博士論文

Perceived social support, coping, and stigma on the quality of life of people living with HIV in Nepal: A moderated mediation analysis

（ネパールのHIV陽性者の生活の質にソーシャルサポート, コーピング, スティグマが及ぼす影響: 調整媒介分析）

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Acronyms and abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
BH	Bir Hospital
CD4	Cluster of Differentiation 4
CFA	Confirmatory Factor Analysis
CFI	Comparative Fit Index
HIV	Human Immunodeficiency Virus
MDGs	Millennium Development Goals
MSPSS-N	Nepali Version of Multidimensional Scale of Perceived Social Support
PLHIV	People Living with HIV
QOL	Quality of Life
RNA	Ribonucleic Acid
RMSEA	Root-Mean-Square Error of Approximation
SGS	Second Generation Surveillance system
SEM	Structural Equation Modeling
SES	Socioeconomic Status
SRMR	Standardised Root Mean squared Residual
STIDH	Sukraraj Tropical and Infectious Disease Hospital
TLI	Tucker Lewis Index
TUTH	Tribhuvan University Teaching Hospital
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

ABSTRACT

Background

Perceived social support has been linked to the quality of life (QOL) among people living with HIV (PLHIV). However, little is known about the ways through which perceived social support influences QOL. In particular, the mediating effect of a coping strategy between perceived social support and QOL among PLHIV has not yet been explored. Furthermore, no studies have examined the moderating effect of internalised stigma on the mediating role of coping strategy between perceived social support and QOL. The present study aims to explore whether coping strategy mediates the relationship between perceived social support and QOL as a function of the underlying level of internalised stigma.

Methods

A quantitative study was conducted on 599 PLHIV living in Kathmandu Valley, Nepal. The multidimensional scale of perceived social support, WHOQOL-BREF, Brief-COPE, and AIDS-related stigma scales were used to measure perceived social support, QOL, coping strategy, and internalised stigma, respectively. The data was analysed using structural equation modelling.

Results

The present study showed that the relationship between perceived social support and QOL was significantly and partially mediated by problem-focused coping strategy. Internalised stigma significantly moderated the mediating effect of coping strategies on the association between perceived social support and QOL. For the high internalised stigma group, perceived social support had indirect effect on QOL ($\beta = 1.48$; 61.0 % of total effects) through the mediating effect of coping strategy, especially problem-focused. For the low internalised stigma group, problem-focused coping strategy did not significantly affect QOL, and most perceived social support effects were direct ($\beta = 1.24$; 99.2% of total effects).

Conclusions

The mediating role of problem-focused coping strategy was detected between perceived social support and QOL among PLHIV with internalised stigma moderating this mediating effect. Better coping strategies should be developed among PLHIV reporting high stigma to improve their QOL. The attitudes of PLHIV with high stigma towards the use of problem-focused coping provide important clues for future interventions and education.

Keywords: Perceived social support; Quality of life; Problem-focused coping; Internalised stigma; HIV; Nepal

CHAPTER ONE

INTRODUCTION

1.1 Background

1.1.1 The global HIV epidemic

Human Immunodeficiency Virus (HIV) infection and / or Acquired Immunodeficiency Syndrome (AIDS) continue to be a major global public health issue. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), 36.7 million people were estimated to be living with HIV in the world by the end of 2016, up from 33.2 million in 2010 [1]. The global prevalence of HIV among people aged 15-49 years has levelled off since 2001 and was 0.8% in 2016 [1]. However, since 2010, the annual figure for new HIV infections among adults had actually declined by an estimated 11% in 2016 [1]. Worldwide, there were around 1.8 million new HIV infections and 1.0 million AIDS-related deaths by 2016 [2]. Although HIV cases have been reported in all regions of the world, the vast majority of people living with HIV (PLHIV) are located in low- and middle-income countries, with an estimated 25.5 million living in sub-Sarahan Africa in 2016 [2]. In Asia and the Pacific, 5.1 million people were estimated to be living with HIV in 2016 [2]. The annual figure for new HIV infections has declined by 13% in Asia and the Pacific since 2010; however, trends vary from country to country.

Access to antiretroviral therapy (ART) has significantly improved life expectancy among PLHIV [3]. ART is a powerful intervention that prevents disease progression, opportunistic infections, mortality, and HIV transmission [4-8]. UNAIDS reported that 19.5 million PLHIV were accessing ART globally, increasing from 17.1 million in 2015 and 7.5 million in 2010 [9]. Despite such progress in ART expansion, only 54% (40-65%) of adults aged 15 years and older living with HIV had access to ART in 2016 [9]. Increased access to

ART averted an estimated 7.6 million AIDS-related deaths globally from 1995 to 2013 [10], with a 26% reduction in AIDS-related deaths from 2010 to 2015 [11]. Since ART is widely available, HIV illness has become a manageable chronic disease. However, PLHIV continue to face a range of challenges such as stigma and discrimination, social hardship, and mental health issues, which affect their overall well-being and QOL.

1.1.2 HIV epidemic in Nepal

The first case of HIV in Nepal was reported in 1988. Thereafter, there has been an increasing trend in PLHIV, especially since 1996 [12]. However, HIV prevalence among adults (15-49) has not changed much over the last five years, remaining within the range of 0.2-0.3% [13]. As of July 2016, the reported cases of PLHIV totalled 28,865 (17,949 male and 10,824 female) across the country [14], decreasing from 40,723 in 2013 and 39,249 in 2014 [13]. It has been estimated that 3,362 people died of AIDS-related illness in Nepal during 2013. However, AIDS related mortality in Nepal dropped to 2,576 in 2014 [13]. HIV prevalence in the country varies with age and sex, with a higher prevalence noted among males of working age (15-49 years). The higher prevalence in males may be due to the dominant volume of temporary labour male migration in the country and poor investigation of HIV among females [15]. Data showed that 88% of PLHIV were between the working age of 15-49 years, the majority of whom were males [16]. These figures indicate that HIV is a big burden for Nepal due to its impact on thousands of working age adults. In Nepal, as in most Asian countries, the epidemic of HIV is centred on particular high-risk groups, such as seasonal labour migrants and their spouses, sex workers and their partners, males having sex with males, transgender people, and injecting drug users [17, 18].

ART is recommended for all HIV-infected individuals to prevent HIV-associated morbidity and mortality. In Nepal, the government started to provide free-of-cost ART at a public hospital in 2003, and national guidelines for ART were developed in 2004 [19]. Since the introduction of free ART services in Nepal, there have been improvements in service delivery and utilisation. Besides the free ART service, PLHIV are offered a care package including clinical follow-up monitoring, tuberculosis screening and isoniazid preventive therapy, as well as community and home-based care programmes, which include the primary care of patients by trained health workers at home and community setting. The aim of this care programme is to reduce any stigmatisation and discrimination, provide positive living, support for sanitation and hygiene, as well as continuity and adherence to ART. In addition, health workers provide medicinal, nutritional, psychological, and legal support. Furthermore, community care centres near to ART sites provides financial support to newly enrolled patients [20, 21]. Nepal has seen a gradual increase in ART coverage for people eligible for treatment (having a CD4 count < 350 cells/mm^3) [13]. As of July 2016, 12,446 PLHIV were on ART, accounting for 43.2% of ART coverage [14]. Due to an expected increase in the number of people on ART, the number of AIDS-related deaths in Nepal is projected to decline to 1,266 in 2020 [13].

In response to the HIV epidemic, the Nepalese government has instituted various policies and programmes to bring the epidemic to a halt and start to reverse it. The National Policy on HIV/AIDS prevention and control was developed for the first time in 1995 and is under implementation. One of the key HIV documented responses in Nepal is the national HIV/AIDS strategy 2011-2016, which was adopted to strengthen the second generation surveillance (SGS) system [20]. The first national HIV/AIDS strategy (2002-2006) was developed in 2002 and implemented through the operation plan (2003-2007) and subsequent annual plans [22]. The recent strategy plan is intended to:

- address all continuum of care dimensions from prevention to treatment, care, and support

- provide effective coverage of quality interventions based on the epidemic situation and geographical prioritisation
- strengthen health and community systems
- integrate HIV services into the public health system in a balanced way to meet the specific needs of the target population
- provide a framework for strong accountability with robust HIV surveillance and programme monitoring and emulation

The various health and social services aspects of the policies and programmes are designed to prolong life and ameliorate the impact of HIV and AIDS. The benefits gained from the policies and programmes can already been seen in the improved survival rates of PLHIV in Nepal. In addition, the infection rate among high-risk groups has been reduced, meeting the target set by Millennium Development Goals (MDGs).

1.1.3 Social support

1.1.3.1 Conceptualisation of social support

Social support is a complex and multifaceted concept, and there is a lack of consistency in research papers over the issue [23]. Social support has been conceptualised using two main measures: structural measure and functional. Structural measures are often referred as qualitative, reflecting social networks in relation to the number and sources of social support and frequency of contact. Functional measures refer to the resources provided by people within an individual's social network. Researchers have suggested that social support has a positive and health-promoting effects. Shumaker and Brownell (1984) defined social support as an exchange of resources between at least two individuals perceived by the provider or recipient to be intended for enhancing the well-being of the recipient [24]. It has also been defined as a process for promoting health and well-being [25]. Some researchers have considered social support as social interactions that are perceived by the recipient to facilitate coping and assist in responding to stress [26]. Others have viewed social support as a multiple construct, operating both as a means of meeting basic needs and buffering stress [27, 28].

1.1.3.2 Dimensions of social support: perceived and received social support

Social support can also be perceived and received. Perceived social support is an individual's perception of his or her social network and availability of social provisions, regardless of whether support is actually available. Whereas, received social support refers to the reported receipt of support resources during a specific time period. Previous studies consistently suggest that perceived social support appears to be more closely associated with health status than received social support [29, 30]. Norris and Kaniasty (1996) suggested that the effect of received social support on health is mediated by perceived social support [32]. It is expected that the magnitude of the effect of perceived social support on health may be greater than that of received social support [32].

Although perceived and received social support both usually rely on the self-reporting of respondents, perceived social support is the most frequently assessed construct in the literature [33, 34]. It is important to note that the two dimensions of social support do not appear to be interchangeable [35]. Perceived support and received support are not highly correlated [36]. The beneficial effects of perceived support may be obtained in the absence of any actual support being provided [37].

1.1.3.3 Sources of social support

Sources of social support play an important role in the lives of PLHIV. Two sources of social support have been identified and proved functional among PLHIV. The first relates to family and friends, and the second to community-based support, government agencies, and the health care industry [38]. Some PLHIV are able to identify special persons not necessarily related to them, considered as "significant others", such as parent, teachers, colleagues, pastors (spiritual leaders), and close friends [38, 39]. Perceived support from friends has been associated with positive self-image about being HIV positive [40]. Family members, particularly spouses or partners, have been identified as the most important source of social support, and account for most of the association between social support and health [41, 42]. This may be due to the fact that family is the main source of care and their support cannot be compensated by other sources. In addition, siblings and special persons can be other effective sources of social support for PLHIV [43].

Previous studies conducted in Africa demonstrate that family members have the central role in social support for PLHIV. A study conducted in Mozambique by Cummings et al. (2014) suggests that a family-cented approach is necessary and any prevention programme should emphasise training for family members [44]. Another study conducted in Zambia indicates that family members who are not appropriately informed and prepared to serve as health advocates can become barriers to the well-being of PLHIV [45].

1.1.3.4 Determinants of social support

Interaction between individual factors and the social environment influences the perception of social support. Socio-demographic factors such as age, gender, socioeconomic status (SES), marital status, and family size may be related to the probability of receiving social support. Previous studies report receipt of less social support among unmarried people compared to married [46], older people compared to young people [47], women compared to men in some studies [48], men compared to women in others [46], and people with lower SES compared to those with higher [47].

1.1.3.5 Impact of social support

Besides ART, various psychosocial factors are considered to be essential in the treatment of HIV/AIDS [49, 50]. Among such factors, social support is critical for psychological adjustment among many PLHIV [51]. Effects of social support have been extensively studied among PLHIV [52, 53]. The dominant theory in understanding health is the stress-outcome model [54]. In addition to explaining outcome as a function of stress, the model also suggests mediator of the relationship; particularly, personal factors, coping and social support [55−57]. Following the stress-outcome model, several studies have examined the relationship between social support, and outcome and coping and outcome.

Social support from family and friends may help PLHIV cope better with HIV disease and improve ART adherence and effectiveness [58, 59]. Social support is a means of buffering the negative health outcomes that result from stressors and can promote a sense of emotional well-being [28]. This is important for PLHIV since social support is directly related to the progression towards AIDS which in turn affects QOL. Leserman et al. (1999) conducted a longitudinal study and assessed the effect of social support on disease progression among asymptomatic PLHIV [60]. They found that faster progression towards AIDS was significantly associated with low social support.

1.1.4 Coping

1.1.4.1 Conceptualisation of coping

Coping refers to an individual's attempt to manage a stressful event and minimise its negative effect. According to Lazarus and Folkman (1984), coping is defined as "constantly changing cognitive and bahavioural efforts to manage stressful demands that are appraised as taxing or exceeding the resources of the person [61]". Coping may mediate stress demand on the outcome of the experience. Lazarus and Folkman (1984) viewed coping as two dimensional: problem-focused and emotion-focused. Problem-focused coping is a changeable adaptation for stressors, whereas emotion-focused coping is when a person perceives the stressful situation to be unchangeable or when all problem-focused coping attempts have been exhausted. These two dimensions are considered as two distinct constructs, but not two opposite poles in a single continuum [62].

1.1.4.2 Types of coping

In research, many coping scales are utilised under various stressful situations and among different populations. Moskowitz et al. (2009) conducted a meta-analysis to describe which types of coping are related to psychological and physical well-being among PLHIV [63]. They identified sixty-three articles with a total sample of 15,490 participants. The sample selected for studies had to consist of people diagnosed as HIV-positive aged 18 years and older from the United States, Canada, Europe, Australia, or New Zealand. Eighteen types of coping were analysed, with outcomes categorised into positive effects, negative effects, health behaviours, and physical health. Positive effects included QOL, life satisfaction, and a positive mood. Depression, mood disturbance, emotional distress, anxiety, anger, perceived stress, hopelessness, and traumatisation were grouped into negative effects. Physical health included mortality, disease severity and somatic symptoms, viral load, physical health, CD4 count, survival time, and cortisone level. The authors' analysis demonstrated that direct action, positive reappraisal, and spirituality were associated with greater positive effects; alcohol/drug disengagement, bahavioural disengagement, avoidance, and social isolation were associated with lower positive effect. Acceptance, direct action, fighting spirit, planning, positive reappraisal, and seeking social support were significantly associated with less negative effects. Self-blame, alcohol/drug disengagement, bahavioural disengagement, avoidance, hopelessness, self-controlling, and venting were associated with greater negative effects. Direct action and positive reappraisal were associated with better physical health, while bahavioural disengagement, distancing, and venting were associated with poorer physical health.

The implementation of coping strategies depends both on the individual's cognitive appraisal of the situation and emotional status. Some studies distinguish problem-focused and emotion-focused strategies [61], whereas others categorise active and avoidant coping strategies [64]. There exists a standardised instrument to identify the nature of coping strategies. The most commonly used questionnaire in the literature is the Coping Orientation to Problems Experienced (COPE) inventory and its abbreviated version, the Brief COPE [65].

The 28-item Brief COPE (consisting of 14 subscales), developed by Carver (1997) [65], is the selected measure for coping strategies in the present study since it has been used extensively to examine the relationship between various coping strategies and psychological outcomes in PLHIV [66, 67]. Although the Brief COPE constructs were not subjected to factor validation by its developer, Carver (1997) suggests that researchers can selectively use the Brief COPE scales that are of greatest interest to the research questions without compromising the integrity of the measure [65]. Several studies report that coping strategies can be categorised into problem-focused coping and emotion-focused coping [68, 69, 70]. Specific examples of problem-focused coping include: "I have been taking action to make the situation better” and “I have been concentrating my efforts on doing something about the situation I am in”. Specific examples of emotion-focused coping include: “I have been saying to myself ‘this is not real’” and “I have been refusing to believe it has happened” [65].

Carver et al. (1989) criticised some of the coping items as being conceptually ambigouous [68]. They mention that the broad categories of problem and emotion-focused coping might obscure coping responses, which may be distinct from each other. They may have different implications for coping effectiveness. For instance, taking direct action and seeking support are both considered to be problem-focused coping; the former is likely to be used in situations perceived as manageable by oneself, while the latter is more likely to be needed when the situation is perceived as beyond one’s control. Likewise, denial is considered to be emotion-focused coping, but it may have different psychological functions.

1.1.4.3 Coping as a mediator

Mediation can be defined as the mechanism by which a predictor causes change in the outcome variable [71]. The concept of mediation indicates that the effect of a predictor variable is at least partially transmitted through a mediator to the outcome variable, meaning that an independent variable changes the mediator, which in turn changes the dependent variable. Some studies have identified coping as a mediator between stress and health outcomes among PLHIV [72−73]. Maladaptive coping strategy has been found to mediate the relationship between HIV-related stigma and depression among HIV-infected adult migrants living in Canada [74]. Sanjuan et al. (2013) reported that the negative relationship between stigma perception and subjective and physiological well-being is mediated by the use of avoidant coping strategies among PLHIV living in Spain [73]. However, very few studies have been conducted on the mediating role of coping strategy between perceived social support and QOL. Perceived social support has been reported to influence the choice of coping strategies in predicting emotional well-being among breast cancer patients [75]. However, those findings for cancer patients may not be applicable to PLHIV because coping strategy selection may vary among people based on context and individual preference when managing stress.

1.1.5 HIV-related stigma

1.1.5.1 Conceptualisation of stigma

HIV-related stigma is a complex multidimensional issue, varying from individual to individual. Conceptualisation of stigma has evolved to include a complex social process at community level as well as a cognitive phenomenon at individual level [76]. The attributes of stigmatised individuals can convey a devalued social identity within a particular context [77]. Factors such as social, economic, and political power enable a community to identify undesirable attributes. The social context of PLHIV such as poverty and race can reinforce stigmatisation [78]. Stigma acts on individual well-being through increasing vulnerability to harmful and discriminatory behaviour [79]. Stigma can be divided from the perspective of a non-affected person into perceived and enacted stigma, and from the perspective of an affected person into internalised, perceived, and experienced stigma [80].

1.1.5.2 HIV-related stigma and perceived social support

PLHIV may need to disclose their HIV status in order to receive social support [81], and stigma is considered one of the most common barriers to disclosure. Therefore, stigma may be a factor in determining lack of support among PLHIV. Previous studies report that PLHIV with high internalised stigma are less likely to disclose their HIV status to their friends and family or solicit support from them [82, 83]. Conversely, an inverse relationship has been observed between social support and internalised stigma, indicating that PLHIV with internalised stigma are less able to have supportive relationships with friends and family. Colbert et al. (2010) reported that PLHIV who choose to disclose their status, seek help from others, and have a good social support system are able to deal with stigma-associated problems better than those without such support [84].

1.1.5.3 HIV-related stigma and coping

Stigma can affect PLHIV in many ways, including their individual contact with others and negotiating environment in which they live. The way in which individuals disclose their HIV status and how they cope with it is influenced by cultural and community beliefs and values regarding causes of illness, patterns of response to illness, social and economic context, and social norms [85]. The lives of PLHIV have been described as a constant struggle to cope with or manage stigma [86]. PLHIV who do not cope well with HIV-related stigma may have poor QOL. PLHIV with better coping strategies may achieve a higher QOL and healthier life, which may change their perception of the disease and way of life. Coetzee and Spangenberg (2003) report that problem-focused, active coping styles are superior to emotion-focused, passive coping styles in reducing psychological distress [87].

1.1.5.4 HIV-related stigma as a moderator

A moderator is defined as a variable that can alter the direction or strength of the relationship between a predictor and an outcome. The effect of perceived social support on the psychological domain of QOL is positive and stronger for PLHIV with higher perceived stigma than for those with lower [88]. Furthermore, perceived stigma is related to higher levels of maladaptive coping strategy [89]. Therefore, the role of coping strategy should be taken into account when studying the moderating effect of stigma on the relationship between social support and QOL.

1.1.6 Quality of life

1.1.6.1 Defining quality of life

The World Health Organisation (WHO) defines QOL as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, standards, expectations and concerns [90]. This definition emphasises the importance of an overall subjective feeling of well-being pertaining to aspects of morale, happiness and satisfaction. QOL, therefore, relates to the adequacy of material circumstances and how satisfied an individual is with them.

QOL is multifaceted, incorporating physical, material, psychological, social, and spiritual well-being [91, 92]. It is said to include overall feelings of well-being that are closely related to moral happiness and satisfaction [93]. By people reflecting on their current life circumstances and the sense of well-being and satisfaction they experience, the assessment of QOL aims to provide a comprehensive evaluation of the individual's well-being, including an assessment of their functioning role, community integration, and personal adjustment [94]. This implies that HIV and AIDS do not only affect the physical well-being of PLHIV, but also the overall QOL and perceptions of various aspects of their lives and daily living.

1.1.6.2 ART and QOL

Availability of antiretroviral (ARV) drugs is increasing among PLHIV due to local, national, and international efforts. The use of ART has become the basis of the clinical intervention to prevent transmission and delay HIV progression among PLHIV. Global efforts towards control of HIV have mainly been aimed at reducing new infections and AIDS-related deaths partly through improved access to ART. ART can improve the QOL among PLHIV [95]. QOL has been used as an important outcome indicator for healthcare decision-making and evaluation of intervention effects [96].

In Nepal, the standard ART service uses at least three ARV drugs for maximum suppression of the HIV and to stop the disease progression [97]. There are several ART regimes available in Nepal with acceptable antiretroviral potency. In general, zidovudine (ZDV)/lamivudine (3TC)/neverapine (NVP), ZDV/3TC/efavirenz (EFV), tenofovir disoproxil fumarate (TDF)/3TC/NVP, TDF/3TC/EFV, stavudine (d4T)/3TC/EFV, and d4T/3TC/NVP are used as first-line regimens, while TDF/3TC/lopinavir boosted with ritonavir and didanosine/abacavir/lopinavir boosted with ritonavir are commonly used as the second-line regimens [98]. An ART adherent person is one who does not miss more than three doses of ART treatment in a given time period [97]. Previous studies in Nepal report 85.5% ART adherence among participants of 10 ART clinics located in different districts [99], 79% ART adherence at the Tribhuvan University Teaching Hospital (TUTH) in Kathmandu [100], and 84% ART adherence in the far western region [101].

ART improves the QOL among PLHIV when there is good adherence [102−105]. Both QOL and adherence have been reported to be associated with HIV RNA levels, the HIV disease stage, and symptoms. QOL and ART adherence show an inverse relationship with HIV RNA levels: lower adherence rates predict higher HIV RNA levels, and this virological failure has been associated with lower QOL [103, 106, 107]. Mannheimer et al. (2005) state that subjects reporting 100% ART adherence achieved significantly higher QOL at 12 months of follow up compared to those with poor ART adherence [108]. Improved QOL due to ART, in turn, is positively associated with ART adherence [109]. Although adherence to ART is a critical factor in prolonging the lives of PLHIV, other factors related to the social, economic, and psychological conditions of PLHIV need to be identified and managed in order to optimise their QOL.

1.1.6.3 Factors associated with quality of life

QOL can be affected by socio-demographic, clinical, psychological, and behavioural factors [110]. Employment, immunological status, presence of symptoms, depression, social support, and adherence to ART have been most frequently and consistently reported to be associated with QOL among PLHIV [110]. Campsmith et al. (2003) report that poor QOL among PLHIV is associated with age (older), sex (female), ethnicity (black or Hispanic), intravenous drug use, low CD4 count, education (less than 12 years), lack of health insurance, and low income [111].

Biological factors, including the disease state, HIV symptoms, treatments, and co-morbidity are associated with QOL [112−114]. The psychosocial stress that accompanies the illness affects how well a person functions and interacts with others. Physiological factors, symptom status, functional status, and general health perceptions have been found to significantly contribute to the QOL of ethnic minorities [115]. Stress such as HIV-related stigma, low self-esteem, shame, anxiety, depression, lower social support, substance use, poor nutrition, and medication non-adherence are also known to be associated with poor QOL. Previous studies report that factors such as anxiety, depressive symptoms, substance use, nutritional status, hope, and perceived social support are associated with QOL among PLHIV in Nepal [38, 116, 117].

1.1.6.4 Relationship between social support and quality of life

According to the stress-outcome model, social support can influence one’s health directly. That is, higher social support is directly related to greater QOL, while a lack of social support is directly associated with lower QOL [118]. In the mediation model, social support is assumed to have an indirect effect on health. Higher social support has been linked to the use of positive coping strategies [119, 120], which in turn is associated with better

QOL [121−123]. Therefore, perceived social support also contributes to better QOL through its indirect effect on coping strategies.

In Nepal, despite the increasing number of PLHIV on ART, limited studies have focused on their psychosocial well-being, particularly, in the context of QOL. Depressive symptoms are negatively associated with QOL among PLHIV [116]. Furthermore, perceived family support is negatively associated with internalised AIDS stigma among PLHIV [124].

1.2 Rationale of the study

The United Nations declared HIV to be an urgent international issue and stated that "the HIV response faces a moment of truth" [125]. There is an urgent need to substantially reduce the number of PLHIV. The MDGs have set out a plan to achieve zero new HIV infections, zero discrimination, and zero deaths in several countries including Nepal [126, 127]. Overcoming the stigma attached to HIV identification has been one of the major problems since the beginning of HIV and AIDS epidemic. This specific stressor, as well as other stress from being part of a socially devalued group, can have multiple implications for the health and well-being of PLHIV. For example, PLHIV who belong to a stigmatised group can experience additional life stress and be at greater risk of health problems [128].

Stigma has been described as a factor in determining the lack of social support among PLHIV [83]. In addition, stigma may affect the coping strategy of PLHIV. The PLHIV with better coping strategies may achieve a higher QOL and healthier life, potentially changing their perception of the disease and way of life [87]. Social support helps PLHIV adapt to their condition and can mitigate the impact of prejudice and discriminatory situations. However, the way in which individuals cope with their infection is influenced by several community and cultural factors as well as social norms [85].

The study of psychosocial factors (stigma, social support, and coping) among PLHIV can contribute greatly to the achievement of the United Nations' MDGs for halting and reversing the spread of HIV and AIDS. Since psychosocial factors are related to the QOL among PLHIV, a deep understanding of this relationship of these factors is now of utmost importance. There may be many other possible variables that can work with perceived social support to increase QOL. Of particular interest is the role that coping strategy plays in the relationship between perceived social support and QOL. The use of problem-solving coping is associated with improved QOL, while the use of emotion-focused coping has been associated with poorer well-being in PLHIV [121−123].

Despite the growing interest in coping strategy, limited research has focused on its mediating role. To date, only one study focuses on the mediating role of coping strategy between perceived social support and QOL. According to that study, perceived social support influences the choice of coping strategy in predicting emotional well-being among breast cancer patients [75]. However, such findings may not be applicable to PLHIV because coping strategy selection may vary among people based on context and individual preference when managing stress. In addition, the effect of perceived social support on the psychological domain of QOL is positive and stronger for PLHIV who have higher perceived stigma than for those with lower [88]. Therefore, the role of coping strategy should be taken into account when studying the moderating effect of stigma on the relationship between social support and QOL.

So far, no studies have examined the mediating effect of coping strategy between perceived social support and QOL, and how the mediating effect varies with the level of internalised stigma among PLHIV. Findings of such study would be helpful in designing effective intervention strategies for enhancing the QOL of PLHIV.

In the Nepalese context, despite the increasing number of PLHIV on ART, there is a dearth of research on psychosocial factors and QOL among PLHIV, which is now causing growing concern. One study reports that depressive symptoms are negatively associated with QOL among PLHIV [116]. Another reveals that perceived family support is negatively associated with internalised AIDS stigma among PLHIV [124]. Accordingly, this current study focuses on the relationship between psychosocial factors and QOL among PLHIV.

1.3 Theoretical framework

1.3.1 Transactional model of stress and coping

The conceptual model of this study is built on a transactional model of stress and coping [61, 129]. According to Lazarus and Folkman (1984), "psychological stress is a particular relationship between the person and environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" [61]. This relationship passes through two important stages: cognitive appraisal and coping. Cognitive appraisal is defined as the "process of categorising an encounter, and its various facets, with respect to its significance of well-being." Before actually coping with a situation, cognitive appraisal involves two mechanisms, namely primary and secondary appraisal. Primary appraisal is an assessment of what is at risk. In the primary appraisal stage, people evaluate whether an individual is in trouble or benefiting, now or in the future, and in what way. If they respond in the affirmative, the situation can be categorised as being a threat or challenge. Threat and challenge appraisals can refer to past or anticipated events. Secondary appraisal is related to the assessment of coping resources with people attempting to answer the question: "Can I cope with this situation?" to indicate their ability to cope with the situation when they have the necessary resources to do so. Resources can be physical (e.g. health, energy), social (e.g. social support), psychological (e.g. self-esteem, belief), or material (e.g. financial tools).

Coping refers to “cognitive and behavioural efforts to master, reduce, or tolerate the internal and/or external demands created by the stressful transaction” [61]. Some studies attempt to achieve significant and meaningful categorisation of coping strategies due to the diverse of responses to stress. A large body of studies reports that coping behaviour can be categorized into problem-focused and emotion-focused [130]. Both forms of coping are used in most stressful conditions; however, they are dependent on the way one appraises the situation (i.e., as a threat and/or challenge) and the antecedents of the model. Folkman and Lazarus (1980) report that people tend to use more problem-focused strategies when the situation is appraised as changeable, and more emotion-focused strategies when the situation is appraised as being unchangeable or less changeable [62].

Berjot and Gillet (2011) propose a model for coping with stigmatisation based on the transactional model of stress and coping by Lazarus and Folkman (1984) [129]. This model basically applies to the less tangible threats associated with social identity. The social identity threat is a situationally triggered concern that can put people at risk of being stigmatised [131]. In this model, all the different phases of the transactional model (antecedents, appraisal, and coping) are included, but with some refinements made for adapting to specific stigmatised situations.

1.3.2 Concepts

The transactional model of stress classifies antecedents into personal and situational factors [61]. Social support is considered to be a situational factor. The situational factor involves the environment in which the person lives and could modify how he or she appraises and copes with it. Social support from family members and friends can help in identity-threat situations [129]. Social support is an important resource for people who have to deal with stigmatised conditions in that they can contribute information, help, share emotions and experiences about their situations, or to enact specific strategies [132, 133].

The person determines the coping strategies to be used through a combination of primary and secondary appraisal [134]. The transactional model of stress and coping considers coping as a process. Coping can mediate or impact the relationship between stress and health outcomes/well-being [72−74]. The HIV-positive diagnosis is a stressful condition and can cause great feelings of insecurity. In this situation, social support can promote more effective coping strategies. The dominant theoretical perspective in social support research draws from stress and coping theory [135]. Stress occurs when people interpret situations negatively, leading to health problems, in part, when people do not employ an adequate coping response [61]. Theoretically, a particular type of social support can only enhance appraisal and coping to the extent that it matches the demands of the stressor [136, 137]. Perceived social support and enacted support play somewhat different roles in the stress and coping model. Enacted social support is considered to have the most direct influence on appraisal and coping. An individual's perception of support can reflect his/her history concerning the receipt of effective enacted support, and this perception can directly reduce the negative appraisal of stressors. Indeed, adequate perceived social support together with effective coping strategies are important resources for an individual in dealing with difficult situations, such as HIV disease.

Berjot and Gillet (2011) suggest that the strategies highlighted by the transactional model of stress for coping with regular situations are not the same as the stigmatisation or other situations of identity threat [129]. The use of effective coping strategies can be influenced by different factors, such as subjective appraisal of the situation and the presence of certain personality characteristics, all of which can condition the evaluation of a situation as being more or less stressful.

The outcome is the person’s adaptation to a stressful event. Cognitive appraisal of the stressful event, as well as available resources, can influence the actual coping effort of an individual, leading to adaptation of the stressful event. According to Lazarus and Folkman (1984), adaptation to stressful event can lead to three major outcomes: emotional, functional, and subjective well-being [61]. The WHO definition of QOL seems to be subjective and multidimensional, considering the cultural, social and environmental particularities of each person. One way to conceptualise the subjective nature of QOL is by general well-being [93]. Some theories describe QOL as a synonym for well-being or psychological health [138].

1.3.3 Application of concepts to the study

As discussed earlier and shown in Figure 1.1, social support acts as a stress resistance resource, influencing the outcome (QOL) through its relationship with coping strategies. As a resistance resource, social support influences the use of coping skills such that as social support increases, so does problem-focused coping, although emotion-focused coping decreases. PLHIV can determine the coping strategies they use depending on the availability of social support. Coping strategies mediate the relationship between social support and QOL, i.e., social support can change QOL through coping style. Moreover, PLHIV’s perception of HIV-related stigma is their cognitive appraisal of it as a threat. Therefore, there is a possibility that social support and HIV-related stigma may affect QOL through their interaction.

In the present study, the effective use of a social support system can also be viewed as a coping strategy. Many coping measures include aspects of social support such as seeking emotional support, seeking instrumental support and venting. This grouping partially parallels the conceptual analysis of social support comprising four aspects: instrumental support, emotional support, tangible support, and appraisal support [139]. The definition of seeking instrumental support includes seeking both informational and tangible support [68]. Likewsie, seeking emotional support and venting may be related to acquiring emotional and appraisal support [139]. Social support-seeking may partly overlap with problem-focused coping since the instrumental aspects of social support may benefit efforts to solve a problem or a stressful life situation.

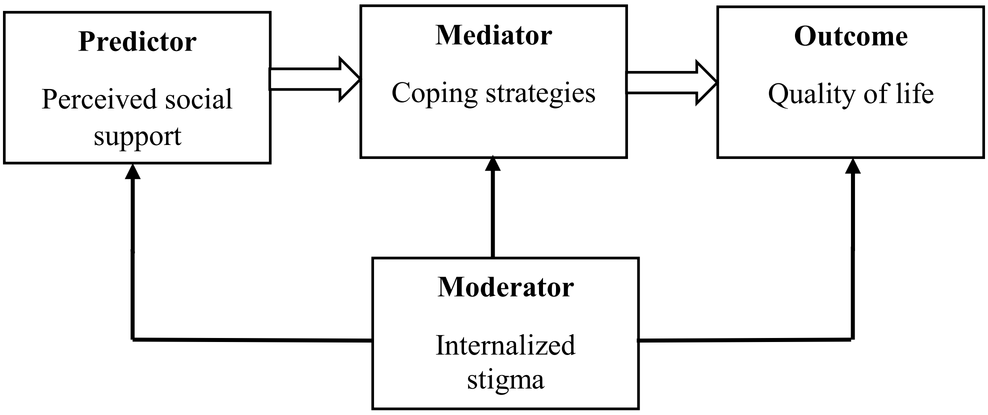

Figure 1.1. Conceptual model of the study

1.4 Research questions and hypotheses

This study examines the relationships between perceived social support, coping strategies, and QOL, and compares the level of internalised stigma in the context of such a relationship. While coping strategies can directly impact on QOL, they can also act as mediating variables between social support and QOL. In accordance with the transactional model of stress and coping [61], the stress process comprises antecedent, mediating, and outcome variables. Social support, as is a causal antecedent to stress adaptation, promotes recovery from critical life events. Coping, a behavioural and cognitive activity aimed at responding to and overcoming adversity to place the person back into an active life, is a mediating process. Outcome variables of the stress process are, for example, psychological well-being and QOL. The level of stigma can be considered as a determining factor in social support. One previous study reports that the effect of perceived social support on QOL may be positive and stronger for PLHIV with higher levels of stigma [88], which in turn is related to higher levels of maladaptive coping strategy [89]. Therefore, this study hypothesises that PLHIV with higher levels of stigma would experience a stronger mediating effect from coping strategies in the relationship between social support and QOL. Specific research questions and related hypotheses (H) are as follows:

Question 1: Do coping strategies mediate the relationship between perceived social support and QOL?

The mediating role of coping has been examined in research on PLHIV for stress and health outcomes [72−74]. For example, the findings by Sanjuan et al. (2013) indicate that the negative relationship between stigma perception and physiological well-being is mediated by the use of avoidant coping strategies among PLHIV [73]. In addition, the mediating role of coping strategy between social support and health outcomes is also examined in other populations. Perceived social support influences the choice of coping strategies in predicting emotional well-being among breast cancer patients [75]. The mediation analysis reveals that coping strategies can play a mediating role between social support and psychological status among stressed people [140]. Thus, the coping strategy is expected to influence the relationship between perceived social support and QOL among PLHIV.

> ***Hypothesis 1A:*** The change in the level of perceived social support is significantly and positively related to the use of problem-focused coping strategy, which, in turn is positively related to QOL.
>
> ***Hypothesis 1B:*** The change in the level of perceived social support is significantly and negatively related to the use of emotion-focused coping strategy, which, in turn is negatively related to QOL.

Question 2: Does internalised stigma moderate the mediating effect of coping strategy between perceived social support and QOL?

Stigmatised people are likely to differ in coping skills because they have different life experiences than non-stigmatised individuals [141]. Sayles et al. (2008) suggest that environments involving stigmatising and unsupportive people often lead to non-disclosure, withdrawal from social networks and social isolation [142]. However, people who seek help from others and have a good social support system are likely to deal with stigma better than those who do not [143]. One possible pathway in which stigma influences coping through social support is by providing opportunities to explore different coping strategies. Perceived stigma is considered to be a moderator on the effect of perceived social support on the psychological domain of QOL [88]. In light of the empirical support for the association between social support and coping with QOL, coupled with studies suggesting that these variables are linked to stigma, this study suggests that internalised stigma may moderate the relationships among perceived social support, coping strategy, and QOL.

> ***Hypothesis 2A****:* The mediating effect of problem-focused coping strategy will be different between low and high internalised stigma groups. The mediating effect will be weaker or absent for low stigma group than high.

> ***Hypothesis 2B****:* The mediating effect of emotion-focused coping strategy will be different between low and high internalised stigma groups. The mediating effect will be weaker or absent for low stigma group than high.

CHAPTER TWO

METHODS

2.1 Study area and population

This study was conducted in the Kathmandu Valley, situated in the northeast central region of Nepal. Nepal is a landlocked country located in South Asia, covering an area of 147,181 square kilometres. Nepal is divided into seven states and 75 districts. The projected total population by 2016 was 28.5 million people with a median age of 24 years [144]. Kathmandu Valley is the urban centre of Nepal and comprises three districts, Kathmandu, Lalitpur, and Bhaktapur (Appendix 1), together covering an area of 899 square kilometres with a projected population of 2.9 million in 2016 [144]. Kathmandu, the capital city of Nepal, accommodated 32.4% of the total urban population of the country in the 2011 census. Among the Kathmandu Valley districts, Kathmandu had the highest annual growth rate per annum of 4.71% in 2001 and 4.78% in 2011.

During the data collection period (January–April 2016), 65 ART clinics were providing free-of-cost ART services to 12,446 PLHIV throughout the country under the auspices of the National Centre for AIDS and STD Control, Ministry of Health and Population [14]. In Kathmandu Valley, there were seven ART centres: five in Kathmandu and two in Lalitpur and Bhaktapur. This study was conducted at three public ART clinics in Kathmandu: Sukraraj Tropical and Infectious Disease Hospital (STIDH), TUTH, and Bir Hospital (BH). These study sites were selected since they dealt with a higher number of PLHIV accessing ART compared to other ART clinics in the Kathmandu Valley. A total of 2,026 PLHIV were attending ART clinics regularly at these three clinics during the study period. This comprised 16.3% of the total PLHIV accessing ART throughout the country (12,446) by mid-2016.

2.2 Participants and sampling

Study participants were HIV-positive men and women aged 18–60 years old accessing ART for at least three months prior to the study period. The 18–60 years age group was selected based on the previous study [145], and 18 is the legal age of majority (the age at which a person is legally a full adult) in Nepal. The exclusion criteria involved PLHIV showing low cognition and/or unable to respond to questions. The PLHIV were purposively selected. It was not possible to conduct random sampling because some PLHIV did not come back to the ART clinic every month as someone else would collect medicine for them. Out of 1,612 eligible PLHIV in the selected three sites (STIDH: 1296; BH: 204; and TUTH: 112), this study recruited a final sample size of 599 (37.2%). Sample size was determined by R software (*pwr* package) considering the expected effect size of social support on QOL as 1.7 [38]. To achieve the power of 0.8 and an alpha level of 0.05, at least 544 PLHIV were needed. The final sample size assumed an expected 10% non-response rate. The number of PLHIV in each ART site was determined using calculations based on probability proportional to size. The number of PLHIV interviewed in STIDH, BH, and TUTH numbered 481, 76, and 42, respectively.

2.3 Survey procedure

The survey was conducted at the selected ART sites in a private setting. The questionnaire was translated into the Nepali language and pre-tested among 44 PLHIV. Four trained interviewers conducted face-to-face interviews (approximately 60–75 minutes) using semi-structured questionnaires (Appendix 2). PLHIV visiting the clinics to refill their prescriptions were first approached by clinic staff and then referred for interview. When the required sample size in each clinic was obtained, further data collection was halted. Each PLHIV received an incentive (USD 1.5) in compensation for their time after completing the survey.

2.4 Measures

2.4.1 Social support

The Nepali version of the multidimensional scale of perceived social support (MSPSS-N) was used to measure the perception social support [146]. The MSPSS-N comprised 12 items rated on a 7-point Likert-type scale ranging from 1 “very strongly disagree” to 7 “very strongly agree.” The scores for individual items on the MSPPS-N were aggregated to derive a total score, with possible scores ranging from 12 to 84. A higher score indicates increased levels of perceived social support. The total MSPSS-N is reported to have a high internal consistency with Cronbach’s alpha (α) of 0.90 [147]. In the current study, it was 0.93 (Table 2.1).

2.4.2 Quality of life

The WHOQOL-BREF [90], a shorter version of WHOQOL-100 survey tool, was used to measure QOL. The WHOQOL-BREF has been previously used in Nepal [148]. The questionnaire consisted of 26 items using the Likert five-point scale, two assessing the overall QOL and general health perception, and the remaining 24 items are distributed in four domains: physical (7 items), psychological (6 items), social relationship (3 items), and environmental (8 items). After reversing the scores for negatively formulated items, the total score was derived by aggregating all items, with a higher score indicating a better QOL. The mean score of the items within each domain was used to calculate the domain scores for compatibility with those used in WHOQOL-100 and subsequently transformed into a 0–100 scale. In this study, Cronbach's alpha for the overall QOL scale was 0.91 (physical domain: 0.80; psychological: 0.75; social relationship: 0.63; and environmental: 0.81) (Table 2.1).

2.4.3 Coping strategy

The Brief COPE inventory [65] was used to measure the coping strategy previously applied in Nepal [149]. The Brief COPE is a 28-item rated on a 4-point Likert-type scale ranging from 1 "I did not do this at all" to 4 "I did this a lot" (Appendix 2). This scale yields fourteen subscales with two items each. For the current study, the individual coping scales were assigned to either problem-focused ($\alpha = 0.78$) or emotion-focused coping strategy ($\alpha = 0.68$) based on nine subscales. The scales assigned to the problem-focused coping strategy were: positive reframing, use of instrumental support, use of active coping, use of emotional support, and planning. The emotion-focused scales consisted of self-blame, bahavioural disengagement, denial, and substance use. Confirmatory factor analysis (CFA) supported the two-factor structure of the coping scales: normed chi-squared (χ^2/df) = 2.80; $p < 0.001$, Comparative Fit Index (CFI) = 0.922, Tucker Lewis Index (TLI) = 0.895, Root-Mean-Square Error of Approximation (RMSEA) = 0.055 (95% CI: 0.048-0.062), and Standardised Root Mean squared Residual (SRMR) = 0.06 (Table 2.2). Other subscales of problem-focused (acceptance, religion, and humour) and emotion-focused coping strategy (self-distraction and venting) were dropped from each category due to a misfit with the models according to the goodness of fit in the CFA analysis.

For further analysis, two-category model of Brief COPE was compared to the previous factor structure of Brief COPE. Two previously specified second-order models of the Brief COPE [150, 151] in the current study population were tested using the CFA. Figures 2.1 and 2.2 present the two measurement models. Model 1 grouped the 14 subscales of the Brief COPE into three categories: problem-focused (active coping, planning, use of instrumental support), emotion-focused (use of emotional support, positive reframing, acceptance, religion, humour), and dysfunctional coping (venting, denial, substance use, behavioural disengagement, self-distraction, self blame) [150]. Model 2 grouped the 14 subscales under adaptive coping (including all the subscales of the problem-focused and emotion-focused coping categories in the first model) and maladaptive coping strategies [151].

In this study, CFA was performed for models 1 and 2 for PLHIV in the current study population (Table 2.3). The normed chi-square, test for absolute model fit, measured 4.37 and 4.28 (df = 337, 337, $p < 0.05$) for models 1 and 2, respectively, showing a poor absolute fit between the two models and the data. The comparative model fits (RMSEA), CFI, TLI, and SRMR were also poor. However, for model 3 used in the current study, the test of absolute model fit and other model fit indices were found to be acceptable. A new two-category model (model 3) of Brief COPE was used since the previous factor structure of Brief COPE was not valid for this study.

2.4.4 Internalised stigma

To assess the internalised stigma, a modified 7-item version of the AIDS-related stigma scale was used [82] (Appendix 2), as previously applied in Nepal [124]. Each item offers a binary (yes/no) response, and the total score was computed as the sum total of endorsed items ranging from 0 to 7. A higher score indicates more negative attitudes or perceived discrimination. For this study, the total scores were dichotomised into lower and higher levels of stigma by the median.

2.5 Statistical analyses

Firstly, descriptive statistics for demographic and other relevant characteristics of the PLHIV were calculated prior to analysing the correlation matrix among the main variables. Structural Equation Modelling (SEM) was used to determine the influence of perceived social support on QOL, with coping strategy as a mediator, using a two-step modelling approach. The first step involved testing and respecifying CFA models for each major latent variable to ensure that the proposed factor solution was adequate, testing the latent variable for the adequacy of its indicators. After the CFA models were deemed acceptable, the second step involved comparing the fit of the original structural models to alternative models. The initial path model was then modified by adding plausible paths with the use of modification indices, and subsequently trimmed to obtain the final model. The model fit was based on the chi-square (χ^2) goodness-of-fit test, CFI, TLI, SRMR, and RMSEA. The χ^2 is sensitive to sample size, therefore, a normed χ^2 (χ^2/df) was used to assess the model fit; a good fit is indicated when $\chi^2/df < 3$. A value of RMSEA at 0.08 is acceptable and 0.05 is excellent. Values of CFI and TLI ≥ 90 are considered to indicate an acceptable fit. Hypothesis 1 regarding the mediating effect of coping strategy on the relationship between perceived social support and QOL in the final model was evaluated using the magnitude of path coefficients (standardised coefficient) and their significance. The effects were broken down into direct, indirect, and total for each path using the delta method, as suggested by Sobel (1987) [152]. In addition, the indirect effects were tested with the Sobel test.

In the present study, a confounder was indicated as a variable with direct effects on both the exposure (perceived social support) and the dependent variable (QOL). The final model was adjuted for age and sex.

The mediating relationship of the final model was examined using multiple groups to establish whether it is moderated by stigma. Multiple-group analysis was conducted on SEM to test the invariance of the final model, with the PLHIV being divided into high stigma and low stigma groups. All the analyses were performed using STATA 13.0.

The statistical procedures used to achieve the specific hypotheses are described in the following paragraphs.

Hypothesis 1. Coping strategies (problem-focused and emotion-focused) mediate the relationship between perceived social support and QOL.

The basic mediation model synthesised in this hypothesis is shown in Figure 2.3.

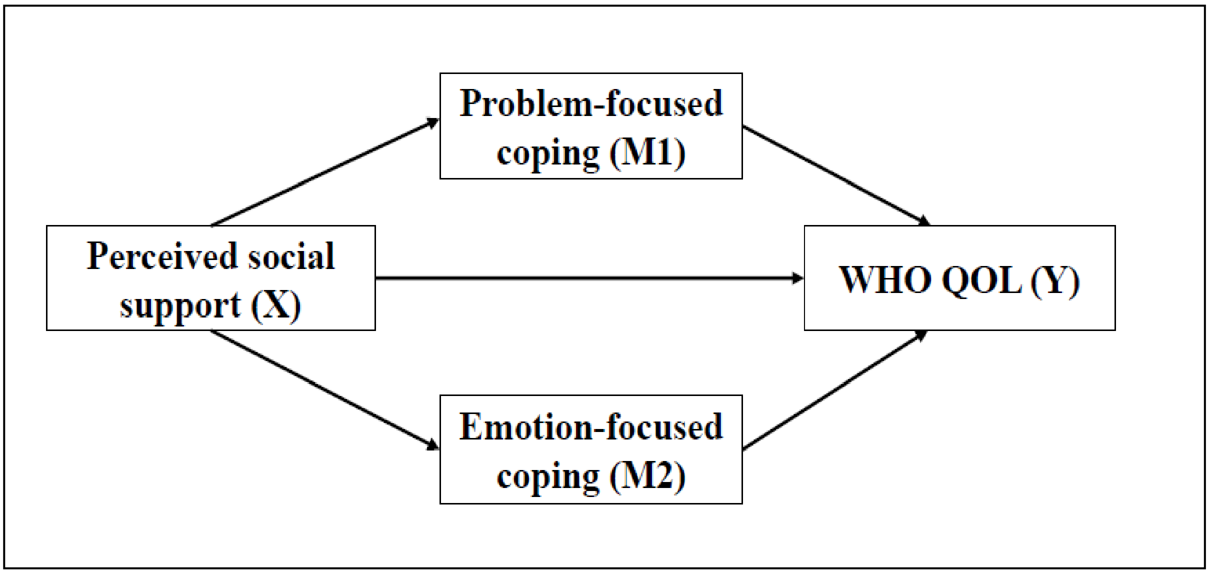

Figure 2.3. Mediation model of the study.

Statistical analysis. To analyse the mediation effect of coping strategy, the counterfactual framework has been applied [153] to allow descriptions of direct and indirect effects, and decomposition of the total effect into direct and indirect effects. When a mediator exists between two variables, the relationship may be categorised as partial or full mediation, as defined in Figure 2.4 [154]. As shown in Figure 2.4, if the path coefficient between M and Y is not significant, then no mediation is evident (A). If the relationship between X and Y is partially mediated, then X affects M, which in turn affects Y. In addition, X affects Y directly (B). Full mediation is suggested when X affects M, which in turn affects Y. But, there is no significant relationship between X and Y (C).

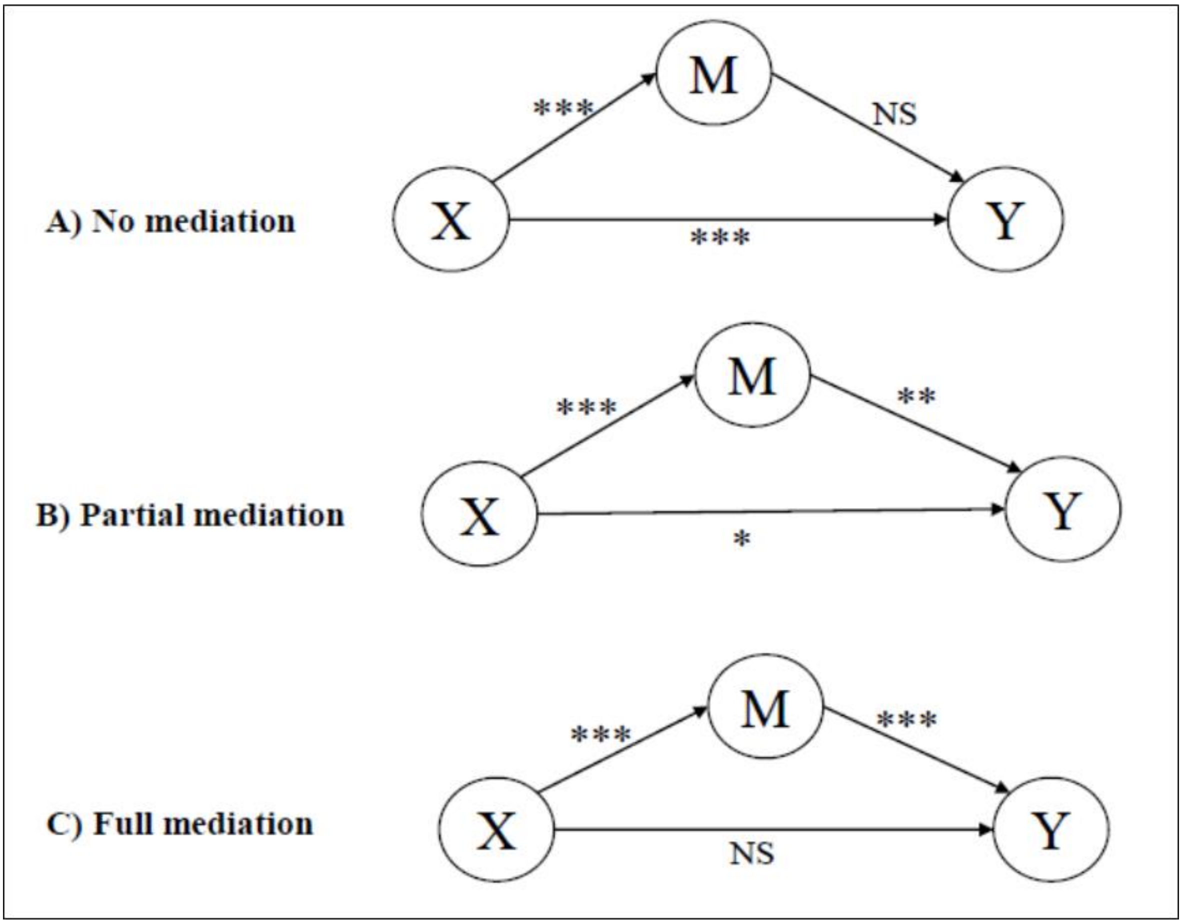

Figure 2.4. Illustration of possible mediation analysis. *indicates the relative strengths of associations, with NS meaning non-significant.

Hypothesis 2. Internalised stigma moderates the mediating effect of coping strategies (problem and emotion focused) between perceived social support and QOL. There is a significant difference between the mediation result for groups with low and high levels of stigma. The moderated mediation model synthesised in this study is shown in Figure 2.5.

Statistical procedure. The multi-group approach was adopted to test the moderation of the relationship between perceived social support and QOL by internalised stigma. This approach involved splitting the sample into subgroups to represent two different levels of moderator variable. The total score for internalised stigma was dichotomised into “high” and “low” categories using the median split method. Both high and low stigma groups were assessed for mediation, using the magnitude of path coefficients and their significance and decomposing the effects into direct, indirect and total. If the evidence of mediation differs between high and low stigma groups, it can be concluded that mediation is moderated by internalised stigma.

In addition, multiple-group SEM analysis was performed to determine whether or not the final mediation model in this study was equivalent across the high and low stigma groups. In order to perform the multiple-group SEM analysis, constraints were successively imposed on the measurement weights, structural weights, structural covariance, structural residuals, and measurement residuals [155]. If the $\Delta\chi^2$ value between models is not significant, it indicates that the invariance across the group is fulfilled.

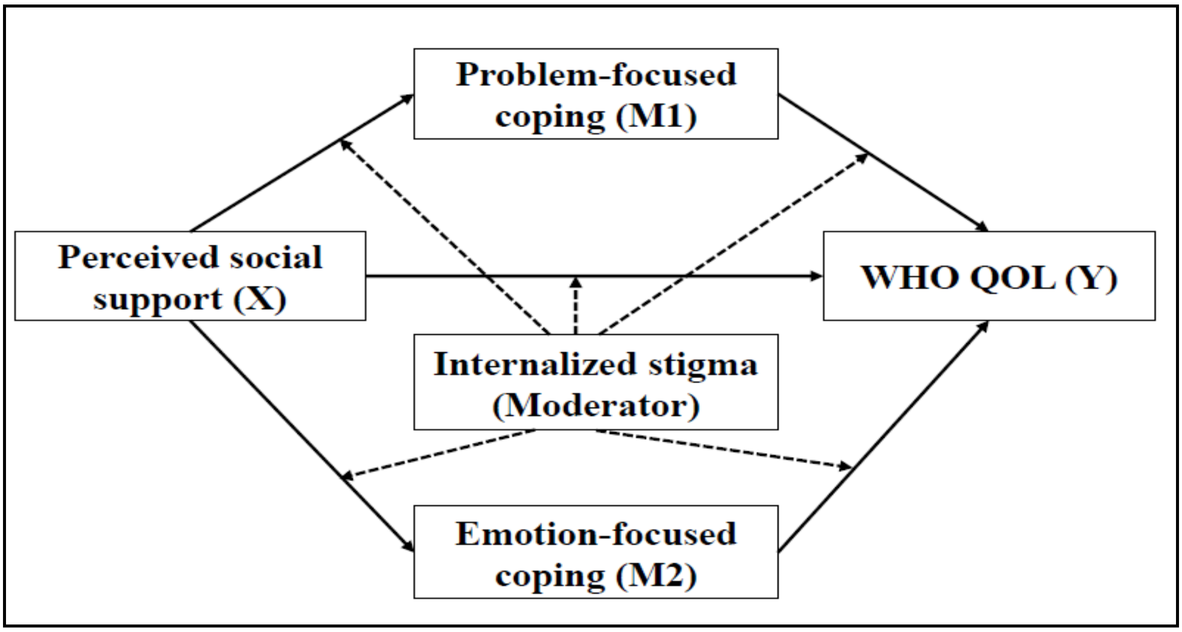

Figure 2.5. Moderated mediation model for internalised stigma.

2.6 Sensitivity analysis

Sensitivity analysis was conducted to assess examine the robustness of conclusions regarding the mediation effects of the two-category model for coping strategies (problem-focused and emotion-focused) on the association between perceived social support and QOL. Mediation analyses were performed on the specific COPE scales. For problem-focused coping, a seperate mediation analysis was carried out on each of the follwing scales: positive reframing (items 12 and 17), use of instrumental support (items 10 and 23), active coping (items 2 and 7), use of emotional support (items 5 and 15), and planning (items 14 and 24). Likewise, for emotion-focused coping, the following scales were used for the mediation analysis: self-blame (items 13 and 26), behavioural disengagement (items 6 and 16), denial (items 3 and 8), and substance use (items 4 and 11).

2.7 Ethical considerations

Ethical approval for this quantitative study was obtained from the Research Ethics Committee of the Graduate School of Medicine, University of Tokyo, Japan (approval number: 10903) (Appendix 3) and the Nepal Health Research Council, Kathmandu, Nepal (Appendix 4). Permission to conduct this study was also obtained from the three hospitals concerned. After explaining the study objectives and procedures through an information sheet (Appendix 5), each PLHIV signed the informed consent form (Appendix 6) prior to the interview. Identification codes were used to ensure the confidentiality and privacy of PLHIV. Participation was voluntary and PLHIV could withdraw from the study at any time before, during, or after. The PLHIV could refrain from answering any questions with which they felt uncomfortable, or did not wish to answer.

CHAPTER THREE

RESULTS

3.1 Socio-demographic characteristics of the participants

Table 3.1 presents the background characteristics of the PLHIV (n = 599). A total of 613 PLHIV were surveyed for the study and 599 completed the questionniare (response rate: 97.7%), of whom 51% were male with a median age of 38 years (interquartile range, IQR = 32, 44), 67% had at least some formal education, with 48% educated at above-primary level, and 67% employed in some capacity. The median period since the start of ART was 50 months (IQR = 22, 78), and only 4% had not disclosed their HIV status to anyone.

3.2 Descriptive statistics for psychosocial variables

Table 3.2 presents descriptive statistics for the psychosocial variables. The average score for perceived social support was 58.1. The mean score for problem-focused coping (mean = 22.4) was higher than that of emotion-focused coping (mean =13.1). Likewise, the mean score for overall internalised stigma was 2.5 and 61.0 for QOL.

3.3 Correlation between demographic and psychosocial variables

Table 3.3 shows the correlation between demographic and psychosocial variables. Significant correlation was found between education and employment status ($r = 0.15$, $p < 0.01$). Older PLHIV were male ($r = 0.13$, $p < 0.05$) and had long been on ART ($r = 0.18$, $p < 0.001$). Male PLHIV were more likely to be employed ($r = 0.22$, $p < 0.001$), lived in rented accommodation ($r = -0.10$, $p < 0.05$), and used the drug ($r = 0.19$, $p < 0.001$). CD4 count was correlated with the length of time using ART ($r = 0.17$, $p < 0001$), diagnosis of HIV ($r = 0.21$,

$p < 0.001$), and use of drugs ($r = 0.10$, $p < 0.05$). Male PLHIV ($r = 0.09$, $p < 0.05$) were more likely to disclose their HIV status, whereas those married were less likely to do so ($r = -0.10$, $p < 0.05$).

QOL was positively correlated to perceived social support and problem-focused coping strategy and inversely correlated to internalised stigma. The QOL scores were shown to have a significant positive correlation with gender, marital status, and education. Those who were male, married and educated were more likely to have higher QOL scores. However, QOL showed a negative correlation with age.

Perceived social support showed significant correlation with marital status, education, disclosure and being on ART. Those who were married, educated, disclosed their HIV status, and on ART perceived higher social support. Similarly, problem-focused coping showed significant correlation with gender, marital status, education, employment, and disclosure. In addition, problem-focused coping showed significant correlation with perceived social support. Internalised stigma showed significant correlation with marital status, perceived social support, and problem-focused coping.

3.4 Factor analysis

The coping strategy indicators are presented as primary and modified measurement models in Figure 3.1. In this figure, the path numbers denote factor loadings between coping strategy and its indicators. As shown in Figure 3.1A, items with small factor loadings were removed and then modified by adding plausible paths with the use of modification indices. Consequently, a modified model for coping strategy is shown in Figure 3.1B. Table 2.2 presents model fitting indicators for the primary and modified measurement models of coping strategy, indicating that following modification, all indices increased and met the criteria. Therefore, coping strategy can be defined by 18 indicators (Figure 3.1B).

Figure 3.1 and Table 3.4 present the primary and modified fitting analyses and measurement model. The whole fitting indicators are well defined following modification. The results demonstrate that the modified model fits well with 12 indicators (Figure 3.2B).

3.5 Measurement and structural models

As shown in Figure 3.3, several pairs of error terms of latent variables were allowed to correlate. The error terms of problem and emotion-focused coping strategy were also allowed to covary since they were correlated (*r* = 0.28, $p < 0.001$, $\beta = .06$, $p > 0.05$). The full measurement model produced a good data fit ($\chi 2/df = 2.54$, $p < 0.001$, RMSEA = 0.051; 95% CI: 0.047-0.054, CFI = 0.929; TLI = 0.919, SRMR = 0.067) (Figure 3.3, Table 3.5).

3.6 Mediation analysis

Figure 3.3 presents the relationship between independent and dependent variables and the two mediators. To check the mediation effect, the significance of X on M and M on Y was examined as shown in Figure 2.2. As depicted in Figure 3.3, perceived social support had a positive and significant effect on problem-focused coping strategy ($\beta = 0.37$, $p < 0.001$). This, in turn, was significantly associated with better QOL ($\beta = 0.38$, $p < 0.001$). Subsequently, the direct, indirect, and total effect of perceived social support on QOL was checked, with coping strategies as the mediator (Table 3.6). The direct and indirect effects were significant. The Sobel test results showed that the pathway from perceived social support (independent variable) to problem-focused coping (mediator) and QOL (dependent variable) was significant ($z = 3.858$, $p < 0.001$). This indicates that problem-focused coping partially mediates the relationship between social support and QOL. However, the relationship between perceived social support and emotion-focused coping strategy was not significant, although emotion-focused coping was inversely related to QOL (β = -0.16, p < 0.05). Furthermore, the pathway from perceived social support (independent variable) to emotion-focused coping (mediator) and QOL (dependent variable) was not significant (z = -0.483, p = 0.629), demonstrating that emotion-focused coping does not mediate the effect of perceived social support on QOL.

3.7 Moderated mediation analysis

Figure 3.4 shows the results of SEM analysis among PLHIV with high and low stigma. For the high internalised stigma group, perceived social support had a significant positive effect on problem-focused coping strategy (β = 0.45, p < 0.001), leading to a significant increase in the QOL (β = 0.58, p < 0.001) (Figure 3.4A). In addition, indirect effects (1.48; 61.0 % of total effects) were significant, but the direct effects were not (Table 3.6). A Sobel test showed that the pathway from perceived social support to problem-focused coping and QOL was significant (z = 4.208, p < 0.001). This indicates that problem-focused coping fully mediates the effect of perceived social support on QOL among PLHIV with a high level of stigma. However, the pathway from perceived social support to emotion-focused coping and QOL was not significant (z = 0.182, p = 0.856), indicating that emotion-focused coping does not mediate the relationship between perceived social support and QOL.

However, for the low internalised stigma group, no indirect paths were significant, and most effects of perceived social support were direct (β = 1.24; 99.2% of total effects) (Table 3.6 and Figure 3.4). This indicates that the mediating effect of coping strategy in the relationship between perceived social support and QOL was absent in the low stigma group.

The multiple-group analysis of internalised stigma showed that differences in goodness-of-fit statistics existed among models with no restrictions, restricted structural weights, restricted structural covariance, and restricted structural residuals (Table 3.7). This indicates that the relationships among perceived social support, problem-focused coping strategy, emotion-focused coping strategy, and QOL differ between high and low stigma groups.

3.8 Sensitivity analysis

Among all PLHIV, the COPE scales related to problem-focused coping, such as the use of emotional support and planning, showed significant indirect effects in the association of perceived social support with QOL (Table 3.8). Furthermore, the Sobel test indicated that the pathway from perceived social support to the use of emotional support to QOL was significant ($z = 4.121$, $p < 0.001$). The indirect effects of instrumental support were at the borderline level of significance (Sobel test, $z = 1.84$, $p = 0.066$). However, none of the COPE scales related to emotion-focused coping, such as self-blame, behavioural disengagement, denial and substance use, showed any significant indirect effects on the association of perceived social support with QOL.

The mediating effects of COPE scales were also examined among PLHIV in high and low stigma groups (Tables 3.9 and 3.10). Among PLHIV with high stigma, most of the COPE scales related to problem-focused coping (positive reframing, use of emotional support, and use of emotional support) showed significant indirect effects for the association between perceived social support and QOL (Table 3.9). Furthermore, the Sobel test demonstrated that the indirect effects were significant. The results showed the pathway from the independent variable (perceived social support) to mediator (positive reframing: $z = 2.891$, $p = 0.004$; use of instrumental support: $z = 2.618$, $p = 0.009$; use of emotional support: $z = 3.691$, $p < 0.001$; planning: $z = 1.871$, $p = 0.061$) and outcome (QOL) was significant. In contrast, among PLHIV in the low stigma group, none of problem-focused coping and emotion-focused coping scales showed significant indirect effects for the association of perceived social support with QOL (Table 3.10).

CHAPTER FOUR

DISCUSSION

4.1 Correlation between major variables

4.1.1 Perceived social support

Social support indicates the availability of social provision, consisting of the functional aspect. The present sample mean score of 58.1 on the multidimensional scale of perceived social support is consistent with a previous study using the Nepali version of MSPSS [147]. Perceived social support showed a significant positive correlation with marital status, education, disclosure, and length of time on ART. The present study findings show that age and perceived social support have no correlation, which is inconsistent with previous studies among PLHIV [156, 157]. Age was observed to be negatively correlated with social support, indicating that is, as the age of the study subjects increased, the level of social support decreased. However, the findings of the present study are consistent with that by McDowell and Serovich (2007), who found a non-significant relationship between demographic variables (ethinicity, gender, and employment status) and perceived social support among PLHIV [158].

4.1.2 Coping strategies

In the present study, the Brief COPE is categorised into two major coping dimensions: problem-focused and emotion-focused. Previous studies show inconsistencies in the way a coping strategy is measured, classifying multiple strategies into broader categories of problem-focused and emotion-focused coping. In the present study, five subscales (positive reframing, instrumental support, active coping, use of emotional support, and planning) were combined to measure problem-focused coping. Four subscales (self-blame, behavioural disengagement, denial, and substance use) were combined to measure emotion-focused coping. These classifications were determined in accordance with previous studies [61]. Problem and emotion-focused coping dimensions were constructed as an average of listed subscales under each dimension and showed satisfactory reliability (Cronbach's alpha of 0.78 and 0.68, respectively).

A study among 611 PLHIV in the USA using the Brief COPE categorised five subscales as adaptive coping (positive reframing, use of emotional support, acceptance, religion, and active coping) and three subscales as maladaptive coping (denial, self-blame, and behavioural disengagement) reported a Cronbach's alpha of 0.74 and 0.72, respectively [159]. Likewise, a study among 259 adult PLHIV in Canada categorised three subscales as adaptive (planning, positive reframing, and religion) and three subscales as maldaptive (venting, denial, and substance use), reporting Cronbach's alpha of 0.72 and 0.65, respectively [160]. Another study among PLHIV in South Africa adopted the modified Brief COPE scale, categorising eight subscales as active (acceptance, direct action, positive reframing, religion, emotional support, instrumental support, helping others and information seeking), and seven subscales as avoidant (distraction, escape, denial, emotional venting, feeling out of control, self blame and substance use) and reported a Cronbach's alpha of 0.75 and 0.54, respectively [161]. A recent study among individuals with chronic heart failure used the Brief COPE scale to categorise two subscales as problem-focused (active coping and planning) and four subscales as emotion-focused coping (positive reframing, acceptance, humour, and religion) reported a Cronbach's alpha of 0.78 and 0.62, respectively [162]. Although all these studies used the Brief COPE measure, direct comparison of coping strategies is impossible due to differences in the classification and inclusion of subscales in two major coping dimensions.

The mean scores for problem-focused coping (mean = 22.4) and emotion-focused coping (mean = 13.1) are comparable with other studies [163]. However, the reported mean results vary across studies due to a difference in the computation of scales. Problem-focused and emotion-focused coping are correlated in the present study ($p < 0.001$). Other variables, such as marital status, education, employment, disclosure, and perceived social support showed significant correlation with problem-focused coping. However, no significant correlation was observed between these variables and emotion-focused coping strategies. There was no gender difference in either problem-focused or emotion-focused coping. This finding is consistent with other studies [164, 165].

4.1.3 Internalised stigma

In the present study, a modified 7-item version of the AIDS-related stigma scale was used to assess internalised stigma, reporting a Cronbach's alpha of 0.79. A study using the modified 7-item version of the AIDS-related stigma among PLHIV in Nepal reported a Cronbach's alpha of 0.75 [124]. The median score for overall internalised stigma in the present sample (median value = 2) was lower than the median score (median value = 4) found by Amiya and her colleagues (2015) during a study in Nepal [124].

The present study showed the correlation of internalized stigma with perceived social support and problem-focused coping strategy. This finding is consistent with a previous study conducted among PLHIV [166]. In addition, the present study shows a correlation between stigma and disclosure, with a significantly higher level of internalised stigma existing among those who did not disclose their HIV status compared to those who did. Consistent with the present study, Calin et al. (2007) found that individuals attending an HIV clinic who had not disclosed to anyone or just one person reported higher stigma than those who had disclosed to two or more people [167]. Previous studies indicate that fear of discrimination is a major reason for non-disclosure [168]. Furthermore, negative perceptions of PLHIV are considered to cause low self-esteem and a feeling of shame, which may lead to less voluntary disclosure of HIV status [169].

The findings of the present study concerning the correlation of internalised stigma with age are consistent with other studies conducted among PLHIV [142, 170]. Such studies found no correlation of HIV-related stigma with age, which is consistent with the present study. Likewise, as in the present study, Sayles et al. (2008) and Lee et al. (2002) found no significant correlation between HIV-related stigma and gender [142, 170].

It is surprising to see that no significant correlation exists between internalised stigma and other demographic variables such as education and marital status. Contrary to the present findings, Sayles et al. (2008) showed significantly higher HIV-related stigma scores for PLHIV who reported little or no high school education and were unmarried [142]. This inconsistency may be due to the difference in gender and ethnic composition of the samples.

4.1.4 Quality of life

QOL was measured using the WHOQOL-BREF. In the present study, the mean overall score was 61.0. A previous study using WHOQOL-BREF among PLHIV in Nepal reports a mean overall score of 61.4 [171]. The present study shows a significant negative correlation between QOL and age; as the PLHIV became older, the QOL score decreased. This finding is consistent with previous studies among PLHIV [156, 157]. In the present study, a strong relationship was found to exist between gender and QOL, with females reporting lower levels of QOL than males. This finding is consistent with the previous study [172]. In addition, the present study shows a significant correlation between QOL and marital and educational status, which is consistent with the previous studies [173, 174].

The current study finding is consistent with other studies, regarding the positive correlation between social support and QOL. A study among PLHIV in China suggests that those with lower social support have a diminished QOL [175]. Likewise, the current study shows a positive correlation between problem-focused coping and QOL, which is consistent with the previous study [176]. In addition, the present study finding is also corroborated by other studies concerning the correlation between internalised stigma and QOL. A study conducted in Israel among people with serious mental illness reported a significant negative correlation between QOL and internalised stigma [177].

4.2 Coping as a mediating variable between perceived social support and quality of life

Although much is known about perceived social support, coping strategies and psychosocial outcomes, there is still a lack of understanding concerning the mechanism through which these variables influence QOL among PLHIV. Understanding relationships among these variables from the perspective of PLHIV is very important. The first research question examines the relationships among perceived social support, coping strategies, and QOL. The first research question hypothesised (*hypotheses 1A and 1B*) that the use of coping strategies (problem-focused and emotion-focused) mediate the relationship between perceived social support and QOL.

Standardised predictor path coefficients were used to examine the mediation model. The total effects were decomposed into direct and indirect based on the counterfactual framework. In addition, the Sobel test was used to analyse the mediated effect (also referred to as an indirect effect). The finding supports the hypothesis (*hypothesis 1A*) that the use of problem-focused coping strategy partially mediates the relationship between perceived social support and QOL. However, in the present study, emotion-focused coping strategy did not mediate the relationship between perceived social support and QOL, and consequently fails to support the hypothesis (*hypothesis 1B*). This result suggests that problem-focused coping strategy can play a critical role in perceived social support and QOL, which is consistent with a study on breast cancer patients [75]. The positive relationship between problem-focused coping strategy and QOL in this study is also consistent with previous studies [178, 179]. Those studies reported that the greater the use of problem-focused coping strategy by PLHIV, the more likely they would be to perceive better QOL. In addition, emotion-focused coping strategy was found to be negatively associated with QOL, as also reported in a previous study [180].

4.3 Moderated mediation model: internalized stigma as a moderator

As discussed in the previous section, a significant indirect positive relationship existed between a change in the level of perceived social support and the use of problem-focused coping which, in turn, was found to be positively associated with QOL. Perceived social support also had a positive effect on QOL. The second research question hypothesises that these significant relationships would differ between high and low stigma groups, with the low stigma group having a weaker or absent indirect effect than the high stigma group (*hypothesis 2*). As expected, in hypothesis 2A, the indirect effect differs between the high and low stigma groups. The hypothesis 2A is supported, in that the indirect effect is weaker or absent for low stigma groups than high. However, the pathway from perceived social support to emotion-focused coping and QOL is not significant for either high or low stigma groups. This suggests that emotion-focused coping does not mediate the relationship between perceived social support and QOL, and consequently fails to support hypothesis 2B.

Moderated mediation analysis reveals that the mediating effect of problem-focused coping strategy only exists in those PLHIV reporting high levels of internalised stigma. A higher level of perceived social support leads to a significant increased use of problem-focused coping strategy, which, in turn, exerts a significant positive effect on QOL among the high stigma group. This analysis permits the joint examination of when (i.e. at high levels of stigma) and how (i.e. through problem-focused coping) perceived social support is associated with QOL. It would appear that when the levels of stigma are relatively high, perceived social support is associated with better QOL through its positive relationship with problem-focused coping.

Although coefficients from perceived social support to emotion-focused coping strategy and QOL moved in the expected direction, the relationships were not significant at < 0.05. However, in the low internalised stigma group, perceived social support only increased problem-focused coping strategy, which did not significantly affect QOL. These findings indicate that the mediating effect of problem-focused coping strategy between perceived social support and QOL varies with the level of internalised stigma.

The mediating effect of problem-focused coping strategy was observed to be greater among PLHIV with higher levels of internalised stigma. This may be due to their additional burden of stigma, in that they suffer more compared to those with lower levels of stigma. This study findings partly relate to the results of a study conducted in Congo [88]. That study reports that the effect of social support on the psychological domain of QOL is positive and stronger for PLHIV reporting high-perceived stigma than for those reporting low stigma. However, the moderating effect on overall QOL was not studied.

This present study indicates that problem-focused strategy, in the presence of social support, is useful for people in stressful situations. An HIV-positive diagnosis is stressful and can cause great feelings of insecurity. In this situation, when PLHIV perceive high social support, it is more likely to promote a problem-focused coping strategy towards the infection.

In general, problem-focused coping is suitable for dealing with the root cause of a problem, providing a long-term solution. Previous studies show that problem-focused strategy is successful in dealing with stressors such as discrimination [181], HIV infections [182] and diabetes [183]. Problem-focused coping strategy works best when the person is able to control the source of stress.

However, problem-focused coping may not work in helpless situations or in those where it is beyond the individual's control to remove the source of stress. For example, when someone dies, problem-focused coping may not be very helpful for the bereaved family; dealing with the feelings associated with the loss of a family member may require emotion-focused coping. Therefore, in the present study, as well as problem-focused coping strategy, adequate perceived social support maybe an important resource for PLHIV in dealing with stressful conditions.

4.4 Strengths and limitations

The present study has certain strengths. This is the first study to examine the mediating effect of coping strategies among PLHIV. In particular, it is the first to investigate the moderated mediation model among psychosocial variables, such as perceived social support, coping strategies, internalised stigma and QOL. This study helps to identify the psychosocial factors that may contribute to the difference in coping strategies among PLHIV with high stigma and assist healthcare professionals in developing appropriate coping strategies for improving QOL based on the level of stigma. In addition, this study uses very robust statistical methods. In recent years, an increasing number of studies and experts advocate testing whether or not the extent of the indirect effect is significant instead of relying solely on the traditional causal steps.

The present study is subject to some limitations. Firstly, since this is a cross-sectional study, the causal paths in the model are still based on hypothetical relationships. It would be useful to perform a longitudinal study to evaluate causal relationships among variables. Secondly, the findings may not be applicable to those not currently receiving treatment. There is also a possibility of response bias due to self-reporting. It is possible that PLHIV who were not utilising the ART services became automatically excluded from the study based on sampling and recruitment procedures. Some PLHIV with high stigma who otherwise might have met the inclusion criteria may also have refused to participate in the study due to fear of disclosure. This selection bias may limit the external validity of the study. Thirdly, this study uses the perceived social support, which might not perfectly correlate with the actual degree of social support received. However, the perception of social support is more predictive of health outcomes than actual social support among PLHIV [58]. Finally, a conceptual overlap between social support and coping questions may arise in this study since many coping measures include aspects of social support, such as seeking emotional or instrumental support, which are partially parallel to the conceptual analysis of social support. In order to address the issue, this study proposes a two-factor model based on CFA. In addition, sensitivity analysis using individual subscales is also conducted to support the mediating role of subscales regarding problem-focused coping in the relationship between perceived social support and QOL.

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

5.1 Conclusions

The main objective of this study was to explore whether or not coping strategies mediate the relationship between perceived social support and QOL as a function of the underlying level of internalised stigma. The findings of present study indicate that problem-focused coping strategy partially mediates the relationship between perceived social support and QOL among PLHIV. This study also indicates that the mediating effect varies with the levels of internalised stigma and is found only in PLHIV with high stigma. Thus, this study highlights that PLHIV with high internalised stigma are more likely to use problem-focused coping for improving their QOL.

The study suggests that problem-focused coping is a common coping mechanism among PLHIV with high stigma, which has positive implications for QOL. From a methodological point of view, SEM methods provide a causal relationship to gain a more in-depth understanding of PLHIV regarding their coping experience. PLHIV could rely more on emotion-focused coping strategies than reported when answering standardised questionnaires, with negative consequences for their QOL. Nevertheless, they would benefit from replying on less evasive (e.g. problem-focused) coping strategies. The attitudes of PLHIV with high stigma towards the use of problem-solving coping provide important clues for future interventions and education.

5.2 Recommendations

The following recommendations are proposed in view of the study findings:

- This study underscores the importance of addressing perceived social support, coping strategy, and internalised stigma in HIV care and management to improve overall QOL. It is also important to develop mechanisms for capturing the level of stigma while designing social support interventions in order to improve psychological well-being. Failure to identify the level of stigma may undermine the effect of social support.
- This study suggests specific coping strategies for PLHIV with high levels of stigma since this group is more likely to require additional personalised efforts to actively cope with the disease and its consequences.
- Given the findings that problem-focused coping mediates the relationship between social support and QOL, it may be particularly helpful to encourage ART adherence and social support to promote problem-focused coping among PLHIV.
- More research is required to further understand the psychosocial trajectory of HIV/AIDS and the different categories of PLHIV for guiding the responsiveness of intervention programmes to suit the different categories.

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TABLES AND FIGURES

Table 2.1. Study instruments internal consistency reliabilities (n = 599).

Instruments	Alpha	# items
Multidimensional scale of perceived social support (MSPSS-N)	0.93	12
Social support from friends	0.92	4
Social support from family	0.95	4
Social support from others	0.93	4
Brief coping	0.79	28
Problem-focused coping	0.78	10
Emotion-focused coping	0.68	8
Internalised stigma	0.79	7
Quality of life	0.91	24
Physical domain	0.80	7
Psychological domain	0.75	6
Social relationship	0.64	3
Environmental domain	0.81	8

Table 2.2. Model fitting analysis for primary and modified measurement models of coping strategy

Fit index	Primary model	Critical value	Modified value
Normed chi-squared (χ^2/df)	6.7	< 3	2.8
Comparative fit index (CFI)	0.56	>0.9	0.92
Tucker Lewis index (TLI)	0.52	>0.9	0.90
Root mean square error of approximation (RMSEA)	0.098 (95% CI: 0.094, 0.102)	<0.08	0.055 (0.048, 0.062)
Standardised Root Mean square Residual (SRMR)	0.106	<0.08	0.060

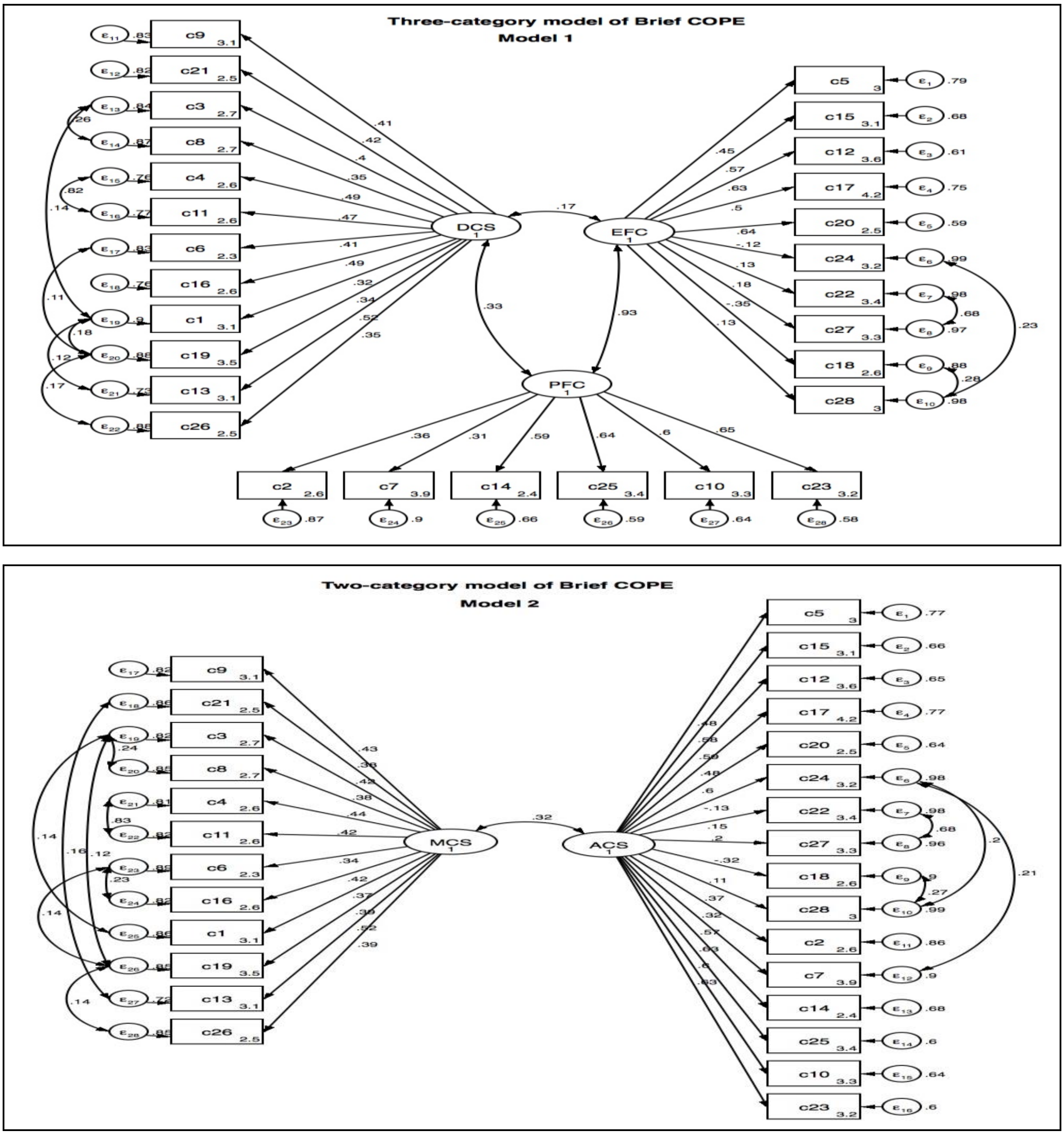


Figure 2.1. Three-category (model 1) and two-category (model 2) models of Brief COPE. DCS, dysfunctional coping strategies; EFC, emotion-focused coping; PFC, problem-focused coping; MCS, maladaptive coping strategies; ACS, adaptive coping strategies. Brief COPE scales are: use of emotional support (c5 and c15); positive reframing (c12 and c17); acceptance (c20 and c24); religion (c22 and c27); humour (c18 and c28); active coping (c2 and c7); planning (c14 and c25); use of instrumental support (c10 and c23); venting (c9 and c21); denial (c3 and c8); substance use (c4 and c11); behavioural disengagement (c6 and c16); self distraction (c1 and c19); and self-blame (c13 and c26).

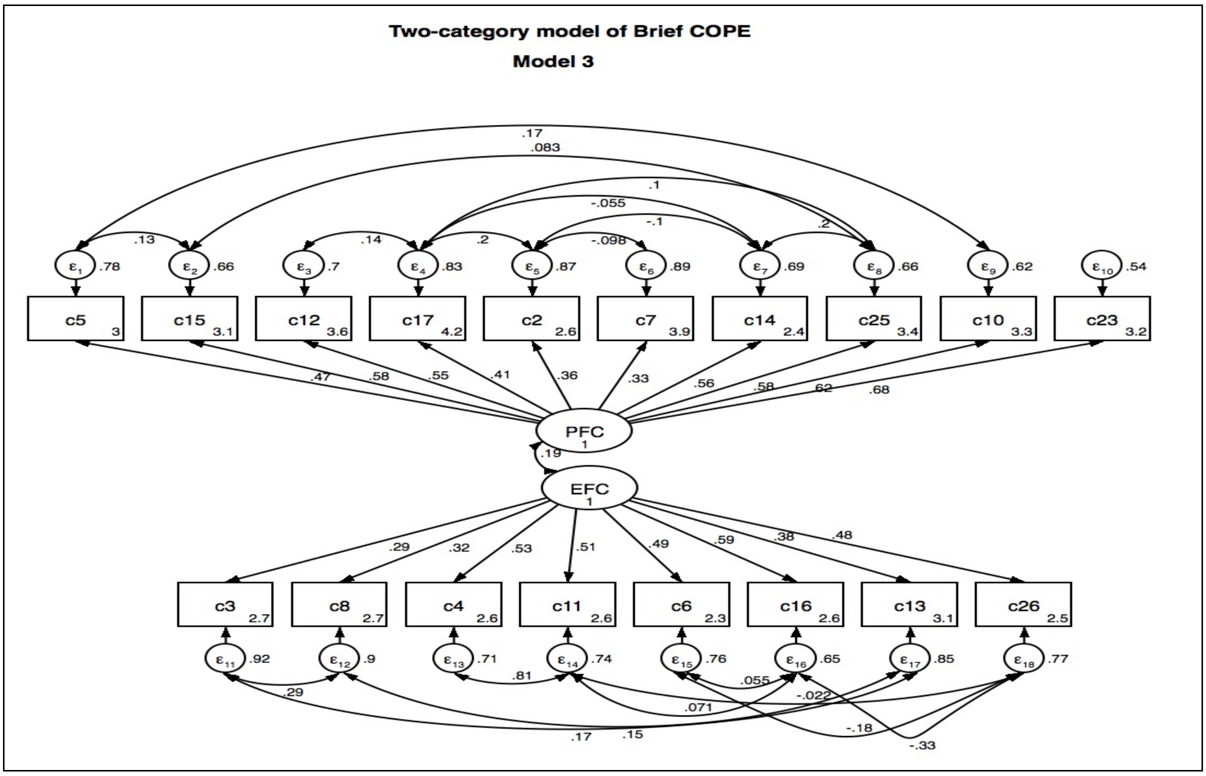


Figure 2.2. Two-category model of Brief COPE. PFC, problem-focused coping; EFC, emotion-focused coping. Brief COPE scales are: use of emotional support (c5 and c15); positive reframing (c12 and c17); active coping (c2 and c7); planning (c14 and c25); use of instrumental support (c10 and c23); denial (c3 and c8); substance use (c4 and c11); behavioural disengagement (c6 and c16); and self-blame (c13 and c26).

Table 2.3. Indices of confirmatory factor analysis (CFA) for model 1, 2 and 3.

Model	Number of factor	χ^2 (df)	Normed chi-squared (χ^2/df)	CFI	TLI	RMSEA (95% CI)	SRMR
Model 1	3	1473.3 (337)	4.37	0.747	0.716	0.075 (0.071, 0.079)	0.082
Model 2	2	1441.8 (337)	4.28	0.754	0.724	0.074 (0.070, 0.078)	0.080
Model 3	2	324.6 (115)	2.82	0.922	0.895	0.055 (0.048,0.062)	0.060

CFI, Comparative Fit Index; TLI, Tucker Lewis Index; RMSEA, Root-Mean-Square Error of Approximation; SRMR, Standardised Root Mean squared Residual.

Table 3.1. Background characteristics of the PLHIV (n = 599).

Characteristics	n	%
Sociodemographic		
Gender		
Male	305	50.9
Female	294	49.1
Age, median (IQR) years	38 (32, 44)	
Marital status		
Married	389	64.9
Unmarried	57	9.5
Divorced	28	4.7
Widow	125	20.9
Education level*		
No formal education	199	33.2
Primary	109	18.2
Lower secondary	201	33.6
Higher secondary	88	14.7
Missing	2	0.3
Employment status		
Employed	402	67.1
Unemployed	197	32.9
Living status		
Own house	283	47.3
Rented house	287	47.9
Others	29	4.8
Ethnicity		
Brahmin	108	18.0
Chhetri	139	23.2
Dalits	42	7.0
Janajati	285	47.6
Madhesi/Muslim	25	4.2

Table 3.1. (Continued)

Characteristics	n	%
Clinical and psychosocial characteristics		
Time since first testing HIV+, median (IQR) months	66 (32, 106)	
Time since ART started, median (IQR) months	50 (22, 78)	
Any illicit drug use (last 6 months)		
Yes	21	3.5
No	578	96.5
Disclosure of HIV status to anyone		
Yes	574	95.8
No	24	4.0
Missing	1	0.2
CD4 cell count (cells/µL), median (IQR)**	430 (316, 600)	

IQR, interquartile range; ART, antiretroviral therapy; CD4, cluster of differentiation 4. *Education level categories were defined based on the structure of the Nepalese education system. **Three PLHIV did not provide any information about their CD4 count.

Table 3.2. Descriptive statistics of psychosocial variable (n = 599).

Variable	Mean	SD	Range
1. Perceived social support	58.1	13.5	12-84
2. Problem-focused coping	22.4	4.1	12-33
3. Emotion-focused coping	13.1	2.8	8-24
4. Quality of life	61.0	7.2	38-80
5. Internalised stigma	2.5	1.8	0-7

SD, standard deviation.

Table 3.3. Correlation matrix of psychosocial and demographic variables (n = 599).

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1	Age	1.00																
2	Gender	0.13^{*}	1.00															
3	Marital status	0.07	-0.30^{***}	1.00														
4	Education	-0.17^{***}	0.35^{***}	-0.15^{***}	1.00													
5	Employment	-0.10^{*}	0.22^{***}	-0.13^{*}	0.15^{**}	1.00												
6	Living status	-0.13^{*}	-0.10^{*}	-0.10^{*}	-0.01	0.08	1.00											
7	Ethnicity	-0.02	0.00	0.02	-0.09^{*}	0.02	-0.01	1.00										
8	Time since ART started	0.18^{***}	-0.01	0.11^{*}	0.00	-0.00	-0.05	-0.04	1.00									
9	Time since first testing HIV^{+}	0.19^{***}	-0.01	0.15^{**}	-0.01	-0.02	-0.07	-0.04	0.69^{***}	1.00								
10	Disclosure	-0.01	0.10^{*}	-0.10^{*}	0.02	-0.03	0.02	-0.04	0.01	0.04	1.00							
11	CD4 count	0.04	-0.07	0.05	0.08	-0.03	-0.03	-0.06	0.17^{***}	0.21^{***}	-0.03	1.00						
12	Drug use	-0.03	0.19^{***}	-0.02	0.12^{*}	0.02	-0.05	-0.04	0.01	0.04	0.04	0.10^{*}	1.00					
13	Perceived social support	0.04	0.32	0.22^{***}	0.20^{***}	0.06	-0.03	0.02	0.10^{**}	0.08	0.17^{***}	0.02	0.04	1.00				
14	Problem-focused coping	-0.02	0.25^{***}	-0.11^{**}	0.21^{***}	0.09^{*}	0.03	-0.03	0.03	0.07	0.13^{**}	-0.00	0.07	0.31^{***}	1.00			
15	Emotion-focused coping	0.08	-0.03	0.06	-0.06	-0.05	-0.04	0.05	0.01	0.04	0.04	-0.02	0.00	0.02	0.17^{***}	1.00		
16	Internalised stigma	0.08	-0.03	0.07	-0.04	-0.08	-0.00	0.08	-0.00	0.02	-0.25^{*}	-0.08	0.07	-0.12^{***}	0.10^{**}	0.06	1.00	
17	QOL	-0.11^{**}	0.28^{***}	0.16^{***}	0.21^{***}	0.07	-0.05	0.01	-0.02	-0.06	0.06	0.05	0.00	0.31^{***}	0.26^{***}	-0.03	-0.33^{***}	1.00

$^{***}p < 0.001$, $^{**}p < 0.01$, $^{*}p < 0.05$

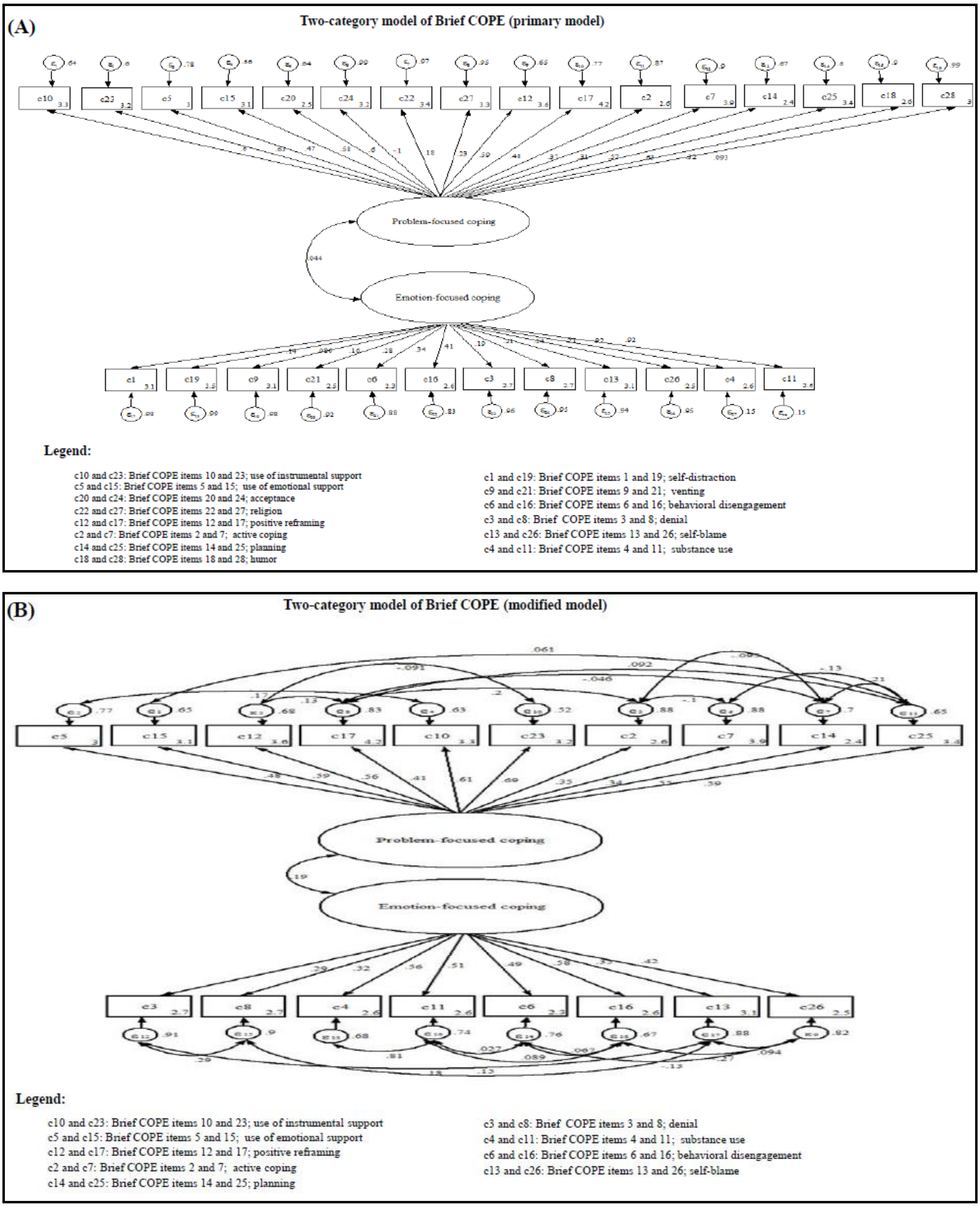


Figure 3.1. Primary and modified measurement models of coping strategy. (A) Primary measurement model; (B) Modified measurement model.

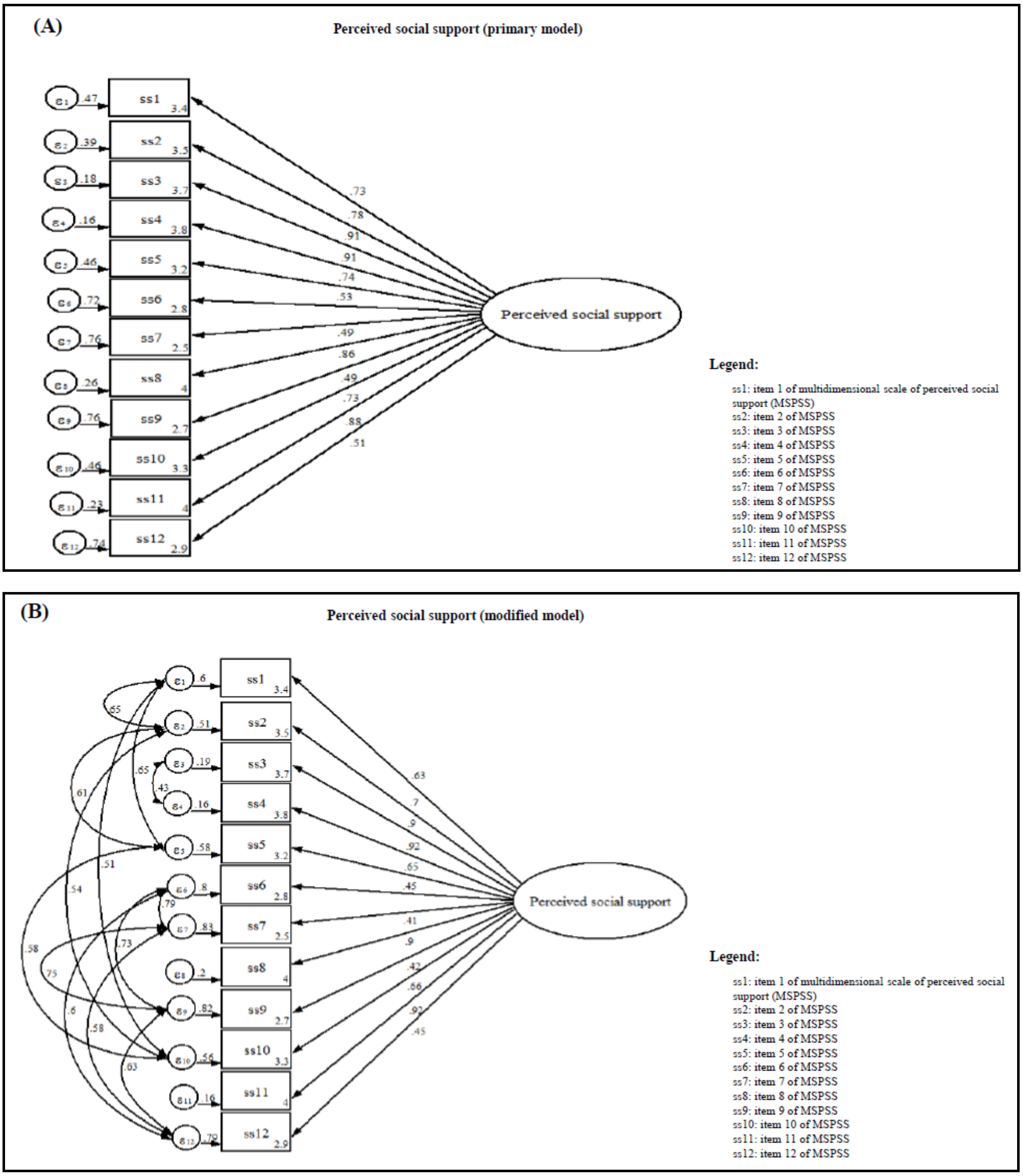


Figure 3.2. Primary and modified measurement models of perceived social support. (A) Primary measurement model; (B) Modified measurement model.

Table 3.4. Fit index of primary model and modified model of perceived social support.

