly true

10. Family members of PLWH are looked down upon by relatives and neighbors

☐0 not at all true ☐1 hardly true ☐2 moderately true ☐3 exactly true

11. Family members are unwilling to live with PLWH

☐0 not at all true ☐1 hardly true ☐2 moderately true ☐3 exactly true

12 Friends are reluctant to be affiliated with a HIV infected person

☐0 not at all true ☐1 hardly true ☐2 moderately true ☐3 exactly true

13. A HIV/AIDS person would be fired if the employer finds his HIV infection status

☐0 not at all true ☐1 hardly true ☐2 moderately true ☐3 exactly true

14. Health care workers might refuse to provide services for you or provide services not as good as others

☐0 not at all true ☐1 hardly true ☐2 moderately true ☐3 exactly true

15. Disease stage of the study participants (completed by interviewers): ☐1 Asymptomatic ☐2 Symptomatic ☐3AIDS

Part 8 (administered by a separate printed sheet provided by "The Psychological Corporation" of Taiwan):

The following questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the <u>one statement</u> in each group that best describes the way you have been feeling during the <u>past two weeks, including today</u>.

1. ☐0 I do not feel sad ☐1 I feel sad much of the time ☐2 I'm sad all the time ☐3 I'm so sad or unhappy that I can't stand it

2. ☐0 I'm not discouraged about my future ☐1 I feel more discouraged about my future than I used to be ☐2 I do not expect things to work out for me ☐3 I feel my future is hopeless and will only get worse

3. ☐0 I do not feel like a failure ☐1 I have failed more than I should have ☐2 As I look back, I see a lot

of failures ☐3 I feel I am a total failure as a person

4. ☐0 I get as much pleasure as I ever did from the things I enjoy ☐1 I don't enjoy things as much as I used to ☐2 I get very little pleasure from the things I used to enjoy ☐3 I can't get any pleasure from the things I used to enjoy

5 ☐0 I don't feel particularly guilty ☐1 I feel guilty over many things I have done or should have done ☐2 I feel quite guilty most of the time ☐3 I feel guilty all of the time

6. ☐0 I don't feel I am being punished ☐1 I feel I may be punished ☐2 I expect to be punished ☐3 I feel I am being punished

7. ☐0 I feel the same about myself as ever ☐1 I have lost confidence in myself ☐2 I am disappointed in myself ☐3 I dislike myself

8. ☐0 I don't criticize or blame myself more than usual ☐1 I am more critical of myself than I used to be ☐2 I criticize myself for all of my faults ☐3 I blame myself for everything bad that happens.

9. ☐0 I don't have any thoughts of killing myself ☐1 I have thoughts of killing myself, but I would not carry them out ☐2 I would like to kill myself ☐3 I would like to kill myself if I had the chance

10. ☐0 I don't cry anymore than I used to ☐1 I cry more than I used to ☐2 I cry over every little thing ☐3 I feel like crying, but I can't

11. ☐0 I am no more restless or wound up than usual ☐1 I feel more restless or wound up than usual ☐2 I am so restless or agitated that it's hard to stay still ☐3 I am so restless or agitated that I have to keep moving or doing something

12. ☐0 I have not lost interest in other people or activities ☐1 I am less interested in other people or things than before ☐2 I have lost most of my interest in other people or things ☐3 It's hard to get interested in anything

13. ☐0 I make decisions about as well as ever ☐1 I find it more difficult to make decision than usual ☐2 I have much greater difficulty in making decisions than I used to ☐3 I have trouble making any decision

14. ☐0 I do not feel I am worthless ☐1 I don't consider myself as worthwhile and useful as I used to ☐2 I feel more worthless as compared to other people ☐3 I feel utterly worthless

15 ☐0 I have as much energy as ever ☐1 I have less energy than I used to have ☐2 I don't have enough energy to do very much ☐3 I don't have enough energy to do anything

16 ☐0 I have not experienced any change in my sleeping pattern ☐1 I sleep somewhat more than usual ☐2 I sleep somewhat less than usual ☐3 I sleep a lot more than usual ☐4 I sleep a lot less than usual ☐5 I sleep most of the day ☐6 I wake up 1-2 hours early and can't get back to sleep

17 ☐0 I am no more irritable than usual ☐1 I am more irritable than usual ☐2 I am much more irritable than usual ☐3 I am irritable all the time

18 ☐0 I have not experienced any change in my appetite ☐1 My appetite is somewhat less than usual ☐2 My appetite is somewhat greater than usual ☐3 My appetite is much less than before

☐4 My appetite is much greater than usual ☐5 I have no appetite at all ☐6 I carve food all the time

19 ☐0 I can concentrate as well as ever ☐1 I can't concentrate as well as usual ☐2 It's hard to keep my mind on anything for very long ☐3 I find I can't concentrate on anything

20 ☐0 I am no more tired or fatigued than usual ☐1 I get more tired or fatigued more easily than usual ☐2 I am too tired or fatigued to do a lot of the things I used to do ☐3 I am too tired or fatigued to do most of the things I used to do

21 ☐0 I have not noticed any recent change in my interest in sex ☐1 I am less interested in sex than I used to be ☐2 I am much less interested in sex now ☐3 I have lost interest in sex completely

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