博士論文

Perceived Family Support, Depression, and Suicidal Ideation Among People Living With HIV/AIDS in the Kathmandu Valley, Nepal

（ネパール国カトマンズ渓谷におけるHIV/AIDS感染者の家族支援認識、うつ症状、および自殺念慮）

網谷 レイチェル マリー
Rachel Marie Amiya

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Department of Community and Global Health
The University of Tokyo, Tokyo, Japan
Research supervisor: Prof. Masamine Jimba
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国際保健学専攻
東京大学
指導授員: 神馬征峰 教授
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平成 23 年 4 月通学
41-117101
網谷 レイチェル マリー
Rachel Marie Amiya

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Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
AOR	Adjusted Odds Ratio
ART	Antiretroviral Therapy
AUC	Area Under the (Receiver Operating Characteristic) Curve
BDI	Beck Depression Inventory
BMI	Body Mass Index
CI	Confidence Interval
DALYs	Disability-Adjusted Life Years
DSM	Diagnostic and Statistical Manual
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
IQR	Interquartile Range
LMICs	Low- and Middle-Income Countries
NGO	Non-Governmental Organization
NRs	Nepalese Rupees
PCA	Principal Component Analysis
PFS	Perceived Family Support
PLWHA	People Living With HIV/AIDS
SEM	Structural Equation Modeling
SPSS	Statistical Package for the Social Sciences
US $	United States Dollars
VIF	Variance Inflation Factor
WHO	World Health Organization

Abstract

Background

Depression and suicidality occur frequently alongside HIV/AIDS, with profoundly detrimental impacts. Yet modifiable psychosocial correlates remain underexplored, particularly in low-resource contexts. This study examined influences of perceived family support (PFS) on depression and suicidality among people living with HIV/AIDS (PLWHA) in Nepal.

Methods

A prospective cohort study collected data from 322 PLWHA residing in the Kathmandu Valley, Nepal. Multiple logistic regression analyses identified cross-sectional correlates of Beck Depression Inventory (BDI)-Ia-defined depression and suicidal ideation. Linear regressions assessed variance in adjusted follow-up depressive symptoms explained by total PFS and negative/positive PFS sub-scale scores, along with impacts of PFS changes on depression and suicidality changes at 18-month follow-up. Structural equation models further examined concurrent and prospective associations among variables.

Results

Baseline depression and suicidal ideation occurred in 25.5% and 14.0% of participants, respectively, with significantly lower rates among those with total PFS scores in highest (depression: AOR=.16, p<.001; suicidality: AOR=.35, p=.050) and middle (depression: AOR=.34; p=.003; suicidality: AOR=.43, p=.049) tertiles relative to lowest-tertile scorers. Among 254 participants retained at follow-up, baseline total and positive PFS inversely predicted follow-up depressive symptoms (p<.05). Prospective increases/decreases in total

PFS correlated with lower/higher follow-up depression incidence (p<.05), while changes in *negative* PFS predicted follow-up suicidal ideation (p<.001).

Conclusions

Findings highlight the importance of both supportive and *un*supportive family interactions in determining experiences of depression and suicidality among PLWHA. Psychosocial interventions to mobilize positive family resources and minimize negative dynamics may help improve mental health and, thereby, clinical outcomes and quality of life for PLWHA in Nepal and similar settings.

KEY WORDS*: depression; suicidal ideation; HIV/AIDS; social support; family relations; Nepal; longitudinal studies; prospective studies; cohort studies*

1. Introduction

1.1. Depression, suicidal ideation, and HIV/AIDS

Expanding access to highly active antiretroviral therapy (HAART) has transformed HIV from an imminent death sentence into something akin to a chronic disease in many parts of the world, high- and low-income alike.[1,2] Yet living longer may not always mean living *well*. With the improved health outlook and prolonged life expectancy facilitated through treatment advances,[3-7] mental health issues are coming to the fore as a critical concern among people living with HIV/AIDS (PLWHA).[8-11]

Since the earliest stages of the epidemic, HIV has been associated with considerable mental stress and elevated psychiatric comorbidity. Especially common among the several mental health problems comorbid with HIV/AIDS are depression and suicidal ideation.[8-16] Though reported rates of depression in PLWHA vary widely depending on regional context, diagnostic criteria, methods of measurement, and study sample, estimates are consistently high across countries – between 12% and 71% as measured by the Beck Depression Inventory (BDI) alone.[9,17] Against an estimated lifetime depressive disorder prevalence of 6.7% in the general population,[18] estimated depression prevalence rates (both lifetime and current) are at least two to four times higher in PLWHA relative to general community samples and comparable HIV-negative individuals.[9,12,17] On top of this, the greater prevalence of comorbid psychiatric conditions among PLWHA contributes to an elevated suicide risk.[19-21] Suicidal ideation, attempts, and completions remain alarmingly common and, compared to the general population, more than three times higher among PLWHA,[11,15,19,22-25] despite a recorded decline in suicide rates since the advent of HAART in the 1990s to levels comparable with those of other chronic disease-afflicted populations.[13,15,19,26]

Worldwide, mental health problems are a serious and growing public health concern – constituting the brunt of the non-fatal burden of disease in 2010. Under this umbrella, depressive disorders represent the leading cause of disability-adjusted life years (DALYs) attributable to mental, neurological, and substance use disorders in high-income and low- and middle-income countries (LMICs) alike.[27] Suicide, meanwhile, accounts for roughly one million deaths annually worldwide.[28] Yet in the context of HIV, the ramifications are uniquely deleterious and important clinically.

Depressive symptoms in PLWHA have been associated with adverse medical outcomes including greater risk for comorbid disorders, faster progression from HIV to AIDS, and higher mortality from both AIDS-related and non-AIDS-related causes.[9,29-36] Moreover, PLWHA with depression are more likely to exhibit poor adherence to medical appointments and antiretroviral therapy (ART)[37,38] and more prone to HIV risk behaviors.[9,39-45] Medication non-adherence is particularly problematic in the context of HIV/AIDS, as sub-optimal adherence can promote viral drug resistance[46] and lead to poor immune and viral load response.[47-49]

Conversely, PLWHA who are effectively treated for their depressive symptoms are more likely to adhere to ART over time, with sustained virologic suppression, and to enjoy better health, higher quality of life, and improved sexual risk behaviors.[50] Failure to recognize and address depression in the context of HIV may thus endanger not only the individual, but the community as well. On top of this, high rates of suicidal ideation among PLWHA are a serious concern in that suicidal thoughts generally precede suicidal behaviors.[51] Such psychosocial health problems are critically important to address among PLWHA, particularly inasmuch as they can act syndemically to the detriment of efforts to curb HIV.[52-59]

The causal associations that account for linkages between HIV/AIDS and poor mental health are complex, still incompletely understood, and likely characterized by a bidirectional cause-effect dimension.[9,60,61] On the one hand, people with baseline mental illness are at higher risk for contracting HIV through heightened social vulnerability, poor health-seeking behavior and access to treatment,[62-64] associated substance misuse, and an increased propensity toward HIV risk behaviors.[9,44,52-58,65-72] Elevated rates of depression observed after HIV infection may thus reflect new episodes of pre-existing disorders rather than new-onset depression. Yet on the other hand, PLWHA are also more susceptible to developing psychiatric illnesses due to a complex tangle of social, psychological, and biological factors.[9,60]

Adjusting to and living with an HIV diagnosis entails profound physical and psychosocial stressors that naturally strain mental health. PLWHA face a number of the same challenges confronted by other chronic disease-affected populations, including long-term discomfort, physical deterioration,[73-78] complex medical treatment regimens, medication side effects,[79-82] illness-related changes in social roles and lifestyle patterns, stigma and discrimination,[83-90] financial and material resource concerns, stress and traumatic events,[91-94] and the prospect of impending death.[95-97] Living with HIV/AIDS may thus bring about dramatic shifts in an individual's self-perception, relationship to others, and overall sense of meaning and purpose.[98-101] These adjustments can be stressful and cause a certain amount of despair or sadness that, over time, may lead to depression and other serious mental health complications.

On top of acute and ongoing psychosocial stressors, actual neurological changes in the physical and chemical structures of the central nervous system that occur as a result of the HIV virus, opportunistic infections, or related treatments might predispose PLWHA to developing a depressive illness.[102-107] Certain antiretroviral medications, notably the nonnucleoside reverse transcriptase inhibitor efavirenz, have been linked to central nervous system toxicity, depressive symptoms, and worsening suicidal ideation.[81,108-111] In individuals with more advanced HIV/AIDS, some depressive symptoms may further be linked to disease progression[31,112] or co-infection with hepatitis C virus.[113-116] Taken together, these psychological, biological, and social vulnerability factors could accentuate the negative impact of stressful life events and promote cognitive and behavioral patterns of responding that increase risk for both depression and suicidality in PLWHA.

Despite growing recognition of the diverse and interrelated factors that mediate the interplay between HIV and psychological disturbances, adequate integration of mental health services into the continuum of care for PLWHA remains sorely lacking.[10] Moreover, most of the available data on correlates of poor mental health in this population are generated from high-income countries, though the risks may be heightened in LMICs due to higher levels of poverty, political instability, exposure to trauma, and lower access to services and treatment, among other factors.

1.1.1. HIV/AIDS and mental health in Nepal

Among the 43,239 adult (15-49 years) PLWHA residing in Nepal as of 2011,[117] a number of qualitative and quantitative studies have already highlighted signs of deeply rooted and widespread psychological distress.[95,118-120] One study, utilizing a grounded theory approach to explore the lived experience of HIV/AIDS in Nepal, underlined the immediate and long-lasting psychosocial effects of the disease, including a prolonged "death phobia" – in the sense of both physical death and a more abstract "social death" – and heavy burden of care. Moreover, their HIV-positive diagnosis led some men to take fatalistic approaches, such as resorting to drugs and alcohol as coping mechanisms, while women were more likely to succumb to suicidal ideation and attempts.[95]

Its recognized public health importance notwithstanding, mental health remains a low priority in most LMICs, and unmet needs for treatment are pervasive.[121-123] In Nepal, among the poorest countries in South Asia,[124] mental health is a largely neglected area and faces numerous barriers to improvement, including social stigma, inadequate personnel and health system resources, and a virtual absence of formal mental health services in isolated rural areas, where approximately 90% of the population resides.[125] No national epidemiological data on Nepal's rates of mental illness, including depression and suicide, have been published. Overall, less than 1% of the national health budget is allocated to mental health, and there is no mental health legislation.[126,127] Though a national mental health policy was adopted in 1997 that proposed mental health as an element of primary care, little progress has been made in implementing this policy framework, and human resources for identifying and treating mental health problems remain inadequate. In the Kathmandu Valley, there was just one psychiatrist per 39,000 people, one psychologist per 126,000 people, and one psychosocial counselor per 35,000 people in 2010; outside of Kathmandu, the situation is even more dire.[128]

Beyond the lack of available mental health treatment resources, Asian cultural values of self-reliance and reservation, and a fear of shaming the family, may keep those with mental health problems from seeking assistance – besides which depression, along with other forms of mental illness, is not commonly recognized as a treatable disease entity in many Asian cultures, Nepal included.[129,130] Instead, mental illness is widely considered an out-of-control behavior, a sign of weakness, a danger to society, and something threatening to bring disgrace to the family.[130-132] In Nepal, as in many other Asian societies, mental illness is a highly stigmatized condition, in part, because an individual's ailments or behavior are perceived to affect the whole family, bringing the threat of social, economic, employment, and educational marginalization.[130,133] The "shame" of a family member considered *paagal*, or "mad" (the local slang for mentally troubled, which encompasses severe depression), can, for instance, affect other family members' marriage prospects because of the assumption that "madness" is contagious.[130] Moreover, long-standing cultural practices and even some laws discriminate against those with mental problems. For example, the husband of a woman deemed *paagal* is entitled to divorce or marry a second wife,[125] and families can withhold portions of land from *paagal* members.[134]

On top of the stigma associated with mental illness in Nepalese culture, there are many layers of stigma associated with HIV status in Nepal, intertwined with deeply rooted religious and cultural associations. The general public perception is that HIV transmission affects sex workers, their clients, those who seek intercourse outside marital relationships, and injecting drug users (IDUs) – all behaviors that invite considerable stigma as it is.[135,136] PLWHA in Nepal may thus face discrimination from society, health facilities, and family members alike. In families, forms of discrimination may include restrictions on venturing outside the home, limited exposure to media, use of different utensils for eating purposes, and financial constraints. Female PLWHA in particular may also be prone to experience of violence in the home.[137,138] Such conditions pose a further major barrier to necessary psychosocial and mental health treatment for PLWHA in Nepal, highlighting the great need for potential environmental support mechanisms to be identified and enhanced.

1.2. Social and family support as a psychosocial resource

Countervailing the heavy burden of mental health comorbidities associated with a chronic illness such as HIV/AIDS, social and family support may serve as a source of psychological resilience and exert a buffering effect to help minimize psychological stress.[139] Such psychosocial resources may thus present a promising mechanism through which the mental health needs of PLWHA might fruitfully be addressed, with especially important applications in low-resource settings like Nepal.

As outlined by Cohen, Underwood, and Gottlieb,[140] the construct of social support can be broadly conceptualized as the "social resources that persons perceive to be available or that are actually provided to them by non-professionals in the context of both formal support groups and informal helping relationships". Although specific definitions of social support vary in the literature, most include both tangible components (e.g., financial assistance and physical aid) and intangible components (e.g., emotional encouragement and guidance).[141] House, Landis, and Umberson[142] outlined in 1988 the following four broad types of social support, the spectrum of which still forms the basis for research conducted today:

1. *Instrumental support* (also referred to as *tangible support*) – involves the provision of tangible assistance, in the form of financial aid, material goods, labor, time, or any direct help.[142,143]
2. *Emotional support* – entails both verbal and nonverbal demonstrations of love, caring, encouragement, esteem, empathy, and group belonging.[142,143]
3. *Informational support* – involves the provision of information, education, advice, or guidance toward managing personal and health-related problems.[142,143]
4. *Appraisal support* (also referred to as *affiliative support* or *social integration*) – involves the number of social relationships an individual maintains with others having mutual interests. This type of support also provides information relevant to self-evaluation in the form of affirmation, feedback, and social comparison.[142]

Assessments of social support have also focused on the source of support, which can include family, friends, coworkers, and community members alike. Overall, different types of social resources may serve different purposes with varying degrees of impact depending on the nature of the stressor and the type of support needed.

To further dissect the social support construct, a synthesis of current literature renders the consensus that there are at least two conceptually distinct aspects of the social support system: *structural* social support (i.e., quantity and density of the social network) and *functional* social support (i.e., quality and diversity of the supportive functions of the social network).[139] Structural support measures the extent (i.e., size and strength) of supportive resources consisting of the network of relationships that bind an individual to the surrounding community, whereas functional support is defined in the *perceived* or *actual* support received – be it instrumental, emotional, or informational.[139] In general, functional measures of support are considered to hold more relevance in actively buffering the effects of stressors on well-being, and have been found to exert more enduring direct effects on positive affect.[139,144] In many cases, the perception of available functional support may be even more important that the actual receipt or utility thereof.[139,145-147]

Overall, strong, supportive interactions and the presence of supportive relationships with others are regarded as universal, fundamental human needs and a critical element to achieving optimal physical and mental health.[148-151] In this, researchers have proposed both main effects[152-154] and buffering effects[139,152,155] of social support. The *main effects model* hypothesizes that social support provides beneficial effects on mental health independent of life stressors. These beneficial main effects are thought to stem from a sense of well-being due to group acceptance, assistance, and stable environments. The *buffering* or *mediating model*, meanwhile, posits that social support alleviates the impact of life stressors on mental health. Within this framework, social support mitigates the adverse effects of stressors on depression only in times of high stress, thus significantly reducing the psychological impacts thereof.

Whatever its mode of action, social support is associated with a decreased risk of mental and physical illness, as well as lower mortality,[156-159] and positively affects cardiovascular, endocrine, and immune functioning in the general population.[160-162] Those with higher levels of social support are better equipped to cope with stress,[139,163] exhibit improved medication adherence,[164-166] and experience higher quality of life.[167-169] Even apart from actual receipt of support, the *perception* of available social support itself has shown a consistent direct beneficial impact on health and mood[139,170] and appears to buffer against the risk for depressive episodes or suicidality conferred by chronic disease and other stressful life events.[171-173]

Recognizing the potential in this observed buffering effect, the role of social support in chronic diseases has been extensively researched over the past several decades. Numerous studies demonstrate the positive impacts of social support on adjustment to and coping with physical illness,[174,175] recovery, positive immune response, and reduced risk of mortality.[142,176,177] Overall, social support is associated with better outcomes and improved survival in chronic illnesses including cancer, end-stage renal disease, coronary heart disease, and diabetes.[178-181] Though the mechanism by which social support exerts such salutary effects is not fully understood, practical aid in achieving compliance, better access to health care, improved psychosocial and nutritional status and immune function, and decreased levels of stress may all play key roles.[182,183] Lack of perceived social support and lower perceived adequacy of such psychosocial resources, meanwhile, have been linked to poorer mental and physical health[184,185] as well as poorer clinical outcomes,[186] and can serve as a significant predictor of psychological distress in chronic disease populations.[147,187,188]

In this vein, the social environment of PLWHA in particular has been the subject of increased attention,[189,190] as it is believed that the quality of social relationships may be particularly important for successful psychological adaptation to and coping with an HIV diagnosis.[33,169,191] Indeed, the World Health Organization (WHO) has recommended that concerted efforts be made to integrate the unique psychosocial needs of PLWHA into HIV care and treatment.[192] Social support in PLWHA is associated with improvements in access and adherence to ART, medication uptake, retention in care, physical functioning, CD4 cell progression, virologic suppression, body weight, and mortality.[193] On top of such benefits, numerous studies have demonstrated a strong inverse relationship between supportive social interactions and psychiatric disorders in diverse samples of PLWHA; those satisfied with the amount of support available to them tend to experience less psychological distress, higher quality of life, and higher self-esteem,[85,147,194-198] whereas those who perceive low levels of social support experience increased distress.[199] In the context of HIV/AIDS, the various functions performed by the social support system may encompass providing assistance in activities of daily living (instrumental support), a sympathetic sounding board for emotional feelings and choices (emotional support), and health-related and other information (informational support) – each of which may be needed in varying proportions at different stages of the disease.[200]

1.2.1. The special role of family in times of illness

Among the different categories of social resources, support from family is generally one of the most important factors affecting how patients adapt to stressors like illness.[201,202] Family is frequently the main source of support in times of illness, whether through instrumental support, such as preparing meals and administering medication, or through emotional support.[203] Overall, family relationships have greater emotional intensity than do most other social relationships, and research suggests that there is a substantive, positive association between the specific bonds within families and chronic disease management and outcomes.

Numerous studies have identified the importance of the family environment as a social support resource for those suffering from a chronic illness, in which context the perception of high levels of family support may be protective against the potential psychopathological effects stemming from the physical and social impacts of the disease. In cancer and end-stage renal disease patients, higher levels of family support are associated with lower levels of depression,[204-206] while lack of family support has been linked with increased suicide rates in chronic disease patients.[207,208] Similarly, one study among HIV-positive women in the U.S. found that those reporting suicidal thoughts also reported less family cohesion, while higher levels of family cohesion buffered the suicidal thought-inducing potential of HIV-related symptoms.[88] In this context, social support – and perceived functional support from family in particular – would appear to represent a clear mechanism through which the mental health needs of PLWHA could fruitfully and feasibly be addressed, especially in low-income communities with poor structural facilities,[209,210] where dependence on informal support networks is likely to be heavier.

1.2.2. The double-edged sword of social and family interactions: negative support

While the beneficial impacts of support from social and family networks are widely recognized, the same intimate relationships can also be a source of tension and discord. Yet it is only recently that investigators have begun to examine the negative along with the positive dimensions of social interaction in teasing out the link between social support and mental health. Though the components that underlie the negative side of social relationships are poorly defined in the literature, researchers have typically distinguished social negativity from the mere absence of aid and from efforts to provide support which have negative consequences, defining negative social interactions as affectively unpleasant, resistive, conflictual, hostile, or hurtful transactions.[211]

Although negative interactions typically occur with less frequency compared to positive exchanges with network members,[212] they have the potential to detract considerably from health and well-being. Previous research identifies negative interaction as a risk factor for poor psychological functioning,[213] psychological distress,[214] mood and anxiety disorders,[215-219] declines in physical functioning,[220] and even mortality.[221] In fact, most researchers classify negative interaction as an acute source of stress or as a chronic strain, and studies of common everyday stressors suggest that those of an interpersonal nature (particularly within family relationships) arouse more distress than do other kinds of stressors.[222,223] Additionally, the adverse effects of interpersonal stressors persist over several days, whereas the effects of other stressors typically dissipate more quickly.[222]

A small but growing body of empirical research examining the simultaneous impacts of positive and negative aspects of social support suggests that these types of social exchanges are distinct, frequently co-occur, and have opposing effects on mental health outcomes.[224] Some of this work has demonstrated that negative social interactions may, in fact, have more potent effects on psychological well-being than positive interactions.[219,224] It has even been argued that the *absence* of negative social interactions might be yet more important for health and well-being than the *presence* of positive social interactions.[225] Other studies, meanwhile, report a stronger effect from positive interactions on psychological well-being,[214] whereas still others report equal effects of the two constructs.[226-228] Although empirical evidence is mixed, previous research has repeatedly posited the *stress-buffering* effect of positive social interactions and the *stress-exacerbating* effect of negative social interactions.[229,230] Moreover, studies of the interactive effects of social support and social undermining have further conceptualized negative support as a stressor in its own right and social support as a moderator of the effects thereof – a phenomenon Walen and Lachman[231] have termed the *joint effects hypothesis*.

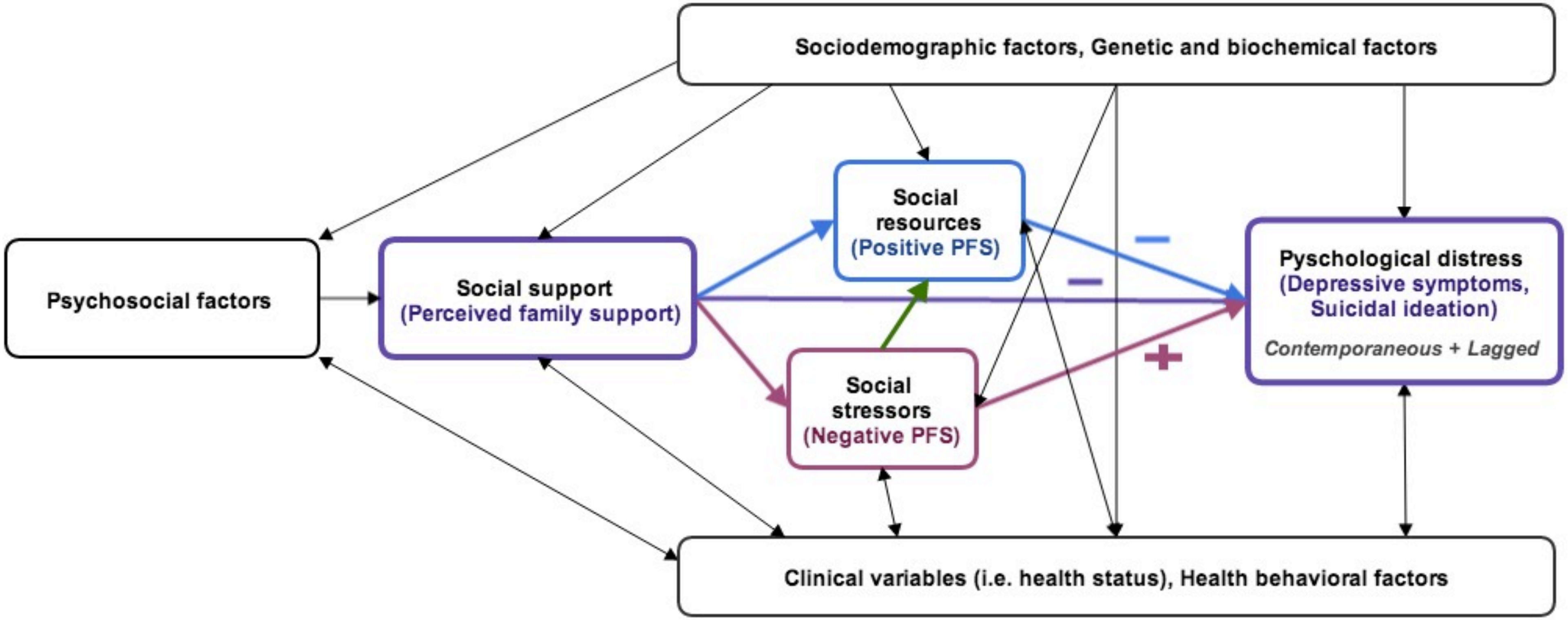
Studies of negative interactions alongside positive dimensions of support have much to offer toward revealing additional linkages between experiences of family support and mental health. This is particularly true in the context of the unique lived experiences and myriad other psychosocial stressors confronted by PLWHA – and where the hardship of HIV-related stigma in combination with the burden of care may place a considerable added strain on existing relationships.[232]

1.3. Research framework and rationale

Advances in HIV treatment have created the need for a shift in the research away from an emphasis on coping with a disease that was invariably fatal to gaining a better understanding of how PLWHA adapt and recover through ongoing treatment and long-term survival. Identifying the modifiable psychosocial risk and resistance factors associated with mental health problems can help to target those who are particularly vulnerable and to identify and implement sound proactive intervention strategies.

As elaborated upon in previous sections, research to date has shown that adverse mental health outcomes in PLWHA may be influenced by a complex interaction of genetic, biochemical, and environmental factors. In particular, environmental factors may encompass a wide array of sociodemographic (e.g., age, sex, education), clinical (e.g., symptom burden, CD4 cell count, viral load), health behavioral (e.g., substance use, diet, physical activity), and psychosocial (e.g., social support, stigma, stress) dimensions. Within this broader framework of risk and protective factors, the present study focuses on family support, an understudied through potentially important sub-category of social support, as a modifiable psychosocial factor potentially impacting psychological distress in PLWHA. Hence, the overarching research framework was formulated as depicted in **Figure 1** to guide the present study, with particular focus on those pathways highlighted in bolded colors.

Figure 1. Conceptual framework for the study



Namely, based on available evidence, it appears that, in PLWHA, (i) psychological distress (e.g., depression, suicidal ideation) is a function of an interactive set of sociodemographic, genetic and biochemical, clinical, and health behavioral characteristics along with key psychosocial factors; (ii) both depression/suicidal ideation and perceived family support (PFS) correlate with sociodemographic, genetic and biochemical, clinical, and health behavioral characteristics; (iii) perceived family support is likely to be a particularly important psychosocial variable predicting psychological distress, both contemporaneous and lagged; (iv) positive dimensions of perceived family support may have an inverse association with depression/suicidal ideation, acting as a social resource; (v) negative dimensions of perceived family support may have a direct association with depression/suicidal ideation, acting as a social stressor; and (vi) positive perceived family support may have a buffering effect on the aforementioned potential impact of negative perceived family support on depression/suicidal ideation (*joint effects hypothesis*).

While research has highlighted the important mental health impacts of sociodemographic, clinical, health behavioral, and other psychosocial factors in the context of HIV/AIDS, few studies so far have examined the multi-dimensional impacts of family support. Moreover, studies examining suicidal ideation along with depressive symptoms as longitudinal outcomes of both positive and negative dimensions of support have been sparse, particularly in the developing country context.[119,147,188,198,199,233-236]

1.3.1. The HIV/AIDS context

The need to consider the influences of both supportive and unsupportive interactions on mental health is particularly salient when examining potentially stigmatizing diseases such as HIV/AIDS, which may impact directly on the support available and create high risk for social isolation, even within families. Indeed, those diagnosed with HIV face what has been called the "double stigma",[237] with the stigma attached to HIV itself layered upon the pre-existing stigma associated with membership of the marginalized groups most at risk of contracting the disease.[238] This makes HIV unique and unlike other progressive and terminal diseases in its psychosocial ramifications.

Discrimination because of HIV status may influence the presence and perceptions of supportive social and family relations, both for those giving and those receiving support. Moreover, close relationships between family and friends may be broken as a result of the onset and progression of the disease, and PLWHA are often alienated, both emotionally and geographically, from the natural support group of their own families. The social unacceptability of an HIV diagnosis is reported to be one of the major concerns of PLWHA,[239,240] and may lead to self-imposed familial estrangement, decreased socialization, or withdrawal.[240-242] Previous studies have shown lower levels of emotional and instrumental support from family among PLWHA,[243] and, compared to men with cancer, men with HIV/AIDS have reported lower satisfaction with social support, even when the actual availability of support is not significantly lower.[244]

1.3.2. The social support context: perceived family support

Importantly, sustained interpersonal strains tend to be more characteristic of relationships with family than with non-related peers overall, as friendships high in unsupportive elements are generally less likely to be maintained relative to the more obligatory bonds of family.[245] Indeed, clinical and empirical findings suggest that family can be a significant source of stress among PLWHA.[246-250] Yet few studies to date have considered the way that each discrete aspect of perceived family support, both negative and positive, may differentially impact mental health. Moreover, little research has conceptualized perceived family support in terms of specific supportive or unsupportive behaviors as in the present study. By asking participants to judge the frequency with which they have experienced or felt each of a set of interpersonal interactions falling into the two categories of functional social support generally deemed most impactful on mental health – emotional and instrumental support – along with several items measuring difficult or problematic interactions (e.g., feeling disliked, experiencing physical abuse), a fuller picture of the types of family support perceived as most helpful or harmful among PLWHA may be gained. Such information could be of particular value in the design of targeted psychosocial interventions in affected populations.

1.3.3. Methodological research gaps

The few previous studies on the mental health impacts of family support have been limited by their reliance on qualitative[241] or cross-sectional data[119,236,242,251,252] and the fact that most have come from treatment settings,[188,253] which often cater almost exclusively to a single transmission group, many of which are at a symptomatic stage of the disease. There is thus a clear need for longitudinal data in community-based settings to provide stronger evidence on temporal relationships between negative and positive dimensions of family support and psychological distress among a more diverse sample of PLWHA.

Utilizing longitudinal data permits measurements of risk factors for depression and suicidal ideation at earlier points in time. This design allows for stronger inferences to be drawn regarding temporal ordering and thus facilitates a closer exploration of whether perceived family support is actually a determining factor in the experience of depression and suicidal ideation among PLWHA. In this way, a better understanding of the manifestations and meanings of perceived family support – in forms both positive and negative – as a potentially modifiable risk factor influencing depression and suicidality in the context of HIV/AIDS may be achieved. Although longitudinal designs are not unambiguous in determining the direction of causality, they represent an improvement over cross-sectional designs in this respect. Further, the importance of longitudinal designs is underscored by evidence showing that main and joint effects of social support and undermining on depressive symptoms differ when assessed cross-sectionally and longitudinally.

1.3.4. The cultural context: Nepal

In Nepal, as in much of South Asia, very few epidemiological studies have been conducted on psychological disorders in the general population, let alone in vulnerable groups such as PLWHA. In the context of the limited resources of LMICs, mental health remains a low priority in general, both in policy and in research terms.[126] In particular, almost all studies of suicidal ideation, attempts, and completions have taken place in the developed as opposed to the developing world, where 85% of suicides occur and where the brunt of the HIV burden lies.[13]

The myopically Western-focused perspective in much of the mental health literature may be problematic when extrapolating to other populations, as fundamental differences in the historical, cultural, and sociological fabric of a country can come into heavy play and limit generalizability of findings.[254,255] In North America and Western Europe, for example, suicide has traditionally been associated with mental illnesses, particularly depression and alcohol abuse. However, studies in Asian countries suggest that different risk factors play a greater role in suicide, including impulsiveness, financial stress, and interpersonal conflict.[13] There is thus a need for research studying factors at play in these populations, as there is much to be learned and understood regarding the potentially unique role that social and family relationships play in contributing to dimensions of mental health.

In the same vein, the restricted focus of much of the social support research, the vast majority of which has been conducted in Western Europe and North America, demands expanded attention in that differences in support-seeking and perceptions of support are closely interwoven into culture.[256-258] Given that much of the research on social support has been conducted in Western cultures, which tend to place particular value on independence[259] whereas many other cultures are more rooted in interdependence, it is important to understand how and whether the protective factors associated with social support differ across cultures. In Asian societies, for example, familial relationships are typically marked by a higher level of responsibility and obligation; consequently, individuals may be more reticent to discuss problems openly out of concern for the potential negative ramifications to the group.[260] In traditional Nepali society, pursuing one's own goals is often superseded by a collectivist emphasis on the family welfare and serving the needs of family members. Hence, valued personal traits include "sacrifice for the common good" and "maintaining harmonious relationships with close others",[261] part of a distinctively collectivist orientation.

Given the high cultural value assigned to family in more collectivistic, interdependent societies and the greater extent to which kin are bound to one another to fulfill emotional and instrumental needs,[262,263] perceived support from family may well be equally or more important to well-being in such settings. In this context, a better understanding of the role of perceived family support as a potentially modifiable factor influencing depression and suicidality among PLWHA in the underexplored context of an Asian LMIC such as Nepal is needed toward developing appropriate psychosocial intervention approaches for those most in need.

1.4. Study objectives

Within this framework, the broad objective of the present study is to contribute stronger evidence on the specific elements of perceived family support (i.e., positive vs. negative dimensions, along with specific supportive or unsupportive behaviors) impacting, both directly and in their interactive effects, on concurrent and future experiences of depression and suicidal ideation using longitudinal data collected from a community-based sample of PLWHA in the Kathmandu Valley, Nepal. Specifically, this research aims:

1. To describe depression, suicidal ideation, and perceived family support in adult PLWHA and changes therein from one point to another over time.
2. To assess the concurrent (cross-sectional) associations of depression and suicidal ideation with perceived family support elements.
3. To determine the extent to which perceived family support dimensions at one point account prospectively for variations in subsequent experience of depression and suicidal ideation.
4. To examine potential moderating interactions between positive and negative dimensions of perceived family support in predicting subsequent experiences of depression and suicidal ideation.
5. To determine whether changes in perceived family support dimensions from one point to another predict incident depression and suicidal ideation, as well as continuous changes in the severity of depressive symptoms and suicidal thoughts over the same period.

2. Methods

2.1. Study design and setting

This prospective cohort study surveyed a community-based sample[264-266] of 322 HIV-positive residents of the Kathmandu Valley in Nepal (see **Appendix 1**), among the poorest countries in South Asia.[124] Baseline and 18-month follow-up interviews were conducted face-to-face during February-March 2010 and June-August 2011, respectively, as part of an ongoing Healthy Living Intervention Study. Data were collected at both time points using pre-tested, structured, Nepali language questionnaires that included measures of depressive symptoms, suicidal ideation, perceived family support, and other demographic, clinical, and psychosocial characteristics. Through such a longitudinal design, the study was able to statistically control for prior levels of depression and to determine whether perceived family support, along with changes therein, prospectively predicted future depression and suicidality levels as well as incident depression and suicidal ideation at follow-up.

A small, landlocked country in South Asia, Nepal was placed at 157 out of 187 countries worldwide on the most recent Human Development Index ranking, putting the country above only Pakistan in comparison with other South Asian countries in terms of social and economic development.[124] About one-third of the Nepali population lives below the poverty line,[267] with wide gaps between rich and poor. The life expectancy at birth is 68 years and the literacy rate is 59%.[268]

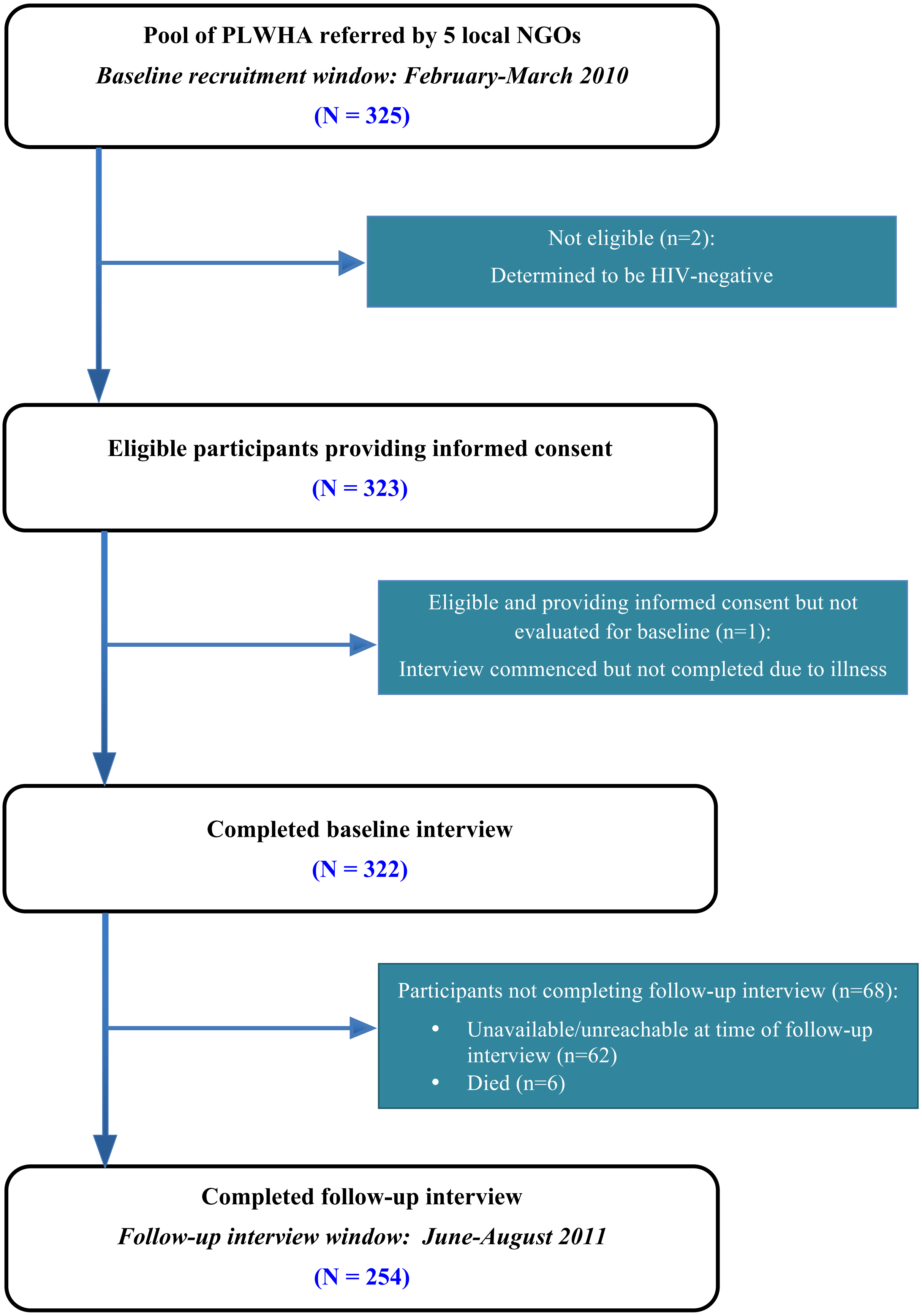
From its first reported case of HIV in 1988, Nepal has faced an escalating concentrated epidemic, with key at-risk populations – men who have sex with men, people who inject drugs, female sex workers, and male labor migrants – constituting 58% of all adult (15-49 years) HIV infections.[269] As of 2011, national estimates indicate that approximately 43,000 adults are HIV-infected, yielding an overall adult prevalence of about 0.3% in the general population.[269] Of those eligible for treatment, 23.7% were receiving ART in 2011.[270] At the end of 2006, almost 16% of the country's HIV-positive population was residing in the Kathmandu Valley,[271] a region in central Nepal comprising three densely populated districts (Kathmandu, Lalitpur, and Bhaktapur) with an estimated population of around 2.5 million as of 2011.[272]

2.2. Participants

Participants were recruited between February and March 2010 in the baseline phase and between June and August 2011 during follow-up. Potentially eligible participants were identified and referred through staff members of five local non-governmental organizations (NGOs) working within HIV-positive communities in the study area. Individuals recruited for participation fulfilled the following inclusion criteria: (1) aged 18 to 60 years, (2) self-reported diagnosis of HIV-positive status, and (3) willing provision of written informed consent for voluntary participation.

Details of the recruitment are presented in **Figure 1**. A total of 322 PLWHA completed the baseline interview and were included in the final cross-sectional analyses, of whom 254 (78.9%) completed the 18-month follow-up interview and were included in the final longitudinal analyses. The 68 individuals lost to follow-up, meanwhile, were excluded from longitudinal analyses.

Figure 2. Recruitment of participants and study completion



2.3. Ethical considerations

Both the Research Ethics Committee of the Graduate School of Medicine at the University of Tokyo and the Nepal Health Research Council reviewed and approved all study protocols and procedures (see **Appendix 2**).

Participation in the study was voluntary. All participants were briefed on the study procedures with the aid of a prepared information sheet (see **Appendix 3**), after which each was asked to provide written informed consent (see **Appendix 4**) prior to being interviewed at both baseline and follow-up. If a patient scored above the established threshold on the depression scale or reported suicidal ideation, at either the baseline or follow-up assessment, psychological referral was duly provided. Moreover, an HIV specialist physician was among the research team members and available for consultation as needed.

Any questions or concerns arising at any stage of the interview process were addressed by the investigator or research assistant. Participants were further informed that their decision about whether to participate in the study would not affect the subsequent care and services received from the NGO, and were advised of their right to discontinue participation at any time without explanation or prejudice. Although complete answering of all questionnaire items was encouraged, participants were also assured that they were not obliged to do so. Confidentiality was strictly preserved throughout the study, with numerical identification numbers used in place of names on all instruments and analyses. Contact information collected for the purposes of scheduling future study visits was stored separately from completed questionnaires.

2.4. Procedures

A structured Nepali language questionnaire was used to conduct the interviews (see **Appendix 5**). This instrument was developed originally in English, translated into the Nepali language, and subsequently back-translated into English to ensure semantic equivalence. Based on the back-translation, the Nepali questionnaire was further revised and modified. At this stage, the questionnaire was then pre-tested in November 2009 among 30 PLWHA drawn from the population of interest. Based on the feedback and observations garnered during pre-testing, additional modifications were made to the final questionnaire. Participants included in the pre-test were not included in the main survey.

After confirming eligibility and seeking informed consent, all participants were asked to complete a structured questionnaire lasting roughly 45-60 minutes, administered by trained interviewers in the Nepali language. All interviews at baseline and follow-up took place at the facilities of the referring NGOs. Interviewers were native Nepali speakers and underwent a one-day training session covering questionnaire content and interview technique to ensure accurate and sensitive administration of the questionnaire.

Approximately 32 individuals were interviewed daily during the baseline period. All surviving participants who had completed the baseline assessment were contacted by telephone at follow-up to arrange interviews during the appointed time period. Participants were reimbursed 100 Nepalese Rupees (NRs) (about US $1.35; US $1.00 = 74.16 NRs on February 16, 2010)[273] for their transportation costs to and from the interview venues at baseline assessment and 250 NRs at the 18-month follow-up assessment. The principal investigator also regularly visited the study sites and supervised the fieldwork.

2.5. Measures

Depression and suicidal ideation. The psychological and psychiatric literature generally uses the term “depression” in two ways: as a psychiatric disorder, and as a point above a given limit of severity on a continuum of depressive symptoms.[274] In the present study, both categorical diagnostic and symptom continuity perspectives on depression were explored. To this end, the 21-item BDI-Ia, Nepali version,[119,275,276] was used to assess the presence and intensity of various cognitive, affective, and somatic signs of depression in participants over the prior 2 weeks (Cronbach’s alpha = .89). The BDI-Ia is a gold standard in measuring depressive symptoms and has been used by different researchers to detect depression among PLWHA in public health settings with high reliability and validity.[119,277] Items are scored on a 4-point Likert scale, with an instrument range of 0 to 62; higher scores indicate more depressed mood. Although the BDI-II was released in 1996 as the most recent revision of the BDI, developed in response to the American Psychiatric Association’s publication of the Diagnostic and Statistical Manual (DSM)-IV, the decision was made to use the BDI-Ia in this study as this is the only version available in a validated Nepalese format.[278] In the process of cultural validation, several important changes were made to the wording of the items, without which the content would not translate appropriately to the context of Nepal. Moreover, the BDI-Ia remains in use for studies of depression etiology in Nepal and other settings.[119,277,279,280]

The BDI-Ia has been validated for use in Nepal with clinical DSM-IV[278] diagnoses of major depressive disorder (area under the curve [AUC] = .92), based on which a score of 20 or higher suggests moderate to severe depressive symptoms with the need for mental health intervention (sensitivity = .73, specificity = .91).[275] This cut-off score is intended only to reflect symptom burden at the level requiring intervention and does not indicate diagnosis of major depressive disorder.

Beyond this categorical approach, researchers are increasingly using measurement approaches that assess depression as a continuum of symptoms with varying degrees of severity, rather than as a strictly threshold-defined diagnosis. This approach fits in with the physiology of depression, which is likely to represent a spectrum of increasing pathology with escalating severity of depression. Accordingly, depressive symptoms were also assessed herein as a continuous variable in longitudinal analyses.

Assessment of suicidal ideation was based on BDI-Ia item #9 ("During the past two weeks, have you thought about ending your life?"), which was used as a dichotomous variable indicating the presence or absence of suicidal thoughts or wishes. Suicidal ideation endorsement was defined as responding to BDI-Ia item #9 with either (1) "I have thoughts of killing myself but I would not carry them out," (2) "I would like to kill myself," or (3) "I would kill myself if I had the chance".[281] Also included on the questionnaire were items asking about ever-experience of suicidal ideation and number of suicide attempts (if any) since being diagnosed with HIV.

Perceived family support. Perceived family support (PFS) is defined herein as the felt availability or provision of different forms of emotional and instrumental services and assistance from family members, along with negative, or *un*supportive, forms of family interaction. The 10-item Nepali Family Support and Difficulty Scale[119,282] (Cronbach's alpha = .87) was used to measure this construct, based on recall of the frequency of given types of social exchanges with family members within the past year.

The scale was developed specifically for use in Nepal based on a review of the social support literature, as broadly detailed in the previous chapter, and with a view to cultural applicability.[282] Focusing specifically on the functional perceived support aspect, which is widely regarded as a stronger predictor of health-related outcomes than actual received support or such structural aspects as network size,[283,284] items were generated based on typologies of general social support. In particular, item generation was designed to include two major categories of perceived functional family support known to be especially important for mental health-related outcomes –tangible assistance (i.e., instrumental support) and emotional support (see Chapter 1 for more detailed descriptions of these constructs). Additionally, several items were generated to reflect the potential negative side of family social exchanges, the importance of which was discussed in Chapter 1, including experience of specific *un*supportive behaviors from family members (i.e., family difficulty) in the form of failure to provide emotional affirmation or closeness and abusive or exploitative behavior.

For each item, participants were asked to rate how true each statement was for their own family, or how often a type of support was available if needed, on a 4-point Likert scale ranging from "Not at all" (0) to "All the time" (3). For the purposes of the present study, the concept of "family" was defined for respondents as encompassing co-residing members of a household. After reversing the scores for negatively formulated items (i.e., measuring unsupportive or problematic experiences of family interaction), the total score was derived by summing all items, with higher scores indicating greater perceived family support (instrument range: 0-30). For the purposes of select cross-sectional analyses, total scores were categorized into *low* (0-22), *moderate* (23-26), and *high* (27-30) levels of perceived support based on tertiles in order to reduce the effect of outliers and random error and to facilitate interpretation of effect sizes. Otherwise and for all longitudinal analyses, scores were assessed continuously.

The 10 items of the Nepali Family Support and Difficulty Scale were subjected to principal component analysis (PCA) using SPSS version 18.0 for Macintosh (SPSS Inc., Chicago, Illinois, USA) to verify which items in the scale formed coherent, relatively independent subsets. Prior to performing PCA, the suitability of data for exploratory factor analysis was assessed. Inspection of the correlation matrix revealed the presence of many coefficients of .30 and above (**Table 1**). Additionally, the Kaiser-Meyer-Oklin value was .88, exceeding the recommended value of .60,[285,286] and Bartlett's Test of Sphericity[287] reached statistical significance, supporting the factorability of the correlation matrix.

Table 1. Correlation matrix among baseline Nepali Family Support and Difficulty Scale items (N = 322)

	1	2	3	4	5	6	7	8	9	10
1. Item #1	-----	-.47**	.44**	-.50**	.54**	.35**	.62**	-.20**	.48**	-.36**
2. Item #2		-----	-.32**	.69**	-.44**	-.48**	-.52**	.32**	-.31**	.43**
3. Item #3			-----	-.36**	.45**	.33**	.41**	-.14*	.38**	-.24**
4. Item #4				-----	-.49**	-.42**	-.47**	.24**	-.36**	.39**
5. Item #5					-----	.36**	.55**	-.16**	.50**	-.27**
6. Item #6						-----	.50**	-.23**	.22**	-.22**
7. Item #7							-----	-.21**	.40**	-.30**
8. Item #8								-----	-.17**	.27**
9. Item #9									-----	-.24**
10. Item #10										-----

* p < .05; ** p < .01 level.
Note: All item scores were assessed as continuous variables.

The number of factors to retain for the solution was decided on the basis of scree plots, eigenvalues, and ease of interpretability. PCA revealed the presence of two components with eigenvalues exceeding 1, explaining 46.4% and 11.3% of the variance, respectively. An inspection of the scree plot revealed a clear break after the first component and another break between the second and third components (see **Appendix 6**). Using Catell's scree test,[288] it was decided to retain two components for further investigation. This was further supported by the results of parallel analysis, which showed only two components with eigenvalues exceeding the corresponding criterion values for a randomly generated data matrix of the same size (10 variables x 322 respondents).

The two-component solution explained a total of 57.7% of the variance. To aid in the interpretation of these two components, oblimin (i.e., oblique) rotation was subsequently performed. This rotation method was chosen because it was believed that the factors would be correlated due to the common underlying construct. Pre-rotation factor loadings are presented in **Appendix 6**, and the pattern and structure matrices and communalities are presented in **Table 2**. The rotated solution revealed the presence of simple structure,[289] with both components showing a number of strong loadings and all variables loading substantially on only one component.

Table 2. Pattern and structure matrix for principal component analysis with oblimin rotation of two-factor solution of the Nepali Family Support and Difficulty Scale

Item	Pattern coefficients		Structure coefficients		Communalities
	Component 1	Component 2	Component 1	Component 2	
5. *Feeling involved in family decision making*	**.810**	.023	**.800**	-.323	.648
9. *Feeling able to share feelings with family*	**.780**	.143	**.799**	-.435	.715
1. *Feeling shown love and caring by family*	**.749**	-.115	**.783**	-.517	.523
3. *Feeling have an important role in family*	**.732**	.021	**.723**	-.291	.688
7. *Feeling supported by family when sick*	**.687**	-.223	**.719**	-.190	.641
6. *Feeling basic needs (e.g., food, clothes) met in family*	**.396**	-.375	**.556**	-.544	.424
8. *Experience of being physically hurt/beaten by family member(s)*	.170	**.779**	-.564	**.810**	.653
2. *Feeling disliked by family*	-.267	**.696**	-.640	**.750**	.523
10. *Feeling exploited (e.g., for domestic labor or farming) by family*	-.021	**.641**	-.163	**.707**	.534
4. *Feeling (emotionally) distant from family*	-.392	**.583**	-.294	**.650**	.423

Note: Major loadings for each item are bolded.

Examination of the items that loaded onto each component revealed a clear pattern of results, with the six positively oriented PFS items (e.g., *Feeling shown love and caring by family*) loading strongly on Component 1 and the four negatively oriented PFS items (e.g., *Feeling disliked by family*) loading strongly on Component 2. A moderate negative correlation was observed between the two components (r = -.59). The results of this analysis thus support the use of the positively and negatively oriented PFS items as separate sub-scales, defining variables hereafter referred to as *positive perceived family support* (*positive PFS*; Cronbach's alpha = .83) and *negative perceived family support* (*negative PFS*; Cronbach's alpha = .74), respectively.

Sociodemographic, clinical, health behavioral, and psychosocial covariates. Standard single questionnaire items assessed basic sociodemographic, HIV-specific clinical, health behavioral, and psychosocial variables. Participants were asked to report the date on which they had learned of their HIV-positive diagnosis, from which duration of HIV-positive status was calculated in months, and, if relevant, the date on which ART had been initiated, from which duration of ART use was calculated in the same manner. Body mass index (BMI) was calculated from the measurement of height and body weight, with underweight status defined as a BMI of less than 18.5 kg/m^2 according to the WHO BMI classification standard for Asians.[290]

A modified 13-item version of the HIV Symptom Index,[291] which assesses the presence and degree of 20 symptoms commonly experienced by HIV-positive individuals, was used to measure HIV symptom burden based on a 1-month recall period (Cronbach's alpha = .90). In previous research, similar measures of symptom burden have been associated with both physical and mental health measures of quality of life as well as provider assessments of disease severity, independent of a patient's viral load or CD4 count. The HIV Symptom Index has evidence of construct validity and is more sensitive and more reproducible than provider-reported HIV symptoms.[291,292]

Though the original version of the HIV Symptom Index assesses the presence and degree of 20 symptoms commonly experienced by PLWHA, seven symptoms (*Fatigue or loss of energy*; *Loss of appetite or change in the taste of food*; *Changes in the way your body looks such as weight gain*; *Problems with weight loss or wasting*; *Felt sad, down or depressed*; *Felt nervous or anxious*; and *Difficulty falling or staying asleep*) were omitted for the purposes of this study to focus on the strictly somatic aspect and avoid overlap with the measure of depressive symptoms (BDI-Ia scores). Participants reported whether each symptom was present, and if so, whether it was bothersome, by using a five-point Likert scale ranging from "I do not have this symptom" (0) to "I have it and it bothers me a lot" (4). Scores were summed to obtain a scale with a possible range of 0-52.[291] For the baseline cross-sectional analyses, total scores were dichotomized into lower and higher levels of HIV symptom burden by the median (12).

A modified 7-item version of a theoretically based and psychometrically sound measure of community-held AIDS-related stigmas, originally developed to measure AIDS-related stigma beliefs in general South African populations,[293,294] was used to assess internalized HIV/AIDS-related stigma (Cronbach's alpha = .82). The scale focuses on internalized stigma, a process through which PLWHA accept their discredited status as valid and develop self-defacing internal representations of themselves.[295] The modified version incorporates seven items from the original scale and reframes the wording to represent negative self-perceptions and self-abasement in relation to being a person living with HIV/AIDS. The items focus on self-blame (e.g., "I sometimes feel worthless because I am HIV positive") and concealment of HIV status from others (e.g., "I hide my HIV status from others”). Responses were given dichotomously (0 = disagree, 1 = agree); scale scores represent the sum total of endorsed items, with higher scores indicating more negative attitudes or perceived discrimination (instrument range: 0-6). For the baseline cross-sectional analysis, total scores were dichotomized into lower and higher levels of stigma by the median (3).

Though 7 items were originally included in the questionnaire, one item (“It is my own fault that I am HIV positive”) with a negative item-total correlation was omitted from further analyses following reliability analysis (see **Appendix 7**). Moreover, “Cronbach’s Alpha if Item Deleted” results showed that this item was decreasing the reliability of the scale slightly, suggesting that it may have been tapping a slightly different concept than originally intended in the Nepalese context.

2.6. Statistical analysis

After describing the data, multivariate regression analyses were carried out, conceptualizing the data first cross-sectionally based on data from all participants surveyed at baseline and then longitudinally using 18-month follow-up data. All major sociodemographic characteristics and other factors having previously established or theoretically feasible associations with the dependent variables were included as covariates or potential confounders in the analyses. Variance inflation factors (VIFs) were low (< 2.0) in all cases, indicating no problematic multicollinearity among independent variables. All statistical tests were 2-sided, evaluated as significant at the 95% confidence level ($p < .05$), and executed using SPSS version 18.0 for Macintosh (SPSS Inc., Chicago, Illinois, USA).

The approach for selecting factors for covariate control was based on substantive knowledge of their possible associations with both the dependent variables and the psychosocial independent variables, and thus on their potential effect as confounders for the association of interest. The inclusion of these factors in the analyses, therefore, was based on existing literature, rather than on statistical significance.[296-298] Moreover, as the common practice of univariate pre-screening of the predictor variables for inclusion in the analyses is less desirable, multiple regression models in which the variables are predetermined a priori would substantiate the findings and also yield results more likely to be reproducible in other samples.[299]

2.6.1. Description of variables and data screening

Descriptive statistics were calculated for all relevant sociodemographic, clinical, health behavioral, and psychosocial characteristics of the study sample – to examine missing values, to evaluate the accuracy of the values, to explore potential univariate outliers, and to characterize the study sample. For all continuous variables, medians, standard deviations, skewness, kurtosis, minimum, and maximum values were inspected for plausibility and for extreme values. Univariate outliers for all continuous variables were inspected by graphical methods (stem-and-leaf and box plots) as well as by inspection of z scores. For discrete variables, meanwhile, frequency tables were examined to ensure that the minimum and maximum values for each item were within the range of potential responses. Finally, similar related variables, such as years of education (continuous variable) and formal education (categorical variable) were compared with cross tabulation tables to identify possible discrepancies between variables.

Inconsistencies and missing values in the data were thus identified and cleaned manually at the outset. Non-response to the individual survey items was low (< 5%), distributed without a noticeable pattern, and hence assumed random and unproblematic.

2.6.2. Cross-sectional analyses

Multiple logistic regression analysis was used to examine factors associated with depressive symptoms and suicidal ideation, with particular emphasis on the association between level of perceived family support and the two mental health outcomes, while controlling for the effect of the covariates identified a priori for inclusion. Additionally, interactions between perceived family support and each of the other variables included as covariates were tested by evaluating the statistical significance of the corresponding first-order cross product terms in separate models; only those identified as statistically significant are presented in the results.

Further multivariate models were also separately constructed to assess potential effects of each of the perceived family support sub-scores and individual scale items on depression and suicidal ideation among the participants, adjusting for the same set of potential confounders. Finally, multiple linear regression was performed to explore factors associated with perceived family support toward assessing the endogeneity of this variable as a function of covariates. Independent variables were entered into each regression using a direct (simultaneous) entry method.

2.6.3. Longitudinal analyses

The longitudinal aspect of the study was designed to facilitate a better understanding of and capture the possible variations in depression that could occur between the two assessment times, and thus to more rigorously examine how perceived family support might relate to such changes temporally. Family support, depressive symptoms, and suicidal ideation data obtained at baseline assessment were compared to data obtained subsequently at 18-month follow-up. In addition, predictive potential and causal directionality between family support and both mental health outcomes as well as changes in these factors over time were examined.

A longitudinal design provides the best information about the continuity of behavior, or lack thereof, over time. It allows for individual tracking of patterns of behavior, as well as trends of development, within a similar group. Research on the epidemiology of depression suggests that symptoms of depression fluctuate markedly in severity over time. These fluctuations may be influenced in part by physical health problems, as are apt to occur among PLWHA. In this context, it was anticipated that fluctuations in depressive symptoms would be observed between the two assessment points in the present study.

Research on the assessment of change has traditionally been carried out at the group level, comparing the change observed in a single group (mean before vs. after treatment), or the change between two groups (mean in the treatment vs. mean in the control group), or the difference in mean change scores between two groups (mean change in the treatment vs. mean change in the control group). However, because group mean comparisons use an estimate that is an average, such an assessment of change at the group level summarizes or aggregates all individual changes in a sample and therefore does not allow for full exploration of changes at the individual level. Intra-individual changes are much more informative in terms of identifying personal and psychological determinants of change. For this reason, the statistical approaches undertaken in the present study were restricted to methods for intra-individual assessment of change.

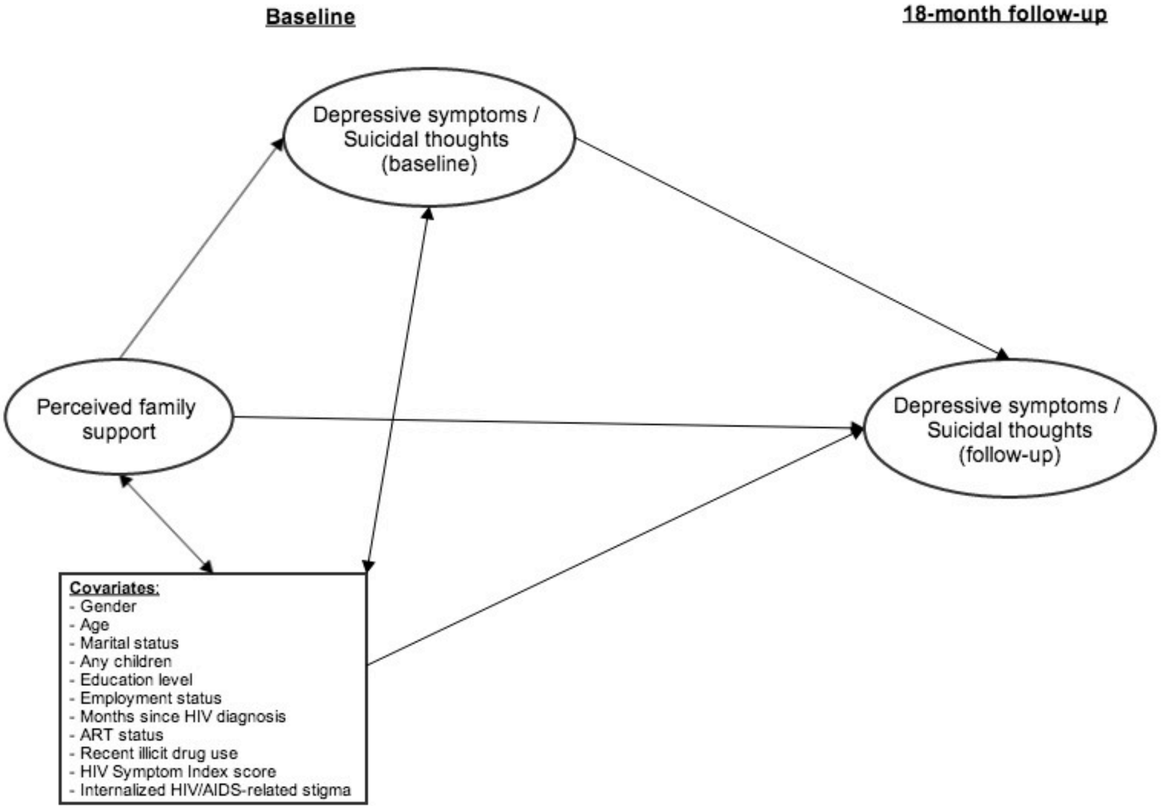
Analyses were conducted in five stages. First, data were checked for any differences in proportions and means of sociodemographic and mental health variables between PLWHA lost and retained at follow-up using Chi-square (for categorical variables) and Mann-Whitney U (for continuous variables) tests as appropriate.

Second, hierarchical multiple linear regression analyses were conducted to assess the proportion of variance in 18-month depressive symptoms that could be explained by baseline perceived family support, while adjusting for baseline covariates as well as the baseline measure of depression. In psychosocial research, it is common practice to use the initial score of the outcome as an adjustment variable in multiple linear regression analysis as a means of accounting for the baseline status of the outcome measure. This *adjusted follow-up score* provides an adjustment for the initial score, and thus allows one to correct for the variance that is accounted for by the baseline score.

As an initial step in the multiple linear regression models, the baseline BDI-Ia score was thus forced into the regression, followed by the sociodemographic, clinical, health behavioral, and psychosocial covariates. Next, the contribution of the total PFS scale score was explored using a partial F test to assess whether perceived family support at baseline still explained a significant proportion of the variance in depression at follow-up, given that depression at baseline was already in the model, as well as other covariates. The same was done for each of the two PFS sub-scale scores – positive perceived family support and negative perceived family support.

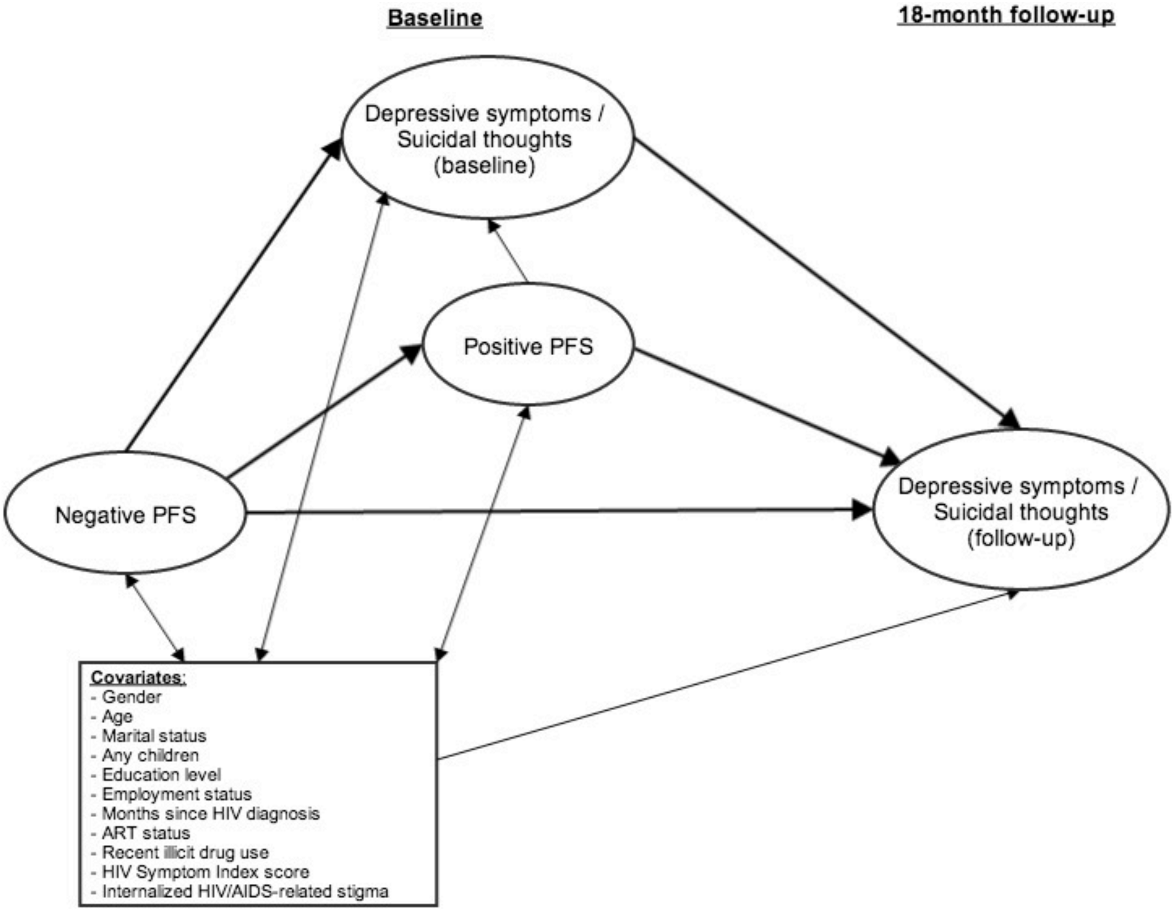
Third, structural equation modeling (SEM) was then used to examine the concurrent and lagged, main and interactive effects of perceived family support dimensions on depression and suicidal ideation, respectively, accounting simultaneously for the associations of covariates with both perceived family support and the outcome variables. The first hypothesized model examined the cross-sectional and longitudinal relationships between baseline total perceived family support and, separately, both depressive symptoms and suicidal thoughts, adjusting for baseline sociodemographic, clinical, health behavioral, and other psychosocial covariates as depicted in **Figure 3** below.

Figure 3. Proposed model of direct relationship between perceived family support at baseline and depressive symptoms and suicidal thoughts at baseline and 18-month follow-up



The second hypothesized model, meanwhile, examined the cross-sectional and longitudinal relationships between baseline negative and positive PFS dimensions and, separately, both depressive symptoms and suicidal thoughts, adjusting for baseline sociodemographic, clinical, health behavioral, and other psychosocial covariates as depicted in **Figure 4** below. This second model looked at negative and positive PFS sub-scales simultaneously in terms of their main as well as interactive effects on depressive symptoms and suicidal thoughts, examining negative PFS as a potential stressor and positive PFS as a potentially buffering factor in predicting psychological distress.

Figure 4. Proposed model of moderated relationship between perceived family support sub-scale scores at baseline and depressive symptoms and suicidal thoughts at baseline and 18-month follow-up



All structural equation models were estimated by means of full-information maximum likelihood estimation using Stata 13 software (Stata Corp., College Station, Texas, USA). Perceived family support dimensions, depressive symptoms (total BDI-Ia score), and suicidal thoughts (BDI-Ia item #9 score) were all evaluated as continuous variables.

Fourth, multiple logistic regressions were used to assess associations between changes in perceived family support dimensions from baseline to follow-up associated with incident depression and suicidal ideation at the 18-month assessment. For the sake of these analyses, PFS changes were classified into two categories: (1) decreased score or sustained low-level (i.e., 1st tertile) score and (2) increased score or sustained high-level (i.e. 3rd tertile) score. Membership of each of these categorized was then used in separate logistic regression models to predict depression incidence and suicidal ideation at 18-month follow-up.

Finally, to supplement these analyses, multiple linear regressions were also used to assess the associations of continuous changes in PFS dimensions against corresponding changes in depressive symptoms and suicidal ideation over the 18-month follow-up period (i.e., changes vs. changes). Toward addressing PFS score ceiling and floor effects on the associations, the analyses were further stratified by "low" and "high" baseline PFS levels based on the median levels within each dimension.

All longitudinal analyses were adjusted for baseline status of the outcome of interest and the same covariates as used in the cross-sectional multiple regression analyses. Underweight status and HIV status disclosure were, however, omitted in longitudinal analyses for the sake of preserving sample size and avoiding over-fitting of the model.

2.6.4. Sample size power

Given that sample size analyses for multivariate multiple linear regression analyses are not readily accessible, power analyses were computed post hoc using G*Power version 3.1 (Franz Faul, Universitat Kiel, German).[300] Such analyses are important to rule out that non-significant findings are not due to lack of power. Power analysis revealed that the sample size retained at follow-up (N = 254) used in longitudinal analyses had well over 80% power to detect medium effect sizes ($t^2 = .15$)[301] in a linear multiple regression model with 13 tested predictors and an alpha level of .05, though the power to detect small effect sizes ($t^2 = .02$)[301] was only 37%.

3. Results

3.1. Description of the study sample

3.1.1. Sociodemographic, clinical, health behavioral, and psychosocial characteristics

Table 3 presents the basic background characteristics of the 322 PLWHA surveyed at baseline. Participants were 58% male and had a median age of 33 (interquartile range [IQR] = 30, 39) years; 82% had at least some formal education, with 59% educated at an above-primary level, and 71% were gainfully employed. Median period since testing HIV-positive was 53 (IQR = 25, 85) months and 73% of participants were on ART at the time of survey, among whom the median length of time on treatment was 24 (IQR = 13, 33) months. Based on BMI (< 18.5), 9% of participants were underweight.

Median HIV Symptom Index score was 12 (IQR = 6, 24), and median internalized HIV/AIDS-related stigma score was 3 (IQR = 2, 5). Overall, 41% of participants had a lifetime history of injecting drug use, while 15% had used some form of illicit drug in the past 6 months. Only 18% had *not* disclosed their HIV status to any of their family members. Median perceived family support, meanwhile, was 25 (IQR = 19, 27), out of a total possible score of 30; median scores on the positive and negative PFS sub-scales were 13 (IQR = 9, 16; out of a total possible score of 18) and 0 (IQR = 0, 2; out of a total possible score of 8), respectively.

3.1.2. Depression and suicidality prevalence rates

Among all participants, 26% met the BDI-Ia threshold for depression. Suicidal ideation in the previous 2 weeks was reported by 14% of respondents. Taking a broader perspective, 43% had *ever* thought about ending their lives and 17% had actually attempted suicide since being diagnosed with HIV, with 35 individuals reporting more than one such suicide attempt (**Table 3**).

Table 3. Background characteristics of participants at baseline (N = 322)

Characteristic	**n**	**(%)**
Sociodemographics		
Gender		
Male	185	(57.5)
Female	137	(42.5)
Median (IQR) Age, years[a] (Range: 20-60)	33	(30, 39)
Marital status		
Unmarried	101	(31.4)
Married	221	(68.6)
Any children		
No	102	(31.7)
Yes	220	(68.3)
Education level[b]		
No formal education	57	(17.7)
Primary (1-5 yrs.)	74	(23.0)
Lower secondary (6-10 yrs.)	160	(49.7)
Higher secondary and above (11+ yrs.)	31	(9.6)
Employment status[c]		
Unemployed	92	(28.7)
Employed	229	(71.3)
Clinical, health behavioral, and psychosocial characteristics		
Median (IQR) Time since HIV diagnosis, months	53	(25, 86)
ART status		
Not currently receiving ART	87	(27.0)
Receiving ART (Median [IQR] = 24 [13, 33] months)	235	(73.0)
Underweight (BMI<18.5)[d]		
No	287	(90.8)
Yes	29	(9.2)
Any illicit drug use, last 6 months		
No	275	(85.4)
Yes	47	(14.6)
Median (IQR) HIV Symptom Index score (Range: 0-52)	12	(6, 24)
Median (IQR) internalized HIV/AIDS stigma score (Range: 0-6)	3	(2, 5)

(Table continues)

Table 3 (*continued*). Background characteristics of participants at baseline (N = 322)

Characteristic	n	(%)
Disclosure of HIV status to any family member		
No	58	(18.0)
Yes	264	(82.0)
Family support and mental health variables		
Total perceived family support (Nepali Family Support and Difficulty Scale score) (Median [IQR]: 25 [19, 27])		
Low (1st tertile; Total score: 0-22)	117	(36.3)
Moderate (2nd tertile; Total score: 23-26)	113	(35.1)
High (3rd tertile; Total score: 27-30)	92	(28.6)
Positive perceived family support (sub-scale score) (Median [IQR]: 13 [9, 16])		
Low (1st tertile; Total score: 0-11)	121	(37.6)
Moderate (2nd tertile; Total score: 12-14)	95	(29.5)
High (3rd tertile; Total score: 15-18)	106	(32.9)
Negative perceived family support (sub-scale score) (Median [IQR]: 0 [0, 2])		
Low (1st tertile; Total score: 0)	186	(57.8)
Moderate (2nd tertile; Total score: 1)	44	(13.7)
High (3rd tertile; Total score: 2-8)	92	(28.6)
Depressive symptoms[e]		
None to mild (BDI-Ia<20)	240	(74.5)
Moderate to severe (BDI-Ia≥20)	82	(25.5)
Suicidal ideation, last 2 weeks		
No	277	(86.0)
Yes	45	(14.0)
Ever thought about ending life since learning of HIV+ status		
No	184	(57.1)
Yes	138	(42.9)
Ever attempted suicide since learning of HIV+ status		
No	268	(83.2)
Yes	54	(16.8)

IQR, interquartile range; ART, antiretroviral therapy; BMI, body mass index; BDI, Beck Depression Inventory.

[a] Two individuals did not respond to this item; their ages were set as the median (33 years) for the sake of analyses.

[b] Education level categories were defined based on the structure of the Nepalese education system.

[c] One individual did not respond to this item.

[d] Height and weight measurements were not collected for six individuals, for whom BMI could thus not be calculated.

[e] A score of 20 or more on the Beck Depression Inventory indicates moderate-to-severe depression with the need for mental health intervention, based on clinical validation of the scale in Nepal (sensitivity = .73, specificity = .91).[302]

3.1.3. Correlations between sociodemographic, clinical, health behavioral, and psychosocial variables

The correlation matrix for sociodemographic, clinical, health behavioral, and psychosocial characteristics of the 322 participants surveyed at baseline is presented in **Table 4**.

Significant correlations were identified between gender and nearly all measured sociodemographic, clinical, health behavioral, and psychosocial covariates in the univariate analyses; female participants were significantly younger (r = -.22, p < .001), more likely to have children (r = .14, p = .012), less likely to be educated beyond the primary level (r = -.31, p < .001), less likely to be gainfully employed (r = -.19, p = .001), more recently diagnosed with HIV (r = -.14, p = .012), more likely to be receiving ART (r = .16, p = .005), less likely to report any illicit drug use in the past 6 months (r = -.32, p < .001), and saddled with heavier burdens of internalized HIV/AIDS-related stigma (r = .16, p = .004). Married participants were both more likely to have children (r = .35, p< .001) and less likely to be underweight (r = -.12, p = .039). Those on ART, meanwhile, were more likely not only to be female, but also to be older (r = .22, p < .001), to have children (r = .14, p = .011), to not be educated beyond the primary level (r = -.16, p = .004), and to report no illicit drug use in the past 6 months (r = -.15, p = .009).

Lower levels of internalized HIV/AIDS-related stigma were correlated not only with male gender but also with gainful employment (r = -.12, p = .032). Also more likely to report lower internalized stigma scores were those who had disclosed their HIV status to at least one family member (r = -.12, p = .036). Such disclosure, meanwhile, was further correlated with being currently married (r = .21, p < .001) and having any children (r = .22, p < .001).

Table 4. Correlation matrix among baseline demographic, clinical, health behavioral, and psychosocial characteristics (N = 322)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1. Female gender	-----	**-.22****	**-.10***	**.14****	**-.31****	**-.19****	**-.14***	**.16****	-.08	**-.32****	.04	**.16****	.03	**-.35****	**.15****	.02
2. Age		-----	.08	**.23****	.03	.01	**.11***	**.21****	.06	.11	-.06	.04	-.01	.11	.08	-.01
3. Currently married			-----	**.35****	-.04	.09	-.06	.07	**-.12***	-.06	.09	-.09	**.21****	**.17****	-.04	-.06
4. Any children				-----	**-.14****	.01	-.06	**.14****	-.04	-.06	-.08	.01	**.22****	.08	.03	-.03
5. Above-primary education					-----	.01	.10	**-.16****	-.05	**.11***	.01	-.05	.02	**.28****	**-.17****	-.09
6. Gainfully employed						-----	**.11***	<.01	-.01	-.04	-.07	**-.12***	.04	.09	**-.20****	**-.16****
7. Time since HIV diagnosis							-----	.03	-.07	.05	-.06	-.09	.10	<.01	**-.16****	-.08
8. Currently receiving ART								-----	.02	**-.15****	-.03	.07	.01	-.08	**.13***	.04
9. Underweight (BMI<18.5)									-----	**.15****	-.01	.01	.01	.01	**.17****	.03
10. Any illicit drug use, last 6 months										-----	-.04	.02	-.08	.08	**.15****	**.19****
11. HIV Symptom Index score											-----	.06	.09	.05	.05	-.06
12. Internalized HIV/AIDS-related stigma score												-----	**-.12***	**-.26****	**.37****	**.14****
13. Disclosure of HIV status to any family member													-----	**.15****	-.10	-.02
14. Total PFS score														-----	**-.36****	**-.22****
15. Total BDI-Ia score															-----	**.54****
16. Suicidal ideation																-----

ART, antiretroviral therapy; BMI, body mass index; PFS, Perceived Family Support; BDI; Beck Depression Inventory.

* p < .05; ** p < .01.

Note: Continuous variables were Age, Time since HIV diagnosis, HIV Symptom Index score, Internalized HIV/AIDS-related stigma score, Total PFS score, and Total BDI-Ia score; all others were binary or categorical.

3.1.4. Correlations between covariates and major variables

Table 4 also presents significant correlations between selected background characteristics of the participants at baseline and the major psychosocial variables of interest. Overall perceived family support showed a negative correlation with female gender (r = -.35, p < .001) and higher internalized HIV/AIDS-related stigma (r = -.26, p < .001), and a positive correlation with being married (r = .17, p = .002), having above-primary-level education (r = .28, p < .001), and disclosure of HIV status to at least one family member (r = .15, p = .008). Female participants (r = .15, p = .006), those not educated beyond the primary level (r = -.17, p = .003), those not gainfully employed (r = -.20, p < .001), those who had been diagnosed with HIV more recently (r = -.16, p = .004), those receiving ART (r = .13, p = .019), those who were underweight (r = .17, p = .002), those reporting any illicit drug use in the past 6 months (r = .15, p = .009), and those with higher levels of internalized HIV/AIDS-related stigma (r = .37, p < .001) presented with higher BDI-Ia scores (i.e. more depressive symptoms). Finally, suicidal ideation was more likely to be endorsed by those without gainful employment (r = -.16, p = .004), those who had been diagnosed with HIV more recently (r = -.12, p = .031), those reporting any illicit drug use in the past 6 months (r = .19, p = .001), and those with higher levels of internalized HIV/AIDS-related stigma (r = .14, p = .011).

3.2. Cross-sectional results

3.2.1. Factors associated with depression and suicidal ideation at baseline

Baseline correlates of depression (BDI-Ia $\geq$ 20) and suicidal ideation (BDI-Ia item #9 > 0) identified from multivariate regression models are presented in **Table 5**. Significantly lower rates of both depression and suicidal ideation were observed among those with PFS scores in the highest (depression: adjusted odds ratio [AOR] = .16, 95% confidence interval [CI] = .06, .39 / suicidal ideation: AOR = .35; 95% CI = .12, 1.00) and middle (depression: AOR = .34; 95% CI = .17, .68 / suicidal ideation: AOR = .43; 95% CI = .18, 1.00) tertiles relative to lowest-tertile PFS scorers.

In addition to the observed inverse relationships with perceived family support, one further variable was negatively associated with *both* psychiatric comorbidities: being gainfully employed (depression: AOR = .43; 95% CI = .22, .82 / suicidal ideation: AOR = .39; 95% CI = .19, .83). On the other side, depression was positively correlated with being on ART for less than 2 years relative to not being on treatment (AOR = 2.66; 95% CI = 1.17, 6.08), with a similar, though statistically non-significant, pattern observed for suicidal ideation. Similarly, suicidal ideation was positively associated with using any illicit drugs in the last 6 months (AOR = 3.19; 95% CI = 1.24, 8.22); again, a similar pattern was observed for depression, though the association was just short of reaching statistical significance. Higher rates of depression were also associated with being underweight (AOR = 3.41; 95% CI = 1.29, 9.03), higher internalized HIV/AIDS-related stigma (AOR = 2.18; 95% CI = 1.16, 4.11), and older age (AOR = 2.14; 95% CI = 1.11, 4.13).

Regarding the moderated regression equations of depression on perceived family support, the interaction term (Family support x Time since HIV diagnosis) was significant at both moderate (AOR = .15; 95% CI = .05, .46) and high (AOR = .08; 95% CI = .02, .31)

PFS levels relative to low PFS levels. This interaction term was also significant in the moderated regression equation of suicidal ideation on perceived family support at moderate PFS levels (AOR = .18; 95% CI = .04, .80), with a similar, though statistically non-significant pattern also observed at high PFS levels. This suggests that the negative relationship between perceived family support and psychological distress was stronger in those individuals who had been living with their HIV diagnosis for longer periods (54 months or more).

Table 5. Multivariable analysis of factors associated with depression and suicidal ideation (N = 315[a])

Variable		Depression (BDI-Ia≥20)				Suicidal ideation (BDI-Ia Item #9>0)			
	N	**n**	**(%)**	**AOR**	**(95% CI)**	**n**	**(%)**	**AOR**	**(95% CI)**
Gender									
Female	135	39	(28.9)	.85	(0.40, 1.82)	20	(14.8)	.72	(.29, 1.80)
Male (Ref)	180	41	(22.8)			23	(12.8)		
Age, years (Median=33)									
34-60	154	49	(31.8)	**2.14**	**(1.11, 4.13)***	19	(12.3)	.81	(.37, 1.74)
20-33 (Ref)	161	31	(19.3)			24	(14.9)		
Marital status									
Married	217	56	(25.8)	1.40	(.69, 2.81)	27	(12.4)	.87	(.38, 1.97)
Unmarried (Ref)	98	24	(24.5)			16	(16.3)		
Any children									
Yes	214	58	(27.1)	1.08	(.54, 2.19)	28	(13.1)	.82	(.36, 1.88)
No (Ref)	101	22	(21.8)			15	(14.9)		
Education level									
Secondary or higher	186	39	(21.0)	.85	(.45, 1.60)	20	(10.8)	.67	(.31, 1.42)
Primary or lower (Ref)	129	41	(31.8)			23	(17.8)		
Employment status									
Employed	223	45	(20.2)	**.43**	**(.22, .82)***	22	(9.9)	**.39**	**(.19, .83)***
Unemployed (Ref)	92	35	(38.0)			21	(22.8)		
Time since HIV diagnosis, months (Median=53)									
54-258	160	34	(21.3)	.85	(.45, 1.60)	16	(10.0)	.73	(.34, 1.57)
0-53 (Ref)	155	46	(29.7)			27	(17.4)		
Time on ART, months (Median=24)									
24-120	116	25	(21.6)	1.42	(.56, 3.59)	10	(8.6)	1.17	(.38, 3.56)
0-23	114	41	(36.0)	**2.66**	**(1.17, 6.08)***	24	(21.1)	2.54	(.99, 6.49)
Not currently receiving ART (Ref)	85	14	(16.5)			9	(10.6)		

(Table continues)

Table 5 *(continued)*. Multivariable analysis of factors associated with depression and suicidal ideation (N = 315[a])

Variable		Depression (BDI-Ia≥20)				Suicidal ideation (BDI-Ia Item #9>0)			
	N	n	(%)	AOR	(95% CI)	n	(%)	AOR	(95% CI)
Underweight (BMI<18.5)									
Yes	29	14	(48.3)	**3.41**	**(1.29, 9.03)***	5	(17.2)	.98	(.31, 3.09)
No (Ref)	286	66	(23.1)			38	(13.3)		
Any illicit drug use, last 6 months									
Yes	45	17	(37.8)	2.34	(.99, 5.52)	12	(26.7)	**3.19**	**(1.24, 8.22)***
No (Ref)	270	63	(23.3)			31	(11.5)		
HIV Symptom Index score (Median=12)									
13-52	156	44	(28.2)	1.16	(.63, 2.11)	19	(12.2)	.62	(.30, 1.29)
0-12 (Ref)	159	36	(22.6)			24	(15.1)		
Internalized HIV/AIDS-related stigma score (Median=3)									
4-6	147	54	(36.7)	**2.18**	**(1.16, 4.11)***	26	(17.7)	1.54	(.71, 3.35)
0-3 (Ref)	168	26	(15.5)			17	(10.1)		
Disclosure of HIV status to any family member									
Yes	257	65	(25.3)	1.65	(.75, 3.67)	34	(13.2)	1.69	(.66, 4.33)
No (Ref)	58	15	(25.9)			9	(15.5)		
Perceived family support									
High (3rd tertile; Total score: 27-30)	89	11	(12.4)	**.16**	**(.06, .39)****	7	(7.9)	**.35**	**(.12, 1.00)***
Moderate (2nd tertile; Total score: 23-26)	111	23	(20.7)	**.34**	**(.17, .68)****	12	(10.8)	**.43**	**(.18, 1.00)***
Low (1st tertile; Total score: 0-22) (Ref)	115	46	(40.0)			24	(20.9)		
Interaction terms									
Perceived family support x Time since HIV diagnosis									
High PFS x 54+ months HIV+	44	3	(6.8)	**.08**	**(.02, .31)****	2	(4.5)	.22	(.04, 1.16)
Moderate PFS x 54+ months HIV+	58	7	(12.1)	**.15**	**(.05, .46)****	3	(5.2)	**.18**	**(.04, .80)***
Low PFS x 54+ months HIV+ (Ref)	60	24	(40.0)			11	(18.3)		

BDI, Beck Depression Inventory; AOR, adjusted odds ratio; CI, confidence interval; BMI, body mass index; PFS, perceived family support.

* p < .05; ** p < .01.

[a] Seven individuals were omitted from the analysis due to missing information regarding employment status (one individual) and BMI (six individuals).

3.2.2. Family support as a correlate of depression and suicidal ideation

Table 6 presents the results for multiple logistic regression analyses of sub-scale scores and individual items from the perceived family support scale associated with depression and suicidal ideation among participants. Of the two different sub-types of support measured, only negative PFS was significantly associated with *both* measures of psychological disturbance; those perceiving high levels of negative interaction with their family were nearly four times more likely to be depressed (AOR = 3.77; 95% CI = 1.90, 7.47) and over four times more likely to report suicidal ideation (AOR = 4.17; 95% CI = 1.80, 9.67) than were their counterparts perceiving low levels of such unsupportive family exchanges. Those reporting high levels of positive PFS were also nearly four times *less* likely to register depression as were those reporting low levels of such support (AOR = .26; 95% CI = .12, .60), but this same significant association was not observed with suicidal ideation as the dependent variable.

Turning to the item-wise analysis of the perceived family support scale elements, only one item from the positive PFS sub-scale (a distinctly *emotional* support element) had a significant inverse association with both mental health outcomes: *Feeling shown love and caring by family* (depression: AOR = .61; 95% CI = .43, .85 / suicidal ideation: AOR = .66; 95% CI = .44, 0.98). In contrast, among the four negative PFS sub-scale items, a total of three showed significant positive associations with both depression and suicidal ideation: *Feeling disliked by family* (depression: AOR = 1.59; 95% CI = 1.14, 2.21 / suicidal ideation: AOR = 2.08; 95% CI = 1.45, 2.99), *Feeling (emotionally) distant from family* (depression: AOR = 1.63; 95% CI = 1.14, 2.33 / suicidal ideation: AOR = 2.14; 95% CI = 1.43, 3.20), and *Feeling exploited (e.g., for housework or farming) by family* (depression: AOR = 2.06; 95% CI = 1.44, 2.95; suicidal ideation: AOR = 1.80; 95% CI = 1.23, 2.65).

Regarding the moderated regression equations of depression on perceived family support sub-scale elements, the interaction term (Negative PFS sub-score x Any kids) was significant at high negative PFS levels relative to low negative PFS levels (AOR = 12.72; 95% CI = 2.53, 63.99). This suggests that the association between experiences of negative family interaction and depression was substantially stronger among those with children.

Table 6. Multivariable analyses[a] of individual perceived family support items associated with depression and suicidal ideation (N = 315[b])

Item[c]	**Depression (BDI-Ia≥20)**		**Suicidal ideation (BDI-Ia item #9>0)**	
	AOR	**(95% CI)**	**AOR**	**(95% CI)**
Positive perceived family support				
Feeling shown love and caring by family	**.61**	**(.43, .85)****	**.66**	**(.44, .98)***
Feeling have an important role in family	.87	(.62, 1.22)	.73	(.49, 1.07)
Feeling involved in family decision making	**.71**	**(.54, .93)***	.73	(.52, 1.01)
Feeling basic needs (e.g., food, clothes) met in family	.79	(.51, 1.20)	.66	(.42, 1.03)
Feeling supported by family when sick	.75	(.55, 1.02)	**.66**	**(.46, .93)***
Feeling able to share feelings with family	**.67**	**(.50, .90)****	.93	(.65, 1.33)
Positive PFS sub-scale score				
High (15-18)	**.26**	**(.12, .60)****	.52	(.20, 1.34)
Moderate (12-14)	.49	(.24, 1.03)	.53	(.21, 1.30)
Low (0-11) (Ref)				
Negative perceived family support				
Feeling disliked by family	**1.59**	**(1.14, 2.21)****	**2.08**	**(1.45, 2.99)****
Feeling (emotionally) distant from family	**1.63**	**(1.14, 2.33)****	**2.14**	**(1.43, 3.20)****
Being physically hurt/beaten by family member(s)	0.85	(.42, 1.72)	1.23	(.61, 2.45)
Feeling exploited (e.g., for housework or farming) by family	**2.06**	**(1.44, 2.95)****	**1.80**	**(1.23, 2.65)****
Negative PFS sub-scale score				
High (2-12)	**3.77**	**(1.90, 7.47)****	**4.17**	**(1.80, 9.67)****
Moderate (1)	1.48	(.61, 3.60)	1.58	(.54, 4.60)
Low (0) (Ref)				

(Table continues)

Table 6 *(continued)*. Multivariable analyses[a] of individual perceived family support items associated with depression and suicidal ideation (N = 315[b])

Item[c]	Depression (BDI-Ia≥20) AOR	Depression (BDI-Ia≥20) (95% CI)	Suicidal ideation (BDI-Ia item #9>0) AOR	Suicidal ideation (BDI-Ia item #9>0) (95% CI)
Interaction terms				
Negative PFS sub-scale score x Any kids				
High negative PFS x Any kids	**12.72**	**(2.53, 63.99)****	2.40	(.43, 13.31)
Moderate negative PFS x Any kids	.47	(.08, 2.92)	2.80	(.33, 23.84)
Low negative PFS x Any kids (Ref)				

AOR, adjusted odds ratio; *CI,* confidence interval; *ART,* antiretroviral therapy; BDI, Beck Depression Inventory; PFS, perceived family support.

* $p < 0.05$; ** $p < 0.01$.

[a] Separate analyses were carried out for each of the ten individual items on the family support scale, adjusting as well for all variables listed in Table 2.

[b] Seven individuals were omitted from the analysis due to missing information regarding employment status (one individual) and BMI (six individuals).

[c] Each individual item was assessed as a continuous variable, with responses ranging from 0 (Not at all) to 3 (All the time).

3.2.3. Factors associated with perceived family support

Three variables were significantly associated with global perceived family support among participants at baseline: gender, education level, and internalized HIV/AIDS-related stigma. Namely, female participants and those reporting higher levels of internalized stigma perceived lower levels of family support. On the other side, those educated to the primary level or higher enjoyed higher perceived family support levels (**Table 7**).

Table 7. Multivariable analysis of factors associated with perceived family support (N = 315[a])

Variable	**Coefficient *(B)***	**SE**	**95% CI**	
			Lower	Upper
Gender (Female)	**-3.31**	.72	**-4.72**	**-1.89****
Age, *years*	.04	.05	-.05	.13
Marital status	.72	.71	-.68	2.12
Any children	1.35	.73	-.08	2.78
Above-primary education	**2.50**	.64	**1.25**	**3.75****
Gainfully employed	.03	.67	-1.29	1.35
Time since HIV diagnosis, *months*	-.01	.01	-.02	<.01
Receiving ART	-.14	.71	-1.52	1.25
Underweight (BMI<18.5)	.18	1.04	-1.87	2.23
Any illicit drug use, last 6 months	-.40	.91	-2.19	1.39
HIV Symptom Index score	.03	.03	-.02	.08
Internalized HIV/AIDS-related stigma score	**-.54**	.14	**-.82**	**-.25****
Disclosure of HIV status to any family member	1.41	.81	-.18	2.99

SE, standard error; ART, antiretroviral therapy; BMI, body mass index.
* p < .05; ** p < .01.
[a] Seven individuals were omitted from the analysis due to missing information regarding employment status (one individual) and BMI (six individuals).

3.3. Longitudinal results

3.3.1. Participants lost and retained at follow-up

Overall, 254 participants completed the 18-month follow-up interview, yielding a retention rate of 78.5%. Those lost to follow-up were more likely to be male (p = .028), to be employed (p = .008), to be underweight (p = .004), and to report not using any illicit drugs in the past 6 months (p < .001). Among participants on ART at the time of the baseline survey, those not available to participate in the follow-up interview also reported a significantly lower median time since initiating treatment (13 months vs. 24 months; p = .004; **Table 8**).

Table 8. Baseline background characteristics of participants who completed the 18-month follow-up interview (N = 254) compared to those who did not complete the follow-up interview (N = 68)

Characteristic	Baseline + Follow-up (N = 254)		Baseline only (N = 68)		*p*-value[a]
	n	**(%)**	**n**	**(%)**	
Sociodemographics					
Gender					**.028**
Male	138	(54.3)	47	(69.1)	
Female	116	(45.7)	21	(30.9)	
Median (IQR) Age, years[b] (Range: 20-60)	33 (33, 38)		34 (30, 42)		.138
Marital status					.169
Unmarried	75	(29.5)	26	(38.2)	
Married	179	(70.5)	42	(61.8)	
Any children					.456
No	83	(32.7)	19	(32.7)	
Yes	171	(67.3)	49	(67.3)	
Education level[c]					.795
No formal education	45	(17.7)	12	(17.6)	
Primary (1-5 yrs.)	61	(24.0)	13	(19.1)	
Lower secondary (6-10 yrs.)	125	(49.2)	35	(51.5)	
Higher secondary and above (11+ yrs.)	23	(9.1)	8	(11.8)	
Employment status[d]					**.008**
Unemployed	64	(25.2)	28	(41.8)	
Employed	190	(74.8)	39	(58.2)	

(Table continues)

Table 8 *(continued)*. Baseline background characteristics of participants who completed the 18-month follow-up interview (N = 254) compared to those who did not complete the follow-up interview (N = 68)

	Baseline + Follow-up (N = 254)	Baseline only (N = 68)	
Characteristic	**n (%)**	**n (%)**	***p*-value**[a]
Clinical, health behavioral, and psychosocial characteristics			
Median (IQR) Time since HIV diagnosis, months	57 (27, 90)	39 (13, 86)	.069
ART status			.419
Not currently receiving ART	66 (26.0)	21 (30.9)	
Receiving ART	188 (74.0)	47 (69.1)	
Median (IQR) Time since initiating ART, months	24 (11, 42)	13 (2, 34)	**.004**
Underweight (BMI < 18.5)[e]			**.004**
No	17 (6.8)	12 (18.5)	
Yes	234 (93.2)	53 (81.5)	
Any illicit drug use, last 6 months			**<.001**
No	226 (89.0)	49 (72.1)	
Yes	28 (11.0)	19 (27.9)	
Median (IQR) HIV Symptom Index score (Range: 0-52)	12 (6, 24)	12 (12, 22)	.573
Median (IQR) internalized HIV/AIDS-related stigma score (Range: 0-6)	3 (1, 5)	3 (2, 5)	.873
Disclosure of HIV status to any family			.789
No	45 (17.7)	13 (19.1)	
Yes	209 (82.3)	55 (80.9)	
Family support and mental health variables			
Perceived family support (Nepali Family Support and Difficulty Scale score)			.802
Low (1st tertile; Total score: 0-22)	90 (35.4)	27 (39.7)	
Moderate (2nd tertile; Total score: 23-26)	90 (35.4)	23 (33.8)	
High (3rd tertile; Total score: 27-30)	74 (29.1)	18 (26.5)	

(Table continues)

Table 8 *(continued)*. Baseline background characteristics of participants who completed the 18-month follow-up interview (N = 254) compared to those who did not complete the follow-up interview (N = 68)

	Baseline + Follow-up (N = 254)		Baseline only (N = 68)		
Characteristic	**n**	**(%)**	**n**	**(%)**	***p*-value**[a]
Positive family support (sub-scale score)					.180
Low (1st tertile; Total score: 0-11)	89	(35.0)	32	(47.1)	
Moderate (2nd tertile; Total score: 12-14)	79	(31.1)	16	(23.5)	
High (3rd tertile; Total score: 15-18)	86	(33.9)	20	(29.4)	
Negative family support (sub-scale score)					.746
Low (1st tertile; Total score: 0)	149	(58.7)	37	(54.4)	
Moderate (2nd tertile; Total score: 1)	33	(13.0)	11	(16.2)	
High (3rd tertile; Total score: 2-8)	72	(28.3)	20	(29.4)	
Depressive symptoms[f]					.400
None to mild (BDI-Ia<20)	192	(75.6)	48	(70.6)	
Moderate to severe (BDI-Ia≥20)	62	(24.4)	20	(29.4)	
Suicidal ideation, last 3 months					.556
No	220	(86.6)	57	(83.8)	
Yes	34	(13.4)	11	(16.2)	
Ever thought about ending life since learning of HIV+ status					.620
No	156	(61.4)	44	(64.7)	
Yes	98	(38.6)	24	(35.3)	
Ever attempted suicide since learning of HIV+ status					.943
No	212	(83.5)	57	(83.8)	
Yes	42	(16.5)	11	(16.2)	

IQR, interquartile range; ART, antiretroviral therapy; BMI, body mass index; BDI, Beck Depression Inventory.

[a] For categorical variables, the Chi-square test was used to assess the differences between those submitting for both baseline and follow-up interviews and those unavailable for follow-up. For continuous variables, the Mann-Whitney U test was used to compare distributions across the groups.

[b] Two individuals did not respond to this item; their ages were set as the median (33 years) for the sake of analyses.

[c] Education level categories were defined based on the structure of the Nepalese education system.

[d] One individual did not respond to this item.

[e] Height and weight measurements were not collected for six individuals, for whom BMI could thus not be calculated.

[f] A score of 20 or more on the Beck Depression Inventory indicates moderate-to-severe depression with the need for mental health intervention, based on clinical validation of the scale in Nepal (sensitivity = 0.73, specificity = 0.91).[302]

3.3.2. Assessment of changes in depression and PFS from baseline to 18-month follow-up

Delta change scores, calculated as the difference between follow-up and baseline scores, were computed for both depressive symptoms and perceived family support in order to provide an assessment of intra-individual changes over the follow-up period (**Table 9**). An inspection of the distribution of these scores revealed notable fluctuations over time in both variables. Delta change scores for depressive symptoms ranged from a low of -40 (indicating an improvement in depression symptoms over time) to a high of 29 (indicating a worsening in depression symptoms over time). For perceived family support, meanwhile, delta change scores ranged from -20 to 23.

Table 9. Delta change scores for depressive symptoms and family support from baseline to 18-month follow-up (N = 254)

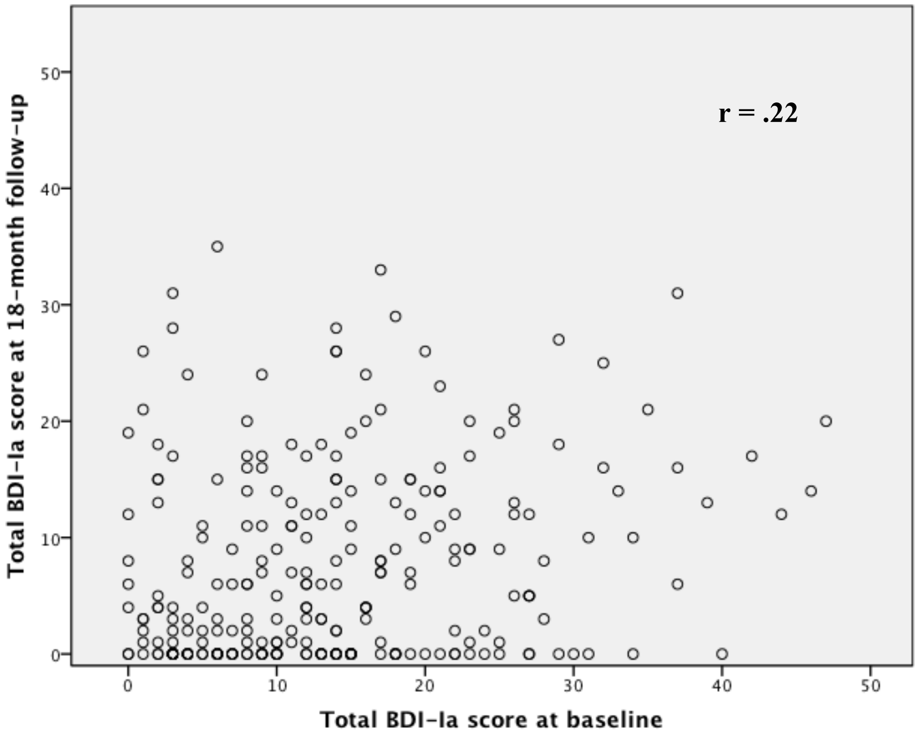
		Perceived Family Support (Nepali Family Support and Difficulty Scale score)		
Changes scores	**Depressive symptoms** (BDI-Ia score)	**Total PFS** score	**Positive PFS** sub-scale score	**Negative PFS** sub-scale score
Median change	-6	0	0	0
Minimum change	-40	-20	-14	-12
Maximum change	29	23	23	9
25th percentile	-13	-2	-1	-1
75th percentile	0	4	3	0

BDI, Beck Depression Inventory; PFS, perceived family support.

Of particular note for the present analyses, there were notable variations in the individual scores of depression between baseline and follow-up assessments. Out of the 254 participants retained at baseline, most (70.4%, n = 179) showed either a decrease or an increase of 5 points or more (corresponding to a clinically important difference[303]) in their BDI-Ia scores. Among the 62 participants who met the BDI-Ia threshold for moderate-to-severe depression at baseline and completed follow-up interviews, 16.1% (n = 10) were still depressive (BDI-Ia $\geq$ 20) at follow-up. Meanwhile, of the 192 participants interviewed at follow-up who fell below the BDI-Ia-defined threshold for depression at baseline, 8.3% (n=16) were newly depressive (BDI-Ia $\geq$ 20) at follow-up.

This instability in the scores of depressive symptoms over time among participants is reflected in the low, though significant, correlation coefficient between baseline and follow-up BDI-Ia scores (r = .22; p < .01), as depicted in the scatterplot of baseline and follow-up depressive symptoms shown in **Figure 5**.

Figure 5. Correlation between depressive symptoms at baseline and at 18-month follow-up



This instability has implications for the analysis. In the longitudinal approach, baseline perceived family support is defined as a predictor variable for follow-up depressive symptoms, adjusting for baseline BDI-Ia scores. As the majority of participants showed important variations in depression over the follow-up period, even after adjusting for baseline depressive symptoms, much variance remains to be explained by the independent variables. The relative instability of depressive symptoms over the follow-up period of this study therefore contributes to the utility of the longitudinal analysis.

3.3.3. Influence of baseline perceived family support on adjusted follow-up depression

Table 10 presents results of the multiple linear regression using baseline perceived family support scores as the dependent variable predicting adjusted follow-up depressive symptoms. The baseline BDI-Ia scores explained 5% of the variability (R^2) in depression at follow-up. After addition of sociodemographic, clinical, health behavioral, and psychosocial covariates, Model 2 explained 15% of the variability in depression at follow-up. Finally, results from the addition of total score on the Nepali Family Support and Difficulty Scale in Model 3 showed that perceived family support contributed significantly (p = .001) to the variance in depression at follow-up, beyond that afforded by demographic and clinical covariates, explaining an additional 3% for a total of 19% variance in follow-up depression explained by the model. In the final model, perceived family support (*B* = -.31, 95% CI = -.51, -.12) and gainful employment (*B* = -2.67; 95% CI = -4.94, -.40) were statistically significant in their protective effects on adjusted follow-up depressive symptoms, while female gender (*B* = 3.31; 95% CI = .95, 5.68) and using illicit drugs in the past 6 months (*B* = 3.46; 95% CI = .30, 6.62) emerged as risk factors for depressive symptoms at follow-up.

Table 10. Hierarchical regression results showing additional variance in adjusted follow-up depressive symptoms explained by total perceived family support score at baseline (N = 254)

Variable			**95% CI**	
	B	**SE**	Lower	Upper
Model 1: **Baseline BDI-Ia score adjustment**				
(Constant)	4.93	.87	3.21	6.65
Baseline depressive symptoms	**.19**	.05	**.09**	**.29****

R^2 change = .05
R^2_{adj} = .05
F (1, 252) = 13.08
p < .001

(Table continues)

Table 10 *(continued)*. Hierarchical regression results showing additional variance in adjusted follow-up depressive symptoms explained by total perceived family support score at baseline (N = 254)

Variable			**95% CI**	
	B	**SE**	Lower	Upper
Model 2: **+ Sociodemographic/clinical/health behavioral/psychosocial covariate adjustment**				
(Constant)	-1.75	3.32	-8.30	4.79
Baseline depressive symptoms	.11	.06	-(<.01)	.22
Gender (Female)	**4.37**	1.18	**2.05**	**6.69****
Age	.07	.08	-.10	.23
Marital status (Married)	.99	1.13	-1.24	3.23
Any children	1.44	1.16	-.84	3.72
Above-primary education	-.41	1.06	-2.50	1.68
Gainfully employed	**-2.54**	1.17	**-4.85**	**-.23***
Months since HIV diagnosis	**.02**	.01	<.01	.04*
On ART	.86	1.17	-1.44	3.15
Any illicit drug use, last 6 months	2.99	1.63	-.21	6.20
HIV Symptom Index score	.06	.04	-.02	.14
Internalized HIV/AIDS-related stigma score	.18	.25	-.32	.67
R^2 change = .14 **R^2_{adj} = .15** **F (11, 241) = 3.91** **p < .001**				
Model 3: **+ Total perceived family support**				
(Constant)	5.57	3.97	-2.26	13.39
Baseline depressive symptoms	.05	.06	-.06	.16
Gender (Female)	**3.31**	1.20	**.95**	**5.68****
Age	.10	.08	-.07	.26
Marital status (Married)	1.20	1.12	-1.00	3.39
Any children	1.77	1.14	-.47	4.02
Above-primary education	.09	1.05	-1.99	2.16
Gainfully employed	**-2.67**	1.15	**-4.94**	**-.40***
Months since HIV diagnosis	.02	.01	<.01	.04
On ART	.82	1.14	-1.43	3.07
Any illicit drug use, last 6 months	**3.46**	1.60	**.30**	**6.62***
HIV Symptom Index score	.07	.04	-.01	.15
Internalized HIV/AIDS-related stigma score	.10	.25	-.39	.58
Total perceived family support	**-.31**	.10	**-.51**	**-.12****
R^2 change = .03 **R^2_{adj} = .19** **F (1, 240) = 10.34** **p = .001**				

SE, standard error; BDI, Beck Depression Inventory; ART, antiretroviral therapy.
* p < .05; ** p < .01.

Table 11, meanwhile, presents the hierarchical regression results for the additional variance in adjusted follow-up depressive symptoms explained by baseline positive and negative PFS sub-scale scores. These showed that negative perceived family support was a significant ($p = .04$) predictor of depressive symptoms beyond sociodemographic, clinical, health behavioral, and psychosocial covariates in the third step (i.e., when considered separately from positive perceived family support). Namely, individuals who reported higher perceptions of negative family interaction at baseline also reported higher levels of depression at follow-up. However, the effect disappeared once positive family support was also added to the model; hence, perceptions of negative family interaction did not appear to have a main effect on depression at follow-up after accounting for the effect of positive family interaction perceptions. Positive perceived family support, however, contributed significantly ($p = .04$) to the variance in depression at follow-up – beyond that afforded by sociodemographic, clinical, health behavioral, and psychosocial covariates and by negative perceived family support – explaining an additional 1% for a total of 18% variance in follow-up depression explained by the final model (Model 4).

Table 11. Hierarchical regression results showing additional variance in adjusted follow-up depressive symptoms explained by positive and negative perceived family support sub-scale scores at baseline (N=254)

Variable	***B***	**SE**	**95% CI**	
			Lower	Upper
Model 1: **Baseline BDI-Ia score adjustment**				
R^2 change = .05 **R^2_{adj} = .05** **F (1, 252) = 13.08** **$p < .001$**				
Model 2: **+ Sociodemographic/clinical/health behavioral/psychosocial covariate adjustment**				
R^2 change = .14 **R^2_{adj} = .15** **F (11, 241) = 3.91** **$p < .001$**				

(Table continues)

Table 11 *(continued)*. Hierarchical regression results showing additional variance in adjusted follow-up depressive symptoms explained by positive and negative perceived family support sub-scale scores at baseline (N=254)

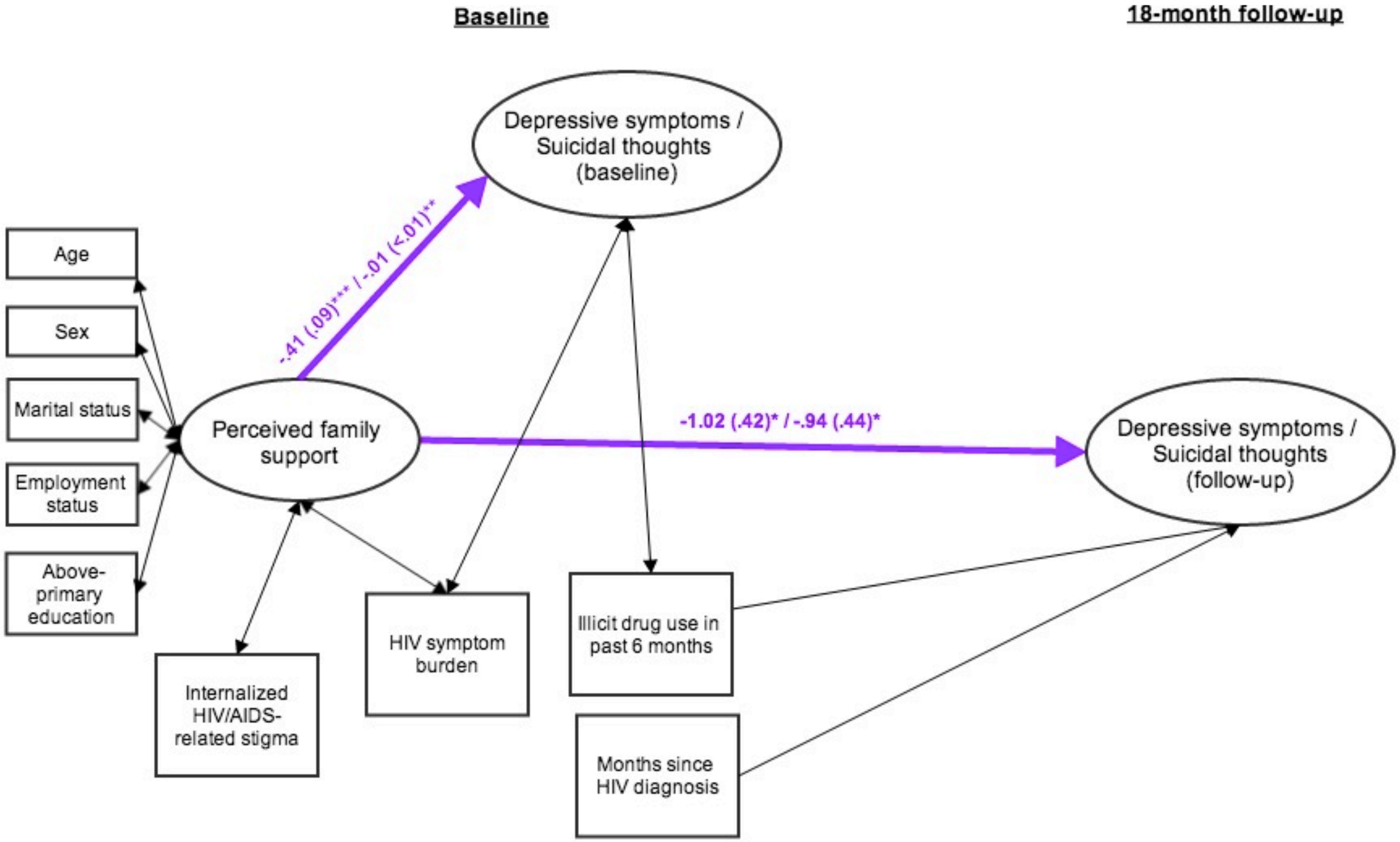
Variable	***B***	**SE**	**95% CI**	
			Lower	Upper
Model 3: **+ Negative perceived family support**				
(Constant)	-2.36	3.31	-8.88	4.16
Baseline depressive symptoms	.07	.06	-.04	.18
Gender (Female)	**3.89**	1.19	**1.55**	**6.24****
Age	.09	.08	-.08	.26
Marital status (Married)	1.06	1.13	-1.16	3.28
Any children	1.46	1.15	-.80	3.73
Above-primary education	-.28	1.06	-2.36	1.80
Gainfully employed	**-2.64**	1.17	**-4.93**	**-.34***
Months since HIV diagnosis	**.02**	.01	**<.01**	**.04***
On ART	.62	1.16	-1.67	2.91
Any illicit drug use, last 6 months	3.16	1.62	-.02	6.35
HIV Symptom Index score	.07	.04	-.02	.15
Internalized HIV/AIDS-related stigma score	.19	.25	-.31	.68
Negative perceived family support	**.47**	.22	**.03**	**.91***
R^2 change = .02 **R^2_{adj} = .17** **F (1, 240) = 4.47** **p = .04**				
Model 4: **+ Positive perceived family support**				
(Constant)	2.24	3.97	-5.59	10.06
Baseline depressive symptoms	.06	.06	-.06	.17
Gender (Female)	**3.44**	1.20	**1.07**	**5.81****
Age	.09	.08	-.08	.25
Marital status (Married)	1.31	1.13	-.91	3.53
Any children	1.80	1.15	-.47	4.07
Above-primary education	.17	1.07	-1.94	2.28
Gainfully employed	**-2.69**	1.16	**-4.97**	**-.40***
Months since HIV diagnosis	.02	.01	<.01	.04
On ART	.88	1.16	-1.41	3.16
Any illicit drug use, last 6 months	**3.48**	1.61	**.30**	**6.65***
HIV Symptom Index score	.07	.04	-.01	.15
Internalized HIV/AIDS-related stigma score	.09	.25	-.41	.59
Negative perceived family support	.14	.27	-.39	.68
Positive perceived family support	**-.35**	.17	**-.68**	**-.02***
R^2 change = .01 **R^2_{adj} = .18** **F (1, 239) = 4.26** **p = .04**				

SE, standard error; BDI, Beck Depression Inventory; ART, antiretroviral therapy.
* $p < .05$; ** $p < .01$.

3.3.4. Structural equation models of PFS effects on depressive symptoms and suicidality

Figure 6 shows the path coefficients calculated by SEM of the direct relationship between perceived family support at baseline and depressive symptoms and suicidal thoughts at baseline and at 18-month follow-up. Consistent with regression results presented above, baseline perceived family support inversely predicted depressive symptoms and suicidal thoughts both concurrently (depressive symptoms: *B* = -.41, SE = .09, p < .001; suicidal thoughts: *B* = -.01, SE < .01, p = .004) and prospectively (at 18-month follow-up; depressive symptoms: *B* = -1.02, SE = .42, p = .02; suicidal thoughts: *B* = -.94, SE = .44, p = .03), adjusting for other covariates.

Figure 6. Structural equation model findings for direct relationship between perceived family support at baseline and depressive symptoms and suicidal thoughts at baseline and 18-month follow-up

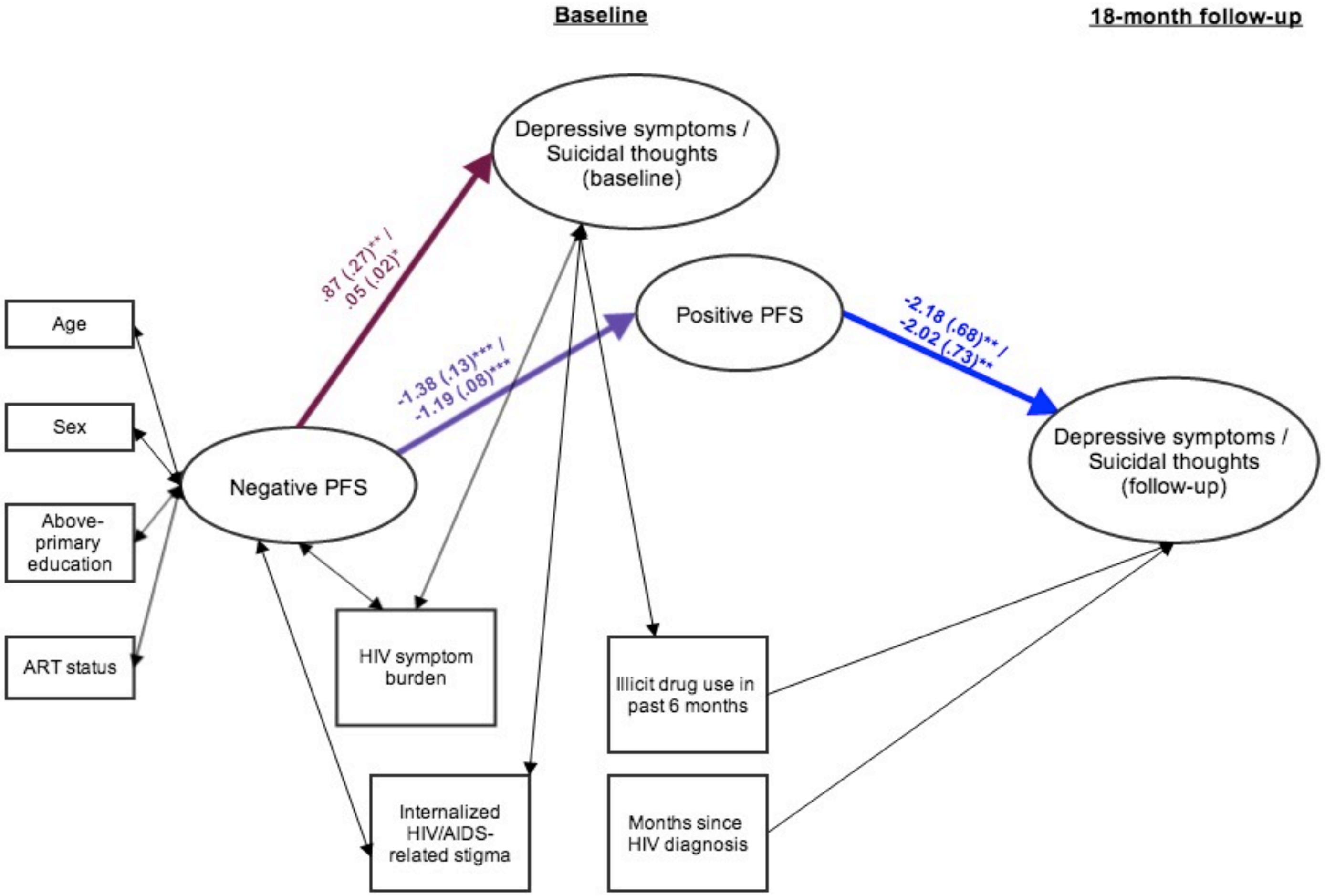


* p < .05, ** p < .01, *** p < .001.

Note: Values shown are unstandardized regression coefficients with standard errors. Only significant (p < .05) pathways are shown.

Figure 7 shows the path coefficients calculated by SEM of the moderated relationship between perceived family support sub-scale scores at baseline and depressive symptoms and suicidal thoughts at baseline and at 18-month follow-up. This second structural model examined the interrelationships among baseline negative PFS, baseline positive PFS as a potential moderator, and baseline and 18-month depressive symptoms and suicidal thoughts. Expanding upon regression results presented earlier, SEM revealed baseline negative PFS, when considered in conjunction with the effects of baseline positive PFS, to be a significant predictor of baseline depressive symptoms (*B* = .87, SE = .27, p = .001) and suicidal thoughts (*B* = .05, SE = .02, p = .02) but not of follow-up depressive symptoms or suicidal thoughts, consistent with a possible buffering effect through positive PFS. Baseline positive PFS, meanwhile, inversely predicted follow-up depressive symptoms (*B* = -2.18, SE = .68, p = .001) and suicidal thoughts (*B* = -2.02, SE = .73, p = .01) but was not associated with baseline mental health outcomes when considered alongside negative PFS.

Figure 7. Structural equation model findings for moderated relationship between perceived family support sub-scale scores at baseline and depressive symptoms and suicidal thoughts at baseline and 18-month follow-up



* p < .05, ** p < .01, *** p < .001. ART, antiretroviral therapy; PFS, perceived family support.

Note: Values shown are unstandardized regression coefficients with standard errors. Only significant (p < .05) pathways are shown.

3.3.5. Influence of delta changes in PFS on incidence of depression and suicidal ideation

Table 12 shows the results of logistic regression analyses of categorical changes in perceived family support dimensions from baseline to follow-up associated with incident depression and suicidal ideation at 18-month follow-up. Regarding total PFS scores, a decrease (i.e., negative delta change) or sustained low level in perception of family support from baseline to follow-up was associated with higher incidence of BDI-Ia-defined depression at follow-up among those not depressed at baseline (AOR = 4.21; 95% CI = 1.17, 15.16). Conversely, an increased or sustained high level in perception of family support from baseline to follow-up was associated with lower incidence of new depression at follow-up (AOR = .22; 95% CI = .06, .83).

Analyzing the impacts of changes in the PFS sub-scale scores separately in the same manner, the largest effect sizes and most significant associations observed were between changes in negative perceived family support from baseline to follow-up and suicidal ideation observed at follow-up. Namely, participants who experienced decreased or sustained low levels of negative perceived family support from baseline to follow-up were over six-and-a-half times *less* likely to report suicidal ideation at follow-up (AOR = .15; 95% CI = .05, .45). By the same token, those who experienced increased or sustained high levels of negative perceived family support from baseline to follow-up were over seven times *more* likely to report suicidal ideation at follow-up (AOR = 7.30; 95% CI = 2.33, 22.87). In contrast, those reporting increased or sustained high levels of *positive* support from baseline to follow-up were significantly less likely to experience new depression at follow-up (AOR = .26; 95% CI = .07, .95).

Table 12. Multivariable analyses[a] of changes in perceived family support dimensions from baseline to follow-up associated with incident depression and suicidal ideation at 18-month follow-up

PFS change category[a]	**Depression (BDI-Ia≥20) incidence (N=189[b])**		**Suicidal ideation (BDI-Ia item #9>0) (N=254[c])**	
	AOR	**(95% CI)**	**AOR**	**(95% CI)**
Total Perceived Family Support				
Decrease (negative Δ change) or sustained lowest-tertile level[d]	**4.21**	**(1.17, 15.16)***	2.49	(.81, 7.64)
Increase (positive Δ change) or sustained highest-tertile level[e]	**.22**	**(.06, .83)***	.47	(.16, 1.44)
Positive Family Support (sub-scale score)				
Decrease (negative Δ change) or sustained lowest-tertile level[d]	2.38	(.71, 8.01)	1.10	(.36, 3.32)
Increase (positive Δ change) or sustained highest-tertile level[e]	**.26**	**(.07, .95)***	1.11	(.37, 3.31)
Negative Family Support (sub-scale score)				
Decrease (negative Δ change) or sustained lowest-tertile level[d]	.49	(.14, 1.69)	**.15**	**(.05, .45)****
Increase (positive Δ change) or sustained highest-tertile level[e]	2.27	(.65, 7.99)	**8.09**	**(2.72, 24.11)****

BDI, Beck Depression Inventory; AOR, adjusted odds ratio. CI, confidence interval. PFS, perceived family support.

* $p < 0.05$; ** $p < 0.01$.

[a] Separate logistic regression analyses were carried out for each category of perceived family support change, adjusting as well for sex, age, baseline marital status, baseline education level, baseline employment status, time since HIV diagnosis, ART status, recent illicit drug use, baseline HIV Symptom Index score, baseline internalized HIV/AIDS-related stigma score, and (in the case of the regression on suicidal ideation) baseline suicidal ideation.

[b] Analyses of depression incidence were limited to those 189 participants *without* BDI-Ia-defined depression at baseline who also participated in the 18-month follow-up interview.

[c] Analyses of suicidal ideation in the past 2 weeks (as measured at 18-month follow-up) were conducted on all 254 individuals who completed follow-up interviews.

[d] Reference category: Participants showing an increase or sustained highest- or middle-tertile level of PFS dimension.

[e] Reference category: Participants showing a decrease or sustained lowest- or middle-tertile level of PFS dimension.

3.3.6. Influence of delta changes in PFS on delta changes in depressive symptoms and suicidal ideation

Expanding on the analysis of impacts in changes in PFS on mental health outcomes over the 18-month follow-up period, **Table 13** shows the results of linear regression analyses of continuous changes in perceived family support dimensions from baseline to follow-up associated with corresponding changes in depressive symptoms and suicidal thoughts. As in the analysis of categorically defined PFS changes associated with incident depression and suicidal ideation at follow-up, changes in total and positive PFS were negatively associated with changes in depressive symptoms over the 18-month follow-up (*Total PFS*: *B* = -.48, SE = .14, p = .001; *Positive PFS*: *B* = -.38, SE = .18, p = .037), though the same associations were not found with changes in suicidal thoughts. Notably, as indicated in the stratified analyses, these changes were only significant (or nearly significant) for individuals with *low* baseline PFS scores (*Total PFS*: *B* = -.50, SE = .17, p = .004; *Positive PFS*: *B* = -.45, SE = .24, p = .065).

Meanwhile, as in the analysis of categorically defined PFS changes associated with incident depression and suicidal ideation at follow-up, the most significant associations were observed with changes in *negative* PFS. Unlike the categorical analyses, however, these positive associations were observed for changes across mental health outcomes – in depressive symptoms (*B* = 1.36, SE = .32, p < .001) as well as suicidal thoughts (*B* = .08, SE = .02, p < .001). Moreover, the associations were significant regardless of the baseline negative PFS levels, though the coefficients were slightly larger in the case of low baseline negative PFS scores.

Table 13. Multivariable analyses[a] of changes in perceived family support dimensions from baseline to follow-up associated with changes in depressive symptoms and suicidal thoughts from baseline to follow-up, with stratified analysis by baseline PFS scores (N=254)

PFS change dimension[a]	**Depressive symptoms (Δ change in BDI score)**		**Suicidal thoughts (Δ change in BDI #9 score)**	
	Coefficient *(B)*	**SE**	***B***	**SE**
Total Perceived Family Support	**-.48**	**.14****	-.01	.01
w/ *Low* baseline score	**-.50**	**.17****	-.01	.01
w/ *High* baseline score	-.29	.31	.02	.02
Positive Perceived Family Support	**-.38**	**.18***	.02	.01
w/ *Low* baseline score	-.45	.24	.01	.02
w/ *High* baseline score	-.23	.36	.04	.02
Negative Perceived Family Support	**1.36**	**.32*****	**.08**	**.02*****
w/ *Low* baseline score	**1.67**	**.82***	**.10**	**.04***
w/ *High* baseline score	**1.32**	**.40****	**.08**	**.04***

BDI, Beck Depression Inventory; SE, standardized error. PFS, perceived family support.
* $p < 0.05$; ** $p < 0.01$; *** $p < .001$.
[a] Separate logistic regression analyses were carried out for each category of perceived family support change, adjusting as well for sex, age, baseline marital status, baseline education level, baseline employment status, time since HIV diagnosis, ART status, recent illicit drug use, baseline HIV Symptom Index score, and baseline internalized HIV/AIDS-related stigma score.

4. Discussion

Levels of depressive symptoms among the surveyed PLWHA were high though ostensibly unstable after 18 months, suggesting the importance of immediate environmental factors in determining coping with and adaptation to life with HIV/AIDS. As Rabkin[9] posits in his 2008 review of global evidence on HIV and depression, "most people with HIV are not depressed most of the time, and their resilience is as noteworthy as their psychopathology". Yet, whether transient or persistent, endogenous or exogenous, depression and suicidal ideation are critical burdens to be addressed in HIV prevention and care; the key, then, is to hone in on the modifiable risk and resilience factors to promote consistent and sustained mental health and well-being.

Most notably, results from the present study indicate family support perceptions as a key leverage point for psychosocial interventions in the context of HIV/AIDS in a low-income South Asian country. Against heavy burdens of BDI-Ia-defined depression (26%) and suicidal ideation (14%) among PLWHA in the Kathmandu Valley of Nepal, cross-sectional and prospective analyses showed that perceptions of positive family support – especially in the emotional realm and over time – appeared to have a protective effect and perceptions of negative family support a potentially even stronger contributing effect. Meanwhile, cross-sectional and prospective associations between the assessed mental health outcomes and a number of key sociodemographic, clinical, health behavioral, and other psychosocial characteristics were also observed.

4.1. Cross-sectional associations at baseline

4.1.2. Perceived family support

Among the central findings of this study, the global construct of perceived family support emerged as a major correlate of both depression and suicidal ideation in baseline cross-sectional analyses. Indeed, those participants reporting the highest level of perceived family support were over six times less likely than those at the lowest level to register BDI-Ia-defined depression and almost three times less likely to endorse suicidal ideation. In the case of depression, the effect was moderated somewhat by the length of time since being diagnosed with HIV, suggesting an escalating role of family support with more months lived under the unique strains of the disease. This result uniquely extends theory on the link between perceived family support and psychological distress to an HIV-specific population in a developing, non-Western country context, elucidating the strong and potentially protective effect of family support in terms of depression and suicidality risks. Although families generally function differently depending on cultural context, these findings point to overarching commonalities regarding the influence of perceived family support, beyond the specific setting or the particular nature of the stressors.

Yet, based on item-wise multivariate analysis of the perceived family support scale in relation to depression and suicidal ideation, some elements of family support appear to be more important than others to the lived experience of HIV/AIDS. Namely, consistent with certain under-explored threads in research on social support and psychological well-being,[214,304] the greatest effects across both mental health outcomes were observed in the *negative* support domain, particularly with regard to suicidal ideation – an especially dangerous manifestation of psychological distress. Such variations in the effects observed suggest that these different dimensions of perceived family support are indeed related but distinct constructs, indicating the need for tailored interventions in both areas of support. Also notable in this regard was the greater effect of negative perceived family support on depression observed among PLWHA having at least one child, suggesting a heightened vulnerability to the harmful mental health impacts of family-related interpersonal stressors among those with the stronger tethering to family life that having progeny entails. Moreover, the responsibility of caring for a child may serve as an additional stressor for PLWHA,[305] particularly in the context of a dysfunctional family environment.

With specific reference to the individual PFS scale items as correlates, feelings of being exploited, rejected, and emotionally distant from family members played heavily into experiences of depression and suicidal ideation at baseline. One explanation for this may be that negative interactions are less frequently encountered and hence more saliently felt relative to positive ones. This may be particularly true in the case of family relationships. Moreover, negative interactions can potentially undermine an individual's sense of personal control or self-worth, erode motivation to engage in positive health behaviors, and provoke adverse physiological responses.[306] Such results are in line with the domain-specific model of the link between interpersonal exchanges and mental health, in which interpersonal strains are more potently manifested in negative affective states like depression and suicidality, whereas supportive exchanges may be expected to exert a greater impact on positive well-being.[214]

Among the positive forms of social support, emotional support is generally reported to be the most important for its clear links to health in terms of both direct and buffering effects.[180,201] Moreover, previous studies have shown that family in particular is typically a major source of emotional support.[307,308] Consistent with this, emotional support and nurturance elements of feeling loved, cared for, and understood within the family emerged as important correlates in buffering against negative psychological states, whereas instrumental support factors appeared not to be as critical in determining mental health among the PLWHA surveyed. The distinct role of feeling loved and understood in relation to mental health outcomes may arise from a psychological construct, *mattering*, developed by Rosenberg and McCullough,[309] the main components of which lie in one's perception of being an object of importance to another person and of being depended upon by others for something needed or wanted. Feelings of connectedness to the family are likely to reduce sensations of social isolation and loneliness – antecedents to suicidal thoughts and behaviors. This would appear to be true across a variety of disease states, as echoed in similar findings among patients with cancer and their families.[310] Accordingly, future psychosocial interventions should focus on identifying and enhancing sources of emotional support even more so than more practical instrumental manifestations of assistance, particularly within family networks.

4.1.2. Sociodemographic, clinical, health behavioral, and psychosocial characteristics

Beyond family support, six further independent variables had significant associations with depression and/or suicidal ideation after adjustment: *employment status* (inversely associated with both depression and suicidal ideation), *being underweight* (positively associated with depression), *ART treatment status* (positively associated with depression; statistical significance not reached with suicidal ideation), *reporting any illicit drug use in the past 6 months* (positively associated with suicidal ideation; statistical significance not reached with depression), *internalized HIV/AIDS-related stigma* (positively associated with depression), and *age* (positively associated with depression).

Among all identified correlates of the measured mental health outcomes, only employment status reached statistical significance in its associations with both depression and suicidal ideation. While such a relationship with depression has previously been suggested in the general population,[311] as has a link with quality of life among PLWHA in Canada,[312] evidence of the corresponding links with suicidality in PLWHA has so far been scarce. Notably, employment is generally regarded as an integral component of health and well-being in facilitating structured time and regular activity, regular contact with people outside the immediate family, and connection with goals transcending one's own, and thus imbuing a sense of self-esteem, life satisfaction, and personal identity.[313] For PLWHA, the normalizing function of employment may be especially beneficial in helping to replace the "patient" identity. Moreover, unemployment is typically a major issue among PLWHA because loss of productive work days due to illness dramatically increases the likelihood of job loss.[314] With rates of unemployment at baseline placed at 29% among PLWHA in the present study, these findings highlight the critical importance of incorporating vocational training and employment counseling into psychosocial interventions for such groups.

A similar observation may be made of the observed link between recent illicit drug use and suicidal ideation. Though numerous studies point to the relationship between addiction, mental health, and suicide,[315] few have described the relationship between suicidality and substance use among PLWHA. Given the serious nature of suicidal thoughts as a precursor to actual suicidal behavior, these findings demand critical attention toward adapting HIV care and treatment programs to address co-occurring mental health and substance use disorders. Future interventions might fruitfully explore ways to more closely integrate drug dependence treatment into ongoing HIV care.

PLWHA who were underweight were also more likely to be depressed at baseline in the present study, though no such association was observed with suicidal ideation. The correlation uncovered between depression and low BMI among PLWHA in a low-income South Asian country expands on similar findings in a study of HIV-positive men who have sex with men in the United States.[316] This likely stems from the substantial weight loss that frequently comes with disease progression and/or the side effects of treatment.[317]

Relating also to the possible side effects of treatment, the results suggest that PLWHA treated with ART are more susceptible than those not receiving ART to both depressive symptoms and suicidal ideation (though this result did not reach statistical significance, likely due to inadequate sample size), particularly in the earlier treatment stages – perhaps when patients have not yet had time to adjust to the unique strains of treatment or to develop effective coping mechanisms that lead to reduced depression and suicidality risk over time. The undisputed benefits of ART notwithstanding, previous studies have shown that neuropsychiatric side-effects including cognitive disorders, anxiety, mood disorders, and suicidal ideation are seen in up to 73% of HIV-infected patients on treatment regimens.[79,109] On top of this, profound changes in the lived experience and perception of illness resulting from ART introduction could potentially influence development of depression. In contrast, in other studies, depression symptom severity has been found to decline with cumulative duration of ART,[318] and the psychological benefits of HIV treatment have been described in cross-sectional and longitudinal studies alike, although the biological mechanisms underlying the association remains unclear.[319-322] Against the backdrop of literature detailing a knotty linkage between mental health problems and treatment outcomes, results of the present study highlight the need for further work to decipher the short- and long-term impacts of ART on mental health outcomes and for interventions to address potential neuropsychiatric side effects of treatment regimens.

Meanwhile, the identification of stigma as a risk factor for depression is compounded by the fact that those with higher stigma scores also exhibited lower levels of perceived family support, pointing to a heightened and complexly interwoven vulnerability to depression. Notably, both mental illness and HIV/AIDS are highly stigmatized conditions in Nepal, as in many other countries – in part because of the extent to which an individual's ailments and behavior are seen as negatively impacting the whole family.[133,323] Within families, forms of discrimination against PLWHA in Nepal may include restrictions on everyday activities such as movement outside the home, exposure to media, use of communal eating utensils, and access to financial resources; in some cases, family-level discrimination can even escalate to physical abuse,[137] as underscored in the present study. Toward combatting such deeply ingrained elements contributing to the burden of mental illness in PLWHA, both community- and family-level anti-stigma interventions may be helpful.

Finally, with regard to the observed cross-sectional association between above-median age and depression, given the relatively limited spectrum of ages included in the present study (20-40 years), this may simply reflect age biases in assessment of depression and the masking effect of other risk factor that vary with age. Previous studies in general populations have found no consistent pattern across studies for age differences in the occurrence of depression. Notably, however, the most common trend found has been for an initial rise across age groups, followed by a drop.[324] Had the present study been extended to a more elderly population, a similar pattern might also have been found in older age groups.

4.2. Longitudinal associations

4.2.2. Perceived family support

Perceived family support at baseline had main effects on both depression and suicidality at follow-up among the surveyed PLWHA. Namely, higher levels of perceived family support predicted lower levels of depressive symptoms and suicidal thoughts across time, independent of cross-sectional relations and time effects and beyond the influences of key sociodemographic, clinical, health behavioral, and other psychosocial covariates. Moreover, results indicated that lower levels of positive PFS significantly contributed to the variance in depressive symptoms at follow-up, when the demographic and clinical covariates as well as the baseline measure of depression were taken into account. Negative perceived family support also contributed to the variance in depressive symptoms at follow-up, but only when considered separately from positive perceived family support, suggesting the presence of cross-domain buffering effects between positive and negative aspects of family relations in the psychosocial experiences of PLWHA.

While some studies have reported that negative aspects of support are better predictors of psychological symptoms than positive aspects, this finding was only partially borne out in the present sample of PLWHA. This suggests that, the strong effects of unsupportive family interactions notwithstanding, given the relative paucity of negative family support in the experience of most individuals, positive aspects of family support may generally serve as a better prospective predictor of depression among PLWHA. When negative exchanges do occur, they may be more immediately potent or salient than positive exchanges, but, when aggregated, may be less consequential for psychological health precisely because they occur infrequently. That is, the potent-but-scarce negative exchanges may have less cumulative impact on well-being than do the comparatively weak-but-common positive exchanges.

Overall, findings point to the important role of positive perceived family support not only in its direct effect on mental health outcomes, but also for buffering the deleterious impact of negative perceived family support on depression. The ostensibly protective role of the positive dimension of perceived family support is consistent with previous research on social support and mental disorders. Additional evidence in the general population similarly suggests that social support buffers the effects of negative interaction on depression and psychological distress.[225,231,325] In this sense, family interactions emerge not only as a source of psychological stress but also as an asset that can potentially provide PLWHA with resources to cope with perhaps isolated incidences of negative family exchange. These results are in line with the *joint effects hypothesis* of the interaction between social support and social undermining, which conceptualizes negative social interaction as a stressor in its own right and examines social support as a moderator of the effects of such social undermining.[214,231]

At the same time, the observed impacts of negative PFS in the immediate term and when assessed as changes over time also underscore the special importance of negative family interactions, particularly in predicting the particularly dire mental health disturbance of suicidal ideation. Considering trajectories of change in negative and positive perceived family support separately, only changes in *negative* PFS over the assessment period showed a significant association with either of the mental health outcomes at follow-up – with substantial effect sizes expressed in suicidal ideation reported at 18 months among the PLWHA surveyed. Though previous studies have shown the ameliorating effect of positive forms of family support on risk of suicide behaviors for other populations, this is among the first to demonstrate the converse effect for negative perceived family support in an HIV-positive population.

Notably, moreover, it was the *decreases* (or sustained low levels) in perception of family support that were associated with the greatest effect sizes in both depression incidence and suicidal ideation at follow-up, with similar results observed in the analysis of continuous changes vs. changes. This is consistent with stress-related research, wherein evidence indicates that negative stimulation or the potential loss of resources (material, interpersonal, or intrapersonal) are typically more emotionally and motivationally arousing than positive stimulation or the potential acquisition of resources.[326]

Overall, changes in perceptions of support received from family were highly correlated with and strongly predictive of both depressive symptomatology and suicidal ideation at follow-up. Though social support has been conceptualized, primarily, as a static construct whose role has been established through snapshots at one point in time, findings from the current study suggest that perceptions of support from family may be part of a larger, dynamic process. As social learning theorists have long emphasized, it is, after all, through ongoing interactions with environmental resources (e.g., supportive or unsupportive relationships) that individuals ultimately frame their own sense of self and experience the world around them.[327]

4.2.2. Sociodemographic, clinical, health behavioral, and psychosocial characteristics

Longitudinal regression results revealed just three sociodemographic and psychosocial characteristics to be significant in their prospective associations with depressive symptoms: *female gender*, *unemployment*, and *reported illicit drug use in the past 6 months*. While the latter two variables were previously identified in the cross-sectional analyses, female gender only emerged as a correlate of depression in the longitudinal analyses. This result is in keeping with previous findings – both in that women in the general population are at least twice as likely as men to be diagnosed with depression[328] and in that gender is an important element in the experience of illness generally and HIV specifically.[329]

Compared with men living with HIV/AIDS, women living with HIV/AIDS often experience increased distress, lower health-related quality of life, and fewer social resources.[330] Additionally, conservative values and social norms favor stigmatization of HIV-infected women in certain cultural contexts, which is likely to make them more reluctant to disclose their HIV status, further isolating female PLWHA from social and family support resources.[187,331] In the context of the gender gap accordingly observed in levels of perceived family support in the present baseline cross-sectional analysis (a finding echoed in another study of PLWHA in Nepal[169]), the importance of addressing family-level interactions among female PLWHA becomes especially important. Importantly, research in other populations of PLWHA has indicated that social support may be particularly important for women, as they tend to rely more on social relationships compared to men in similar situations.[332] The findings thus identify a modifiable risk factor for poor mental health that, if addressed, has the potential to improve the health of PLWHA and attenuate the widening gender inequities observed in the distribution of HIV/AIDS harms worldwide.[333]

4.3. Study limitations

Results should be interpreted in light of several limitations inherent to the present study. First, this study relies on self-report measures, leaving room for several potential sources of bias. These include biases in responding due to the personal and sensitive nature of the questions and the face-to-face interview format. The potential for such social desirability bias was carefully minimized, however, in the procedures followed for data collection. Interviews were administered in a private environment using a structured questionnaire and a confidential and sensitive approach to survey administration. Interviewers were experienced professionals in the task of survey administration and were carefully trained on specific interview techniques and survey questionnaire content in preparation for this study. Similarly, errors in recall and actor-observer bias also may have distorted some responses. Participants were asked, for example, to report their own illness-related characteristics, such as date of HIV diagnosis and date of ART initiation. It is possible that participants were uncertain about the aforementioned variables, though the resulting impact on the primary results would likely have been minimal.

An additional bias potentially introduced through the use of self-report measures and the possible loop of causality between the dependent and independent variables is the issue of endogeneity. In particular, perceived family support, psychological distress, and health status measures were self-reported, and unmeasured personality characteristics or attributional styles may have affected such measures. This problem was at least partially mitigated by the use of measurements taken at two different time points and by the use of an analytic strategy that examined changes. However, a certain amount of caution must still be exercised in interpreting the results; it cannot necessarily be determined with complete certainty, for example, whether respondents are depressed because they perceive low levels of support available to them, or if the feelings of inadequate support are a function of some third, unmeasured variable influencing measurement of both constructs. On a related note, the possibility of reverse causality cannot be entirely ruled out, though the interpretation of the associations presented is in accordance with an established mechanism of action[139] along with a number of other studies examining social and family support as a determinant of psychological distress.[171-173] Overall, results still offer some useful indication as to the degree to which perceptions about family support are related to experiences of depression and suicidal ideation.

On the other side, one advantage of using self-report measures is that they facilitate an assessment of unobservable, internal cognitive processes. Both theory and a large volume of empirical research has indicated that it is these internal processes that play a key role in determining the effects of stress, social support, and social strain.[334,335] Prior research also suggests that much or all of the effect of support on mental health outcomes is cognitively mediated in that the quantity and type of social interactions improve outcomes only to the extent that they affect one's perceptions or satisfaction with support.[139,336-338] Previous studies have found, moreover, that perception is generally a better predictor of health outcome than the actual receipt of social support and a more sensitive measure of the ability to cope with mental health challenges.[139,145-147,338] As far as the use of self-report measures to assess perceived family support, depression, and suicidal ideation, the present study relied on scales specifically developed for use in Nepal and used with success in previous studies to measure these constructs.

Second, it should be acknowledged that there was only a moderate median level of negative family support observed within the sample. While there was also a relatively substantial amount of variation in the negative family support that participants reported, the overall level was not extreme. The fact that even relatively low levels of perceived family dysfunction appeared to substantively impact mental health thus speaks to the power of these effects and indicates how experiences of negative family interaction may be especially important to consider for PLWHA. However, this also leaves open the question of whether positive family support would have as powerful a buffering effect when individuals are faced with more extreme levels of negative family interaction. Clearly, this is an additional area for future research.

Third, it must be recognized that the analyses undertaken in the present study examine only a limited subset of factors contributing to the complex etiology of mental health problems comorbid with HIV/AIDS. In particular, the focus is placed specifically on dimensions of perceived family support as potentially modifiable factors directly influencing the experience of depression and suicidal ideation among PLWHA. Though the multivariable models used incorporate a number of key sociodemographic, clinical, health behavioral, and other psychosocial covariates, they do not, for example, include other key factors such as alcohol consumption, previous medical history, or CD4 cell count. Genetic, biochemical, and related cognitive variables were also not measured in the present study. Moreover, constructed models do not take into account the potential influences of other sources of formal or informal support, nor do they look at the potential interactive effects of the full range of HIV-specific stressors. As such, the picture that emerges represents only a simplified snapshot of one element in a larger framework of yet-poorly-understood moderation and causation. That being said, the primary purpose of this research ultimately was not to undertake a comprehensive modeling of the etiology of mental health problems in PLWHA, but rather to examine one potential pathway toward ameliorating the observed burden of depression and suicidal ideation in this population.

Fourth, the strength of the longitudinal design notwithstanding, sample attrition and missing data have the potential to create a selection bias. There was some evidence for selective attrition in this sample among, for example those who were employed and those not reporting any illicit drug use in the past 6 months; as such, data missing due to those lost to follow-up was not missing entirely at random and may conceivably have affected the results. Ultimately, attrition, illness, and mortality factors that limited study participation at follow-up were not accounted for in the analyses. It is recognized that the results could, therefore, potentially be biased in favor of those who survived and were healthy enough to participate at follow-up, although there was no indication that attrition was attributable to failing health. At the same time, overall retention of participants in the sample was excellent (79%), particularly given the traditionally hard-to-reach nature of the population of interest, and lost-to-follow-up analyses revealed no significant differences in any of the primary variables of interest.

Fifth, despite the relatively large overall sample size achieved, the size of certain groups was still small, limiting statistical power in some of the analyses where significance was approached but not reached. This was particularly true in the case of regressions on suicidal ideation, the rate of which was relatively low. Caution must be used in interpreting these results, as such limited numbers result in unstable rate estimates and can easily underestimate or overestimate associations. Though statistical significance was not reached for several associations, one could infer that there may be a trend for possible statistical significance with a larger sample size. Overall, an even larger sample size would have been preferable to better ascertain the differential impacts of positive and negative dimensions of support and might yield more statistically significant results concerning the specific psychosocial correlates of depression and suicidal ideation in this population. Realistically, however, a larger sample size is difficult to achieve in such a cohort for both clinical and logistic reasons.

Finally, the sample was not nationally representative, so the question of whether the pattern of results observed here will generalize to broader samples remains. Although a relatively large number of participants from multiple NGO outreach networks across the Kathmandu Valley were surveyed, findings are specifically representative of PLWHA falling within the network of partnering NGOs. Because the sample was not random, the sample surveyed cannot be said to represent a target population of all PLWHA residing in the Kathmandu Valley and biases affecting generalizability of the findings to other study populations cannot be excluded. The results of this study are limited in their generalizability to the type of PLWHA who satisfied the selection criteria, and to those who were willing and able to complete the interviews at both time points. Importantly, the present sample contained only two non-heterosexual participants, although men who have sex with men represent an important risk group in the HIV epidemic nationally. Moreover, because a control group of HIV-negative individuals was not included, the relative burden of inadequate family support or experience of negative family interactions among PLWHA cannot be estimated. Moving forward, prospective, controlled studies in diverse national samples of PLWHA will help to disentangle the complex pathways that may link the interaction effects of family support elements to developing and ongoing mental health issues in this population.

4.4. Methodological strengths

Notwithstanding such limitations, the present study has clear value in prospectively examining an underexplored area with important implications for policy and research at the intersection of HIV/AIDS and mental health and in its use of well-validated research measures. To our knowledge, this is the first study to report the distinct effects of a set of perceived family support items – encompassing both positive and negative facets – on both depression and suicidal ideation among PLWHA in Nepal or elsewhere. The findings have strong implications for the development of targeted intervention and prevention efforts to address the heavy burden of psychological distress among PLWHA in such contexts. Critically, identified associations highlight the potential of programs to minimize the harmful psychological impacts of HIV-related stressors through enhancing perceptions of supportive family interactions while mitigating unsupportive ones.

Perhaps most notably, this study examined the influence of family support on depressive symptoms using two approaches – cross-sectional and longitudinal. The longitudinal approach allowed for examination of the association between the two variables of interest while also controlling for the additional effect of the baseline measure of depressive symptoms. Moreover, the prospective analytic approach allowed the present study to demonstrate not only the longitudinal correlation of perceived family support with depression, but also that changes in perceived family support exert prospective impacts on changes in and future-onset experiences of depression and suicidal ideation at 18-month follow-up. The consideration of temporal ordering thus allowed for a more complete and rigorous exploration of whether perceived family support is actually a determining factor in the experience of depression and suicidal ideation among PLWHA. Establishing such temporal precedence by identifying features that predict future depression risk is especially relevant for the targeting of preventative intervention strategies.

4.5. Policy, practice, and research implications

4.5.1. Policy and practice implications

With the advent of and expansion of HAART, the entire course of HIV has been revolutionized, allowing further attention to issues around quality of life and psychosocial functioning. As such, concerns surrounding the physical and mental health consequences of a chronic illness become important outcome indicators, also inasmuch as they may impact illness management and clinical outcomes. Meanwhile, the expansion of HIV/AIDS treatment initiatives in LMICs provides an opportunity for integrating mental health care into these programs.[10,339] Accordingly, the WHO recommends that attention to the psychosocial needs of PLWHA should be an integral part of HIV care.[192] This includes assistance with employment, income, housing, informed decision-making, coping with illness and discrimination, and prevention and treatment of mild and serious mental health problems.[192] In line with such recommendations, the present study supports the potential utility of specifically including psychosocial support in national guidelines for the management of HIV/AIDS, with existing family networks and the capacities of community-based NGOs presenting one potentially useful and non-cost-prohibitive avenue for bolstering such support.

This study is one of the first to examine dimensions of family support in the context of both depression and suicidal ideation among PLWHA in a developing Asian country.

Results add to the evidence from prior studies in other chronic disease-affected populations and further underline the high prevalence of depression and suicidal ideation in PLWHA and the importance of routine screening for comorbid psychiatric disorders. Most importantly, they underscore the importance of targeting perceived family support as a potentially modifiable factor influencing depressive symptoms and suicidality, as the quality of such relationships appears to be particularly important for successful psychological adaptation to life with HIV.

Accordingly, those involved in the care of PLWHA must understand the critical role of the wider social and family environment in mental health and should assess the family relationships of their clients. Efforts should be made as well to involve family members in HIV disease management as well as depression management. Findings further suggest that counseling and treatment teams should be especially aware of vulnerable periods in the course of HIV illness, particularly in the initial period, during which individuals may have greater need for support or be at greater risk for experiencing symptoms of mental illness.

In particular, the results of the present study suggest that psychosocial interventions that help PLWHA solicit or accept positive support from their families may facilitate psychological and, thereby, physiological adjustment to HIV, buffering over time against the potential detrimental impacts of such psychosocial stressors as negative family interactions. In this respect, emotional elements of support, such as feeling loved and cared for by family, appear to be especially important in alleviating symptoms of depression. Additionally, information about unsupportive family interactions (e.g., *feeling disliked or emotionally distant*, *feeling exploited*), which may be especially consequential in their immediate mental health impacts, can also be incorporated into preventative interventions for PLWHA, such as wellness and stress management programs. For example, PLWHA can learn specific communication skills for responding to unsupportive social interactions, and can also learn other cognitive, affective, and behavioral strategies for reducing the adverse consequences of these interactions. Notably, individual, family, and couple's counseling as well as other mental health services are often well received and requested by PLWHA in low-income settings.[340-342]

Though the present research is not designed to assess a specific intervention strategy, with adaptation, existing psychosocial interventions may be usefully implemented to incorporate family support elements in multiple cultural settings. Cognitive behavioral stress management interventions, for example, have been shown to lower depression, increase perceived support, and enhance quality of life in PLWHA by changing the way individuals appraise stress, including social stress, and teaching interpersonal skills for assertively communicating concerns to others in their social network.[343-345] Some evidence further suggests that those at risk for clinical depression and experiencing problems with family benefit from receiving a brief family intervention focused on reducing maladaptive social interactions.[346] Similarly group interpersonal psychotherapy or psychoeducational interventions[347-350] may present a low-cost intervention for PLWHA and those affected that does not require specialist mental health care providers to implement. Family relationship interventions might include, for example, methods to foster emotional expressiveness, reduce social isolation, prevent disease from dominating family life, help deal with loss, promote collaboration among family members, improve empathy, deal with stigma, reinforce developmental family roles, and resolve intra-family conflict.[351]

At the same time, such psychosocial interventions must be multifaceted in light of other identified risk factors for psychological distress. Strengthening family support among PLWHA in Nepal and other LMICs cannot occur, for example, without also addressing the pervasive stigmatization and discrimination often associated with HIV in these contexts. Notably, some form of family education and counseling services appear to be provided through certain of the HIV/AIDS NGOs in Nepal already, but coverage is sparse and the evidence base inadequate.[169] Similarly, vocational counseling and support services to assist PLWHA in pursuing and sustaining gainful employment, along with integrated substance use treatment services may also be beneficial in working to achieve better mental health outcomes. At present, HIV/AIDS NGOs in Nepal are providing some services along such lines, but, again, coverage appears to be erratic.[169]

In sum, using evidence from the current study, the following general package of family-focused interventions aiming to improve the psychological health of PLWHA in Nepal is recommended, to be incorporated into government-level policy guidelines and implemented primarily through community-based organizations:

1) Services aimed at improving relationships and functioning of HIV/AIDS-affected families such as through social services or family therapy, with a particular emphasis on fostering emotionally supportive interactions and reducing emotionally unsupportive or exploitative interactions;
2) Services aimed at improving the family-specific social skills and coping mechanisms of PLWHA such as through cognitive behavioral therapy, with the goal of improving perceptions of family support;
3) Services aimed at reducing AIDS-related stigma (both within the family and more generally) such as through awareness-raising campaigns implemented at the government level and through NGOs; and
4) Services aimed at integrating substance use treatment along with vocational training and support services into HIV care and treatment.

4.5.2. Directions for future research

In sum, the results of the present study provide a preliminary insight into the possible ways that both positive and negative aspects of family support may influence depression and suicidality among PLWHA, and pave the way for further exploration of the role of family relationships in this context. Namely, because perceived family support is a construct that can be assessed reliably and may play a role in the etiology and alleviation of depressive symptoms and suicidal ideation among PLWHA, findings underscore the need for increased research within community and clinical settings for optimizing individuals' levels of perceived family support. With greater knowledge of the relationships between psychosocial factors such as perceived family support and mental health among PLWHA, appropriate psychological treatment can be offered, and more effective clinical service delivery and national policies developed.

Findings imply that both positive and negative aspects of family support have a strong bearing on psychological distress among PLWHA in Nepal, highlighting mobilization of positive family support resources and mitigation of negative family interactions as a priority for future HIV research and policy work. Further research that differentiates between positive and negative experiences of family support is necessary to confirm present findings, and to give insight into how both dimensions of perceived family support may operate differently on mental health. Additionally, the measure of family support included in the present study assessed perceived support from family members collectively, and did not examine support from specific family members. Future research might fruitfully examine source-specific support from individual family members, as well as positive indicators of illness adjustment to see if similar patterns of results emerge. If prime providers of support could, for example, be identified, interventions to increase their involvement could be directed at these key family members. Moreover, on a translational level, additional work examining the value and effectiveness of interventions aimed at reducing the occurrence and consequences of negative interactions among PLWHA and their family members is clearly needed. While a definite need for programs that seek to improve support from family has been identified, little research at this time has evaluated specific approaches in this direction.

The present study was designed to examine the impacts of positive and negative family interactions on negative affect outcomes among PLWHA. Positive affect, however, was not explored. It has been proposed that support may have a stronger effect on positive dimensions of well-being than on negative dimensions of well-being. The extension of the current study to incorporate such factors could thus help construct a more comprehensive understanding of the influences of support and strain processes in this context. Further, social support and social strain can both be considered multi-dimensional constructs, and researchers have suggested a number of different dimensions of support and strain. A logical extension of the current study would thus be to delineate the differential influence of specific dimensions of family support or strain. Considering possible contextual factors, such as certain types of stressors that may have distinct relationships to certain dimensions of support or strain may help to enhance understanding.

Another issue related to the results regarding the cross-domain buffering effects is how and under what circumstances positive family support perceptions might buffer the impacts of negative perceived family support. Conceptually, it is unclear whether, after suffering (or perceiving) negative family exchanges, the benefits of support are reaped – through the seeking of support from other family network members or via the simple perception of supportive others. This, too, is an empirical question for further study.

Conclusions

Using validated scales and longitudinal data, this study demonstrates that the burden of depression and suicidal ideation among PLWHA in the Kathmandu Valley of Nepal is heavy and related both concurrently and prospectively to perceived family support – inversely with positive family interactions and directly with negative family interactions. While a comparison of exact rates found by other studies is not possible, due to different sample populations and instruments used, identified levels of depression are comparable with those found by studies conducted with samples of HIV-positive or chronically ill adults in similar resource-deprived countries – consistently found to be elevated relative to general population prevalences. Specifically, participants who perceived more supportive family environments were likely to report lower levels of depression and suicidality, both immediately and after 18 months, than were their counterparts experiencing less supportive or actively *un*supportive interactions with their families. In this vein, the emotional dimension of these perceived interactions appeared to be especially important in terms of the mental health outcomes.

In summary, perceived family support has effects on the experience of depression and suicidality in PLWHA, both directly and via interactions between its sub-dimensions, with negative PFS having especially powerful effects on mental health in the immediate term but positive PFS appearing to mitigate such detrimental impacts over time. Although this expected pattern of results is conceptually similar to the prototypical stress buffering effect, the present study does not directly test the stress-buffering hypothesis. This qualification is due primarily to the uniqueness of the study population in that all participants are, in effect, chronically physically ill. Tests of the stress buffering effect typically use conventional measures of psychosocial stress (i.e., life events or daily hassles) in a non-diseased population. The present research, however, extends upon stress buffering research by examining the association of perceived family support to the ongoing psychological adjustment of individuals living with HIV/AIDS – effectively a chronic physical illness.

Findings suggest that perceptions of interpersonal family dynamics play an important role in adjusting to life with HIV/AIDS and thus highlight a potentially modifiable source of both psychological resilience and stress. Particularly in contexts of limited mental health resources, developing innovative psychosocial interventions that incorporate family counseling and support elements as an integral component of HIV prevention, care, and treatment efforts may help to mitigate psychological distress and, thereby, realize improved quality of life and clinical outcomes among PLWHA in Nepal and similar settings. In particular, future programs should work with PLWHA to navigate the double-edged sword of family support – minimizing, repairing, and preventing negative and potentially harmful family dynamics while creating, building, mobilizing, and maintaining positive family support structures to buffer against psychiatric comorbidities. Notably, the relatively low correlation between the two dimensions of family support measured in this study suggests that positive and negative family support are distinct constructs and not simply opposite poles on a single continuum. This, in turn, indicates the need for interventions in both areas of support, as an increase in one area will not necessarily imply a decrease in the other.

As the findings of the present study highlight the individual's cognitive appraisal of available support from family members rather than the actual receipt of such support, corresponding interventions to improve this variable might feasibly aim to enhance the effectiveness of family support networks by targeting both cognitive and behavioral barriers to rewarding interpersonal relationships. Though the present research has not tested any such intervention and thus cannot recommend any specific measures in this direction, promising results from network enhancement interventions in other population have shown promising results, as discussed earlier. Through adaptation to focus on family and the specific cultural context of Nepal, such interventions might be expected to achieve similarly fruitful results if developed and implemented through the NGO service network utilized in the present study.

Given the identified correlates of perceived family support in the present study, such interventions would perhaps be rendered most impactful through focusing especially on female gender and low levels of education as risk factors for poor family support, and devoting special attention to those with high levels of internalized stigma. Coupled with this is a need for family- and community-level programs to decrease the stigma and discrimination experienced both within and outside of families, thus helping to foster an environment more conducive to positively supportive interactions. Given the association between internalized stigma and perceptions of family support identified in the present study, addressing the stigma felt by PLWHA from their family and surrounding communities might further contribute to improving experiences of family support and thus to alleviating the burden of depression and suicidal ideation in this population.

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"You can kiss your family and friends good-bye and put miles between you,
but at the same time you carry them with you in your heart, your mind, your stomach,
because you do not just live in a world but a world lives in you." -- Frederick Buechner

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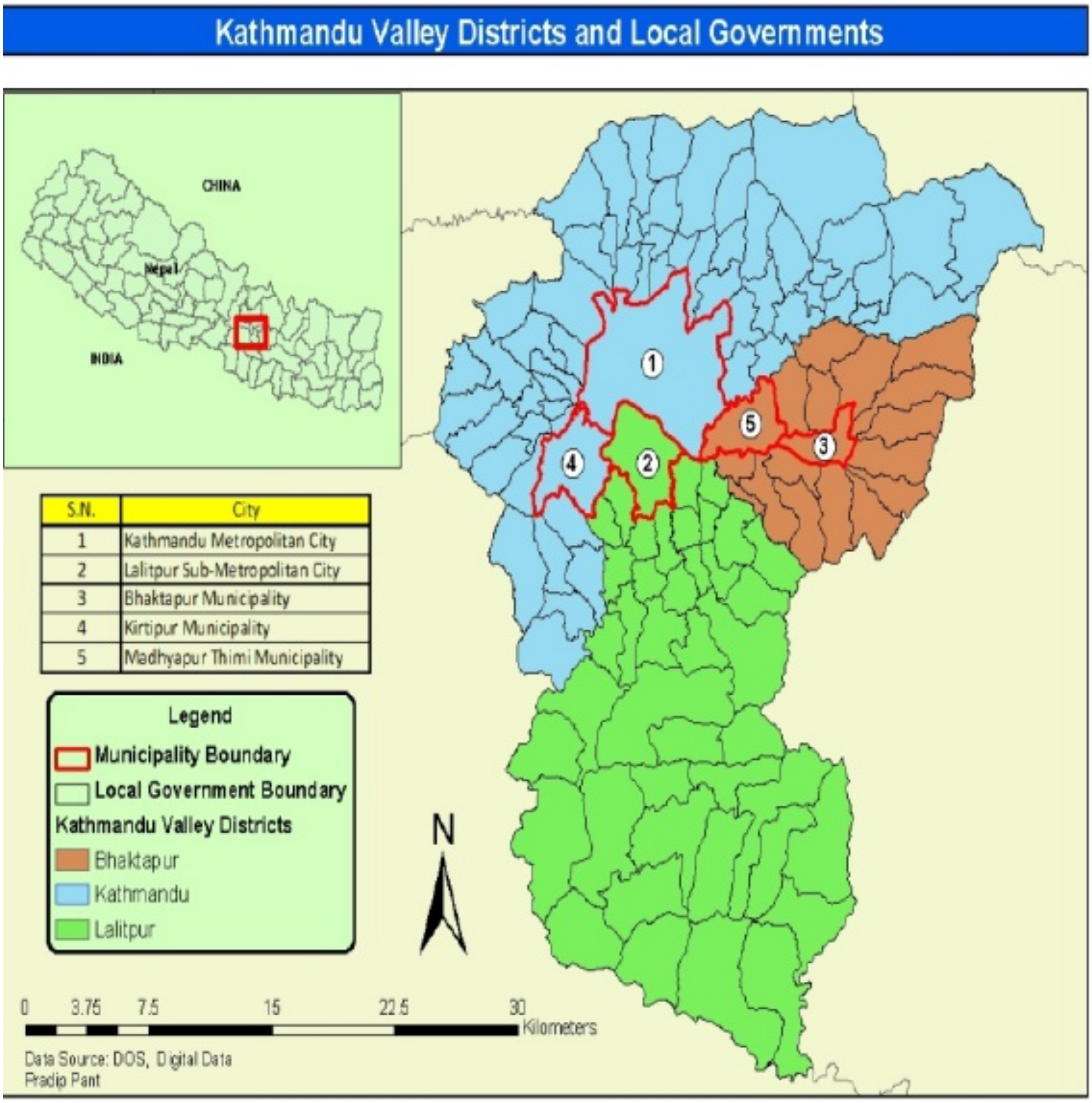