Fit index	Primary model	Critical value	Modified value
Normed chi-squared (χ^2/df)	47.1	< 3	3.0
Comparative fit index (CFI)	0.65	>0.9	0.99
Tucker Lewis index (TLI)	0.57	>0.9	0.98
Root mean square error of approximation (RMSEA)	0.277 (0.268, 0.287)	<0.08	0.065 (0.054, 0.077)
Standardised Root Mean square Residual (SRMR)	0.146	<0.08	0.051

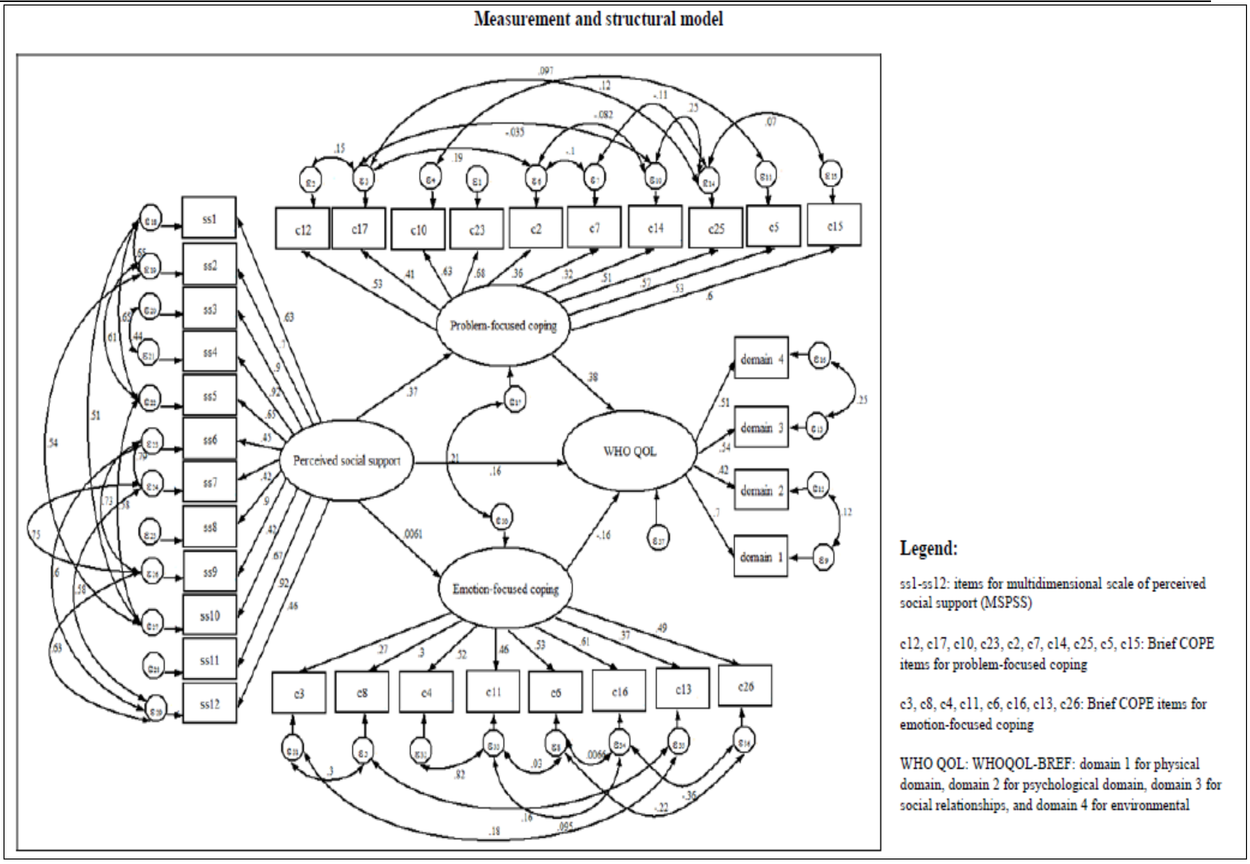


Figure 3.3. Results of SEM analysis for perceived social support, coping, and QOL. All the coefficients are standardised. The path coefficient (0.37) from perceived social support to problem-focused coping is significant at < 0.001 level and to QOL (0.16) is significant at < 0.05 level, that from problem-focused coping (0.38) to QOL are significant at < 0.001 level, that from perceived social support to emotion-focused coping (0.006) is not significant at 0.05 level, and that from emotion-focused coping to QOL (-0.16) is significant at < 0.05 level, and all other coefficients in the figure are significant at 0.001 level. Adjusted for age and sex.

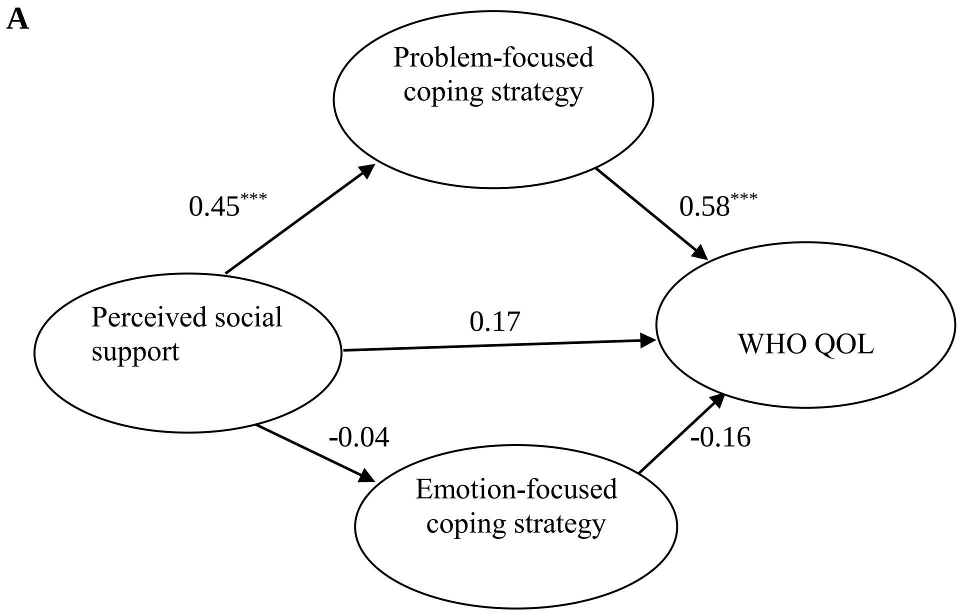
Table 3.5. Fit index of primary model and modified model of full measurement model.

Fit index	Primary model	Critical value	Modified value
Normed chi-squared (χ^2/df)	7.6	< 3	2.54
Comparative fit index (CFI)	0.67	>0.9	0.93
Tucker Lewis index (TLI)	0.65	>0.9	0.92
Root mean square error of approximation (RMSEA)	0.105 (95% CI: 0.102, 0.108)	<0.08	0.051 (0.047, 0.054)
Standardised Root Mean square Residual (SRMR)	0.088	<0.08	0.067

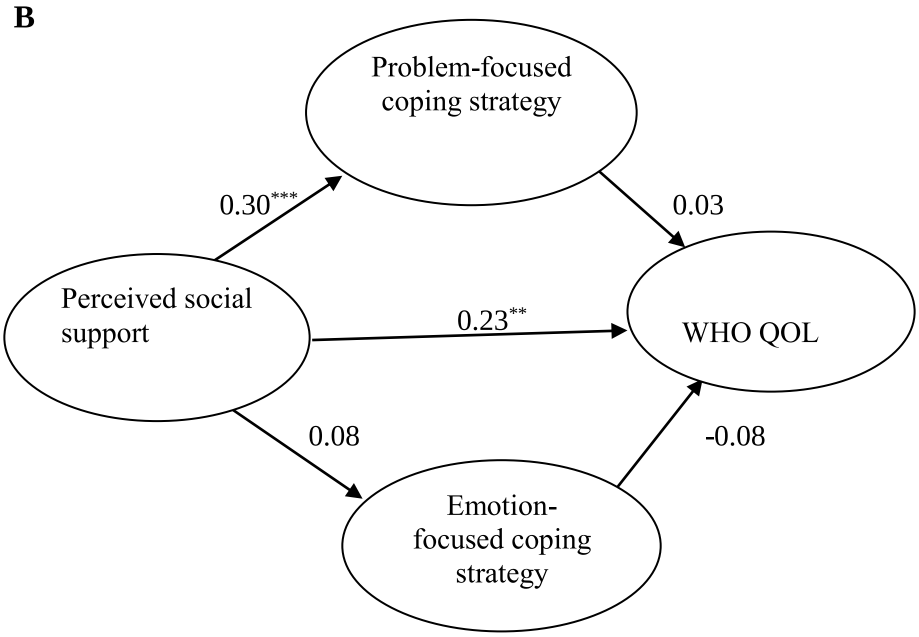
Table 3.6. Results for the direct and indirect effects of perceived social support on quality of life with coping strategy as mediator.

Particular	n	Effects	Point estimate (%)	95% CI
High internalised stigma	245	Direct	0.95 (39.0)	-0.02, 1.93
		Indirect	1.48 (61.0)	0.71, 2.26***
		Total	2.44 (100.0)	1.46, 3.42***
Low internalised stigma	354	Direct	1.24 (99.2)	0.45, 0.02**
		Indirect	0.01 (0.8)	-0.24, 0.26
		Total	1.25 (100.0)	0.50, 1.99***
Whole sample	599	Direct	1.06 (53.8)	0.16, 1.96*
		Indirect	0.91 (46.2)	0.39, 1.44***
		Total	1.97 (100.0)	1.24, 2.71***

$^{***}p < 0.001$, $^{**}p < 0.01$, $^{*}p < 0.05$. Adjusted for age and sex.



$\chi^2/df = 1.67$, CFI = 0.922, TLI = 0.910, RMSEA = 0.052 (95% CI: 0.046-0.058), SRMR = 0.069



$\chi^2/df = 2.18$, CFI = 0.912, TLI = 0.902, RMSEA = 0.058 (95% CI: 0.053-0.063), SRMR = 0.078

Figure 3.4. Results of SEM analysis among the PLHIV with high stigma (A) and low stigma (B). All the coefficients in the figures are standardised. Observed indicators for the latent factors are not shown. $^{**}p < 0.01$, $^{***}p < 0.001$. Adjusted for age and sex.

Table 3.7. Testing measurement invariance across groups (high and low stigma groups).

Goodness-of-fit statistics	χ^2 (*df*)	*p*	$\Delta\chi^2$ (*Δdf*)	*p*	CFI	TLI	SRMR	RMSEA (95% CI)
Model with no restriction	1466.8 (766)	< 0.001			0.932	0.922	0.072	0.055 (0.051-0.060)
Model with restricted measurement weights	1498.1 (793)	< 0.001	31.4 (27)	0.257	0.931	0.925	0.075	0.054 (0.050-0.059)
Model with restricted structural weights	1560.5 (820)	< 0.001	62.4 (27)	< 0.001	0.928	0.923	0.077	0.055 (0.051-0.059)
Model with restricted structural covariance	1956.9 (869)	< 0.001	396.4 (49)	< 0.001	0.894	0.894	0.089	0.065 (0.061-0.068)
Model with restricted structural residuals	1990.3 (873)	< 0.001	33.4 (4)	< 0.001	0.891	0.892	0.088	0.065 (0.062-0.069)
Model with restricted measurement residuals	1995.7 (878)	< 0.001	5.3 (5)	0.376	0.891	0.892	0.096	0.065 (0.061-0.069)

df, degree of freedom. $\Delta\chi^2$ refers to difference in χ^2 values between models, while *Δdf* refers to difference in number of degrees of freedom between models. CFI, comparative fit index; TLI, Tucker-Lewis Index; SRMR, Standardised Root Mean square Residual; RMSEA, root mean square error of approximation.

Table 3.8. Results for the direct and indirect effects of perceived social support on quality of life with various sub-scales of coping strategy as mediator in the whole sample (n = 599)

Coping strategy	Direct	Indirect	Total
Problem-focused coping			
Positive reframing	1.53 (-126.03, 129.08)	0.29 (-127.27, 127.84)	1.81 (1.22, 2.41)***
Instrumental support	1.38 (0.72, 2.05)***	0.47 (-0.07, 1.00)§	1.85 (1.12, 2.59)***
Active coping	1.15 (-5.19, 7.48)	0.65 (-5.68, 6.98)	1.80 (1.20, 2.39)***
Use of emotional support	1.01 (0.30, 1.72)**	0.89 (0.29, 1.49)**	1.90 (1.23, 2.58)***
Planning	1.07 (0.11, 2.03)*	0.09 (0.17, 0.00)*	1.16 (0.43, 1.92)*
Emotion-focused coping			
Self-blame	1.35 (-75.27, 77.98)	-0.08 (-76.70, 76.54)	1.27 (0.73, 1.82)***
Behavioural disengagement	1.30 (0.76, 1.84)***	0.03 (-0.10, 0.16)	1.33 (0.79, 1.87)***
Denial	1.32 (0.76, 1.88)***	0.02 (-0.10, 0.15)	1.34 (0.79, 1.90)***
Substance use	1.79 (1.14, 2.44)***	-0.00 (-0.31, 0.31)	1.79 (1.21, 2.37)***

$^{***}p < 0.001$, $^{**}p < 0.01$, $^{*}p < 0.05$, $^{§}p < 0.1$. Adjusted for age and sex.

Table 3.9. Results for the direct and indirect effects of perceived social support on quality of life with various sub-scales of coping strategy as mediator in high stigma group (n = 245).

Coping strategy	Direct	Indirect	Total
Problem-focused coping			
Positive reframing	1.48 (0.57, 2.38)***	0.80 (0.17, 1.43)*	2.28 (1.37, 3.19)***
Instrumental support	1.14 (0.13, 2.15)*	1.15 (0.31, 2.00)**	2.29 (1.31, 3.28)***
Active coping	-1.24 (-14.59, 12.11)	3.46 (-9.92, 16.84)	2.22 (1.32, 3.13)***
Use of emotional support	0.83 (-0.24, 1.89)	1.35 (0.36, 2.33)**	2.17 (1.20, 3.15)***
Planning	1.85 (0.98, 2.71)***	0.26 (-0.04, 0.57)§	2.11 (1.22, 3.00)***
Emotion-focused coping			
Self-blame	1.77 (-31.90, 35.44)	-0.04 (-33.70, 33.62)	1.73 (0.90, 2.56)***
Behavioural disengagement	1.68 (0.84, 5.51)***	0.08 (-0.08, 0.24)	1.76 (0.92, 2.59)***
Denial	1.81 (-2.35, 5.96)	-0.01 (-4.08, 4.06)	1.80 (0.95, 2.64)***
Substance use	2.15 (114.74, 119.04)	-0.02 (-116.91, 116.87)	2.12 (1.26, 2.99)***

$^{***}p < 0.001$, $^{**}p < 0.01$, $^{*}p < 0.05$, $^{§}p < 0.1$. Adjusted for age and sex.

Table 3.10. Results for the direct and indirect effects of perceived social support on quality of life with various sub-scales of coping strategy as mediator in low stigma group (n = 354)

Coping strategy	Direct	Indirect	Total
Problem-focused coping			
Positive reframing	1.60 (130.10, 133.30)	-0.09 (-131.79, 131.61)	1.51 (0.69, 2.34)***
Instrumental support	0.71 (0.06, 1.37)*	-0.05 (-0.40, 0.31)	0.67 (0.04, 1.29)*
Active coping	1.19 (-13.45, 15.83)	0.11 (-14.52, 14.73)	1.30 (0.54, 2.05)***
Use of emotional support	0.83 (-0.16, 1.81)	0.71 (-0.10, 1.52)§	1.53 (0.65, 2.41)***
Planning	0.58 (0.02, 1.15)*	-0.14 (-0.30, 0.01)	0.44 (-0.07,0.95)
Emotion-focused coping			
Self-blame	0.71 (-10.32, 11.74)	-0.02 (-11.03, 10.99)	0.69 (0.02, 1.35)*
Behavioral disengagement	0.80 (-25.19, 26.79)	-0.07 (-26.05, 25.91)	0.73 (0.07, 1.38)*
Denial	0.68 (0.00, 1.35)*	0.05 (-0.08, 0.19)	0.73 (0.06, 1.40)*
Substance use	1.31 (-215.60, 218.21)	-0.02 (-216.93, 216.88)	1.28 (0.56, 2.01)***

$^{***}p < 0.001$, $^{**}p < 0.01$, $^{*}p < 0.05$, $^{§}p < 0.1$. Adjusted for age and sex.

APPENDICES

Appendix 1

Map of Nepal showing the study area (Kathmandu Valley)

Appendix 2

Interview questionnaire

Respondent no: ☐

Interviewer's name: ____________ Participant's District: _____________

Date of interview: ___________ Time of interview started: _______

Time of interview completed: _____ Total time taken for interview: _________

Signature of supervisor: ______________ Date: ______________

Background Characteristics

1. Sex: 1. Male 2. Female Caste/Ethnicity__________

2. Date of birth: (______Year_______Month______Day) Age: ________

3. Marital status: 1. Married 2. Unmarried 3. Divorced

   4. Widow/widower

4. What is your level of education level?

   1. Illiterate 2. Literate (Years of formal education_____) 3. Others (Specify_____)

5. What is your present job?

   1. Unemployed 2. Office employee 3. Business 4. Others (specify_____)

6. How much do you earn every month? (NRs____________)

7. What is your type of house? 1. Own house 2. Rented house 3. Others

   (specify_____)

8. How many of family members do you have at the present residence? _____ Persons

HIV-related Information

1. When were you diagnosed HIV-positive? Year____Month_____Day_____

2. In your opinion, by which means did you get HIV?

   1. Unsafe sexual intercourse 2. Neeedle/Syringe use 3. Blood transfusion

4. Others___

3. Gender Orientation: 1. Heterosexual 2. Homosexual 3. Both

4. Are you involved in or member of any kind of support group/association?

1. Yes 2. No

5. Have you disclosed your HIV status to anyone? 1. Yes 2. No

If yes, have you ever shared your HIV status with someone from any of the following groups?

a. ______family members

b. ______friends

c. ______Sex partner

d. ______Others infected with HIV

e. ______Health care providers

f. ______Co-worker

g. ______Employer

h. Others_____

6. Your recent CD4 count? ____________

Substance use

1. In the last one month how often did you take alcohol?

1. Almost daily 2. 3-4 times a week 3. 1-2 times a week 4. 2-3 times a month

5. Once in a month 6. Never drank

2. When you drink alcohol how many glasses do you take per day? _______

3. In the last 6 months did you use the following drugs?

a. Marijuana	1. Yes	2. No
b. Cocaine	1. Yes	2. No
c. Injectable drugs	1. Yes	2. No

d. Others (specify)______________

ART related

1. When did you start taking ART? Month_________ Year__________
2. During the last 7 days have you missed to take any of your medications (ART)?

   1. yes 2. No

Social support

		Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree
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	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 emotional help & support	1	2	3	4	5	6	7

	I need from my family							
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 & sorrows	1	2	3	4	5	6	7
10	There is a special person	1	2	3	4	5	6	7

	in my life who cares about my feelings							
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

Stigma

1. It is difficult to tell other people about my HIV infection 1. Yes 2. No
2. Being HIV positive makes me feel dirty 1. Yes 2. No
3. I feel guilty that I am HIV positive 1. Yes 2. No
4. I am ashamed that I am HIV positive 1. Yes 2. No
5. It is my own fault that I am HIV positive 1. Yes 2. No
6. I hide my HIV status from others 1. Yes 2. No
7. I sometime feel worthless because I am HIV positive 1. Yes 2. No

Brief Cope

These items deal with ways you have been coping in your life since you found out you are HIV positive. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously different people deal with things in different ways but, I am interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you have been doing what the item says how much or how frequently. Don't answer on the basis of whether it seems to be working or not-just whether or not you are doing it. Use these responses choices.

		I haven't been doing this at all	I 'have been doing this a little bit	I have been doing this a medium amount	I have been doing this alot
1	I have been turning to work or other activities to take my mind off things.	1	2	3	4
2	I have been concentrating my efforts on doing something about the situation I am in.	1	2	3	4
3	I have been saying to myself "that isn't real."	1	2	3	4
4	I have been using alcohol or other	1	2	3	4

	drugs to make myself feel better.				
5	I have been getting emotional support from others.	1	2	3	4
6	I have been giving up trying to deal with it.	1	2	3	4
7	I have been taking action to try to make the situation better.	1	2	3	4
8	I have been refusing to believe that it has happened.	1	2	3	4
9	I have been saying things to let my unpleasant feelings escape	1	2	3	4
10	I have been getting help & advice from other people.	1	2	3	4
11	I have been using alcohol or other drugs to help me get through it.	1	2	3	4
12	I have been trying to see it in a different light, to make it seem more positive.	1	2	3	4
13	I have been criticizing myself.	1	2	3	4
14	I have been trying to come up with a strategy about what to do.	1	2	3	4

15	I have been getting comfort & understanding from someone.	1	2	3	4
16	I have been giving up the attempt to cope	1	2	3	4
17	I have been looking for something good in what is happening.	1	2	3	4
18	I have been making jokes about it.	1	2	3	4
19	I have been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
20	I have been accepting the reality of the fact that it has happened.	1	2	3	4
21	I have been expressing my negative feelings.	1	2	3	4
22	I have been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23	I have been trying to get advice or help from other people about what to do.	1	2	3	4
24	I have been learning to live with it.	1	2	3	4

25	I have been thinking hard about what steps to take.	1	2	3	4
26	I have been blaming myself for things that happened.	1	2	3	4
27	I have been praying or meditating	1	2	3	4
28	I have been making fun of the sutuation	1	2	3	4

WHO-Quality of life Questionnaire (WHOQOL-BREF)

The following questions ask how you feel about your quality of life, health or others areas of your life. I will read out each question to you, along with the response options. Please choose the answer that appears most appropriate. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks.

1. How would you rate your quality of life?

Very poor: 1
Poor: 2
Neither poor nor good: 3
Good: 4
Very good: 5

2. How satisfied are you with your health?

Very dissatisfied: 1
Dissatisfied: 2
Neither satisfied nor dissatisfied: 3
Satisfied: 4

Very satisfied: 5

The following questions ask about how much you have experienced certain things in the last four weeks.

3. To what extent do you feel that physical pain prevents you from doing what you need to do?

Not at all: 5

A little: 4

A moderate amount: 3

Very much: 2

An extreme amount: 1

4. How much do you need any medical treatment to function in your daily life?

Not at all: 5

A little: 4

A moderate amount: 3

Very much: 2

An extreme amount: 1

5. How much do you enjoy life?

Not at all: 5

A little: 4

A moderate amount: 3

Very much: 2

An extreme amount: 1

6. To what extent do you feel your life to be meaningful?

Not at all: 5

A little: 4

A moderate amount: 3

Very much: 2

An extreme amount: 1

7. How well are you able to concentrate?

Not at all: 1

A little: 2

A moderate amount: 3

Very much: 4

Extremely: 5

8. How safe do you feel in your daily life?

Not at all: 1

A little: 2

A moderate amount: 3

Very much: 4

Extremely: 5

9. How healthy is your physical environment?

Not at all: 1

A little: 2

A moderate amount: 3

Very much: 4

Extremely: 5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

10. Do you have enough energy for everyday life?

Not at all: 1

A little: 2

Moderately: 3

Mostly: 4

Completely: 5

11. Are you able to accept your bodily appearance?

Not at all: 1

A little: 2

Moderately: 3

Mostly: 4

Completely: 5

12. Have you enough money to meet your needs?

Not at all: 1

A little: 2

Moderately: 3

Mostly: 4

Completely: 5

13. How available to you is the information that you need in your day-to-day life?

Not at all: 1

A little: 2

Moderately: 3

Mostly: 4

Completely: 5

14. To what extent do you have the opportunity for leisure activities?

Not at all: 1

A little: 2

Moderately: 3

Mostly: 4

Completely: 5

15. How well are you able to get around?

Very poor: 1

Poor: 2

Neither poor nor good: 3

Good: 4

Very good: 5

16. How satisfied are you with your sleep?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

17. How satisfied are you with your ability to perform your daily living activities?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

18. How satisfied are you with your capacity for work?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

19. How satisfied are you with yourself?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

20. How satisfied are you with your personal relationships?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

21. How satisfied are you with the support you get from your friends?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

22. How satisfied are you with the conditions of your living place?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

23. How satisfied are you with your access to health services?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

24. How satisfied are you with your transport?

Very dissatisfied: 1

Dissatisfied: 2

Neither satisfied nor dissatisfied: 3

Satisfied: 4

Very satisfied: 5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

25. How often do you have negative feelings such as blue mood, despair, anxiety, depression?

Never: 5

Seldom: 4

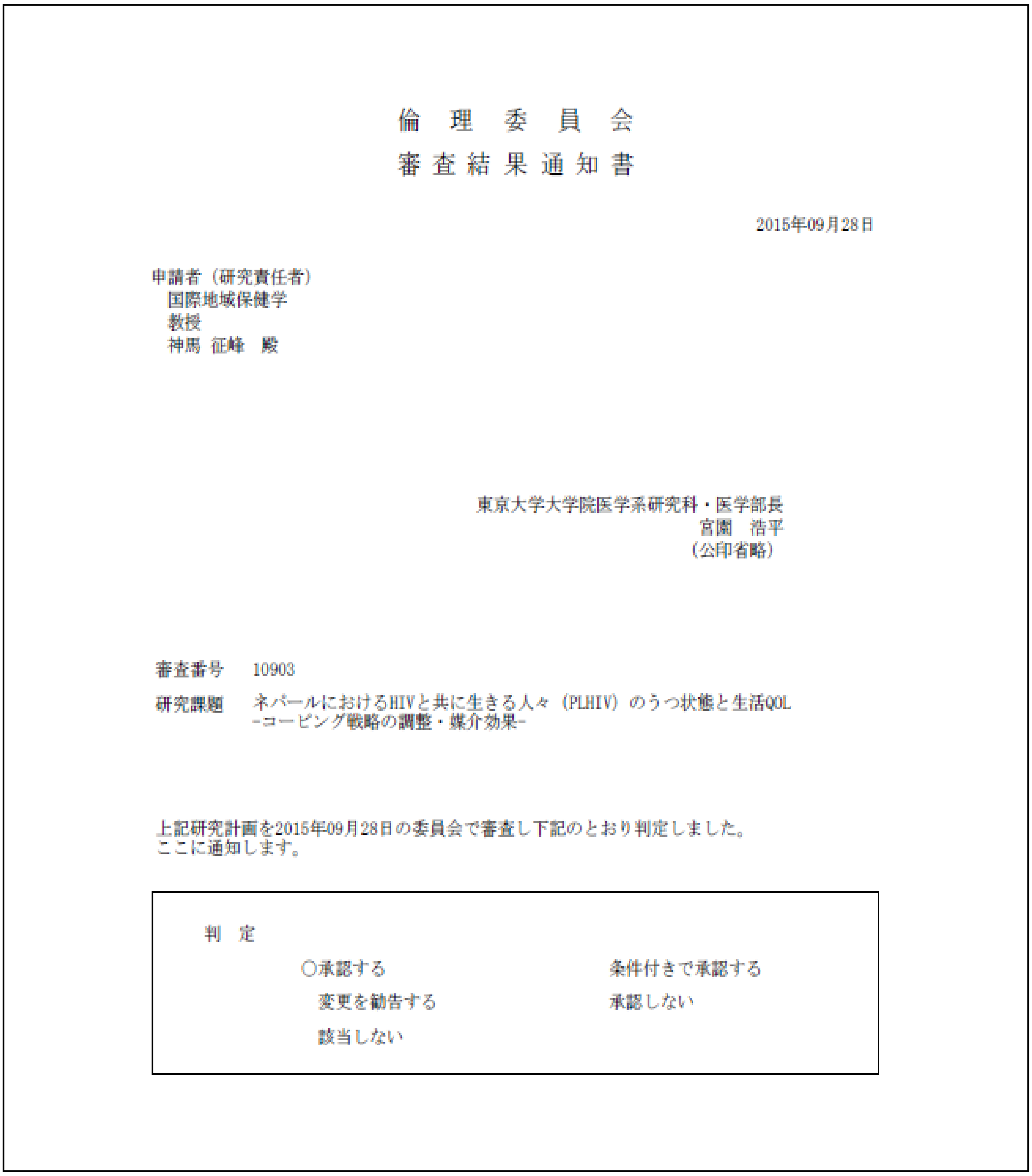
Quite often: 3

Very often: 2

Always: 1

Appendix 3

Ethical approval from the Graduate School of Medicine, the University of Tokyo



倫理委員会
審査結果通知書

2015年09月28日

申請者（研究責任者）
　国際地域保健学
　教授
　神馬 征峰　殿

東京大学大学院医学系研究科・医学部長
宮園　浩平
（公印省略）

審査番号　10903
研究課題　ネパールにおけるHIVと共に生きる人々（PLHIV）のうつ状態と生活QOL
-コーピング戦略の調整・媒介効果-

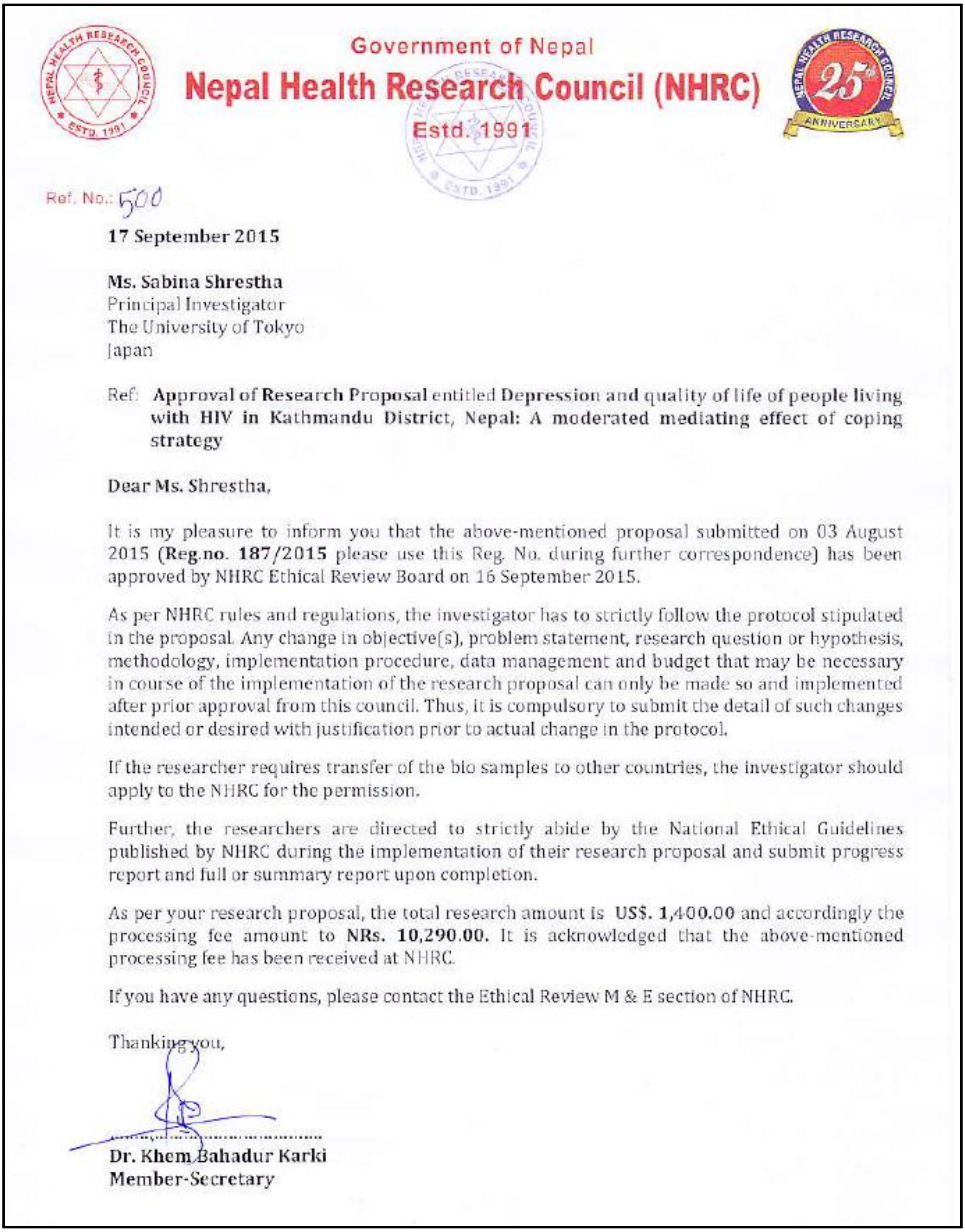
上記研究計画を2015年09月28日の委員会で審査し下記のとおり判定しました。
ここに通知します。

判　定

○承認する
変更を勧告する
該当しない
条件付きで承認する
承認しない

Appendix 4

Ethical approval from Nepal Health Research Council, Kathmandu, Nepal



Government of Nepal
Nepal Health Research Council (NHRC)
Estd. 1991

Ref. No.: 500

17 September 2015

Ms. Sabina Shrestha
Principal Investigator
The University of Tokyo
Japan

Ref: **Approval of Research Proposal** entitled **Depression and quality of life of people living with HIV in Kathmandu District, Nepal: A moderated mediating effect of coping strategy**

Dear Ms. Shrestha,

It is my pleasure to inform you that the above-mentioned proposal submitted on 03 August 2015 (**Reg.no. 187/2015** please use this Reg. No. during further correspondence) has been approved by NHRC Ethical Review Board on 16 September 2015.

As per NHRC rules and regulations, the investigator has to strictly follow the protocol stipulated in the proposal. Any change in objective(s), problem statement, research question or hypothesis, methodology, implementation procedure, data management and budget that may be necessary in course of the implementation of the research proposal can only be made so and implemented after prior approval from this council. Thus, it is compulsory to submit the detail of such changes intended or desired with justification prior to actual change in the protocol.

If the researcher requires transfer of the bio samples to other countries, the investigator should apply to the NHRC for the permission.

Further, the researchers are directed to strictly abide by the National Ethical Guidelines published by NHRC during the implementation of their research proposal and submit progress report and full or summary report upon completion.

As per your research proposal, the total research amount is **US$. 1,400.00** and accordingly the processing fee amount to **NRs. 10,290.00.** It is acknowledged that the above-mentioned processing fee has been received at NHRC.

If you have any questions, please contact the Ethical Review M & E section of NHRC.

Thanking you,

……………………………………

Dr. Khem Bahadur Karki
Member-Secretary

Appendix 5

Information sheet for written informed consent

Study title: Depression and quality of life of people living with HIV in Nepal: A moderated mediating effect of coping strategy

Investigator: Sabina Shrestha (The University of Tokyo)

Greetings!

We are here to collect data for our research. We would like to have some information regarding stigma, social support, coping strategies, quality of life (QOL) and depression among PLHIV. Therefore, we would like to conduct an interview with you with the following objectives:

1) To examine the mediating role of coping strategy in the relationship between social support and QOL and social support and depression of PLHIV.
2) To examine the moderating effect of perceived HIV-related stigma on the mediation effect of coping strategy in the relationship between social support and QOL and social support and depression.

If you agree to proceed with the study, we will conduct an interview. We will ask questions about your HIV status, overall health, feelings and experiences of HIV-related stigma and perceived support you have from friends and families. The interview will take about 60 minutes to complete. You may feel uncomfortable responding to some questions. But, what we learn from you will help improve the QOL of PLHIV in future.

To ensure privacy, any statement you make will be strictly treated as confidential. You don't need to mention your name and instead you will be assigned a code number and interview will not be recorded. Collected data will be handled by the principal researcher (Sabina Shrestha) and kept in a locked cabinet at the University of Tokyo. No body has access to them except the principal researcher and the supervising staff of the Department of International community health, University of Japan. All information will be discarded at the completion of the study.

Your participation for this study is entirely voluntary and you may refuse to answer any question if you don’t want to answer, or may withdraw your consent to participate at any time without penalty or without in any way affecting the health services you receive.

You may ask any question about this study at this time. If you are sure that you have understood what will be required of you and are willing to participate, please sign on the next sheet.

Appendix 6

Informed consent form for participants

Study title: Depression and quality of life of people living with HIV in Nepal: A moderated mediating effect of coping strategy

Investigator: Sabina Shrestha (The University of Tokyo)

I, __(Initials of name)________________after reading and having explained to me the contents of this study, understand what is expected of me as a participant and agree to participate in the study.

I understand:

1. The purpose and procedures of the study
2. The content of the questionnaire
3. That I will not be placed under any harm or discomfort
4. That I may refuse to answer any question if I don't want to answer.
5. That I can withdraw from the study at any time without giving a reason.
6. That I can withdraw from the study at any time (during or after study) without any harm or without in any way affecting the health services I receive.
7. That any information I provide will be strictly treated in a confidential manner that I will not be identified in the reporting of the results

Date: ___________ Signature of the person who gave consent_____________________

Address: ___________

I _________________ certify that I have explained to the participant the content and procedure of the study according to the attached to information page. I have covered all points listed on the consent form from above.

I will protect the confidentiality of the participant.

Date________________ Name/Signature of the person who received consent_______________

For further queries, please contact the following persons

Japan	**Nepal**
Sabina Shrestha	Dr. Sushil Shakya
The University of Tokyo	Bir Hospital
7-3-1, Hongo, Bunkyo-ku, Tokyo, 113 0033	Mahabouddha, Kathmandu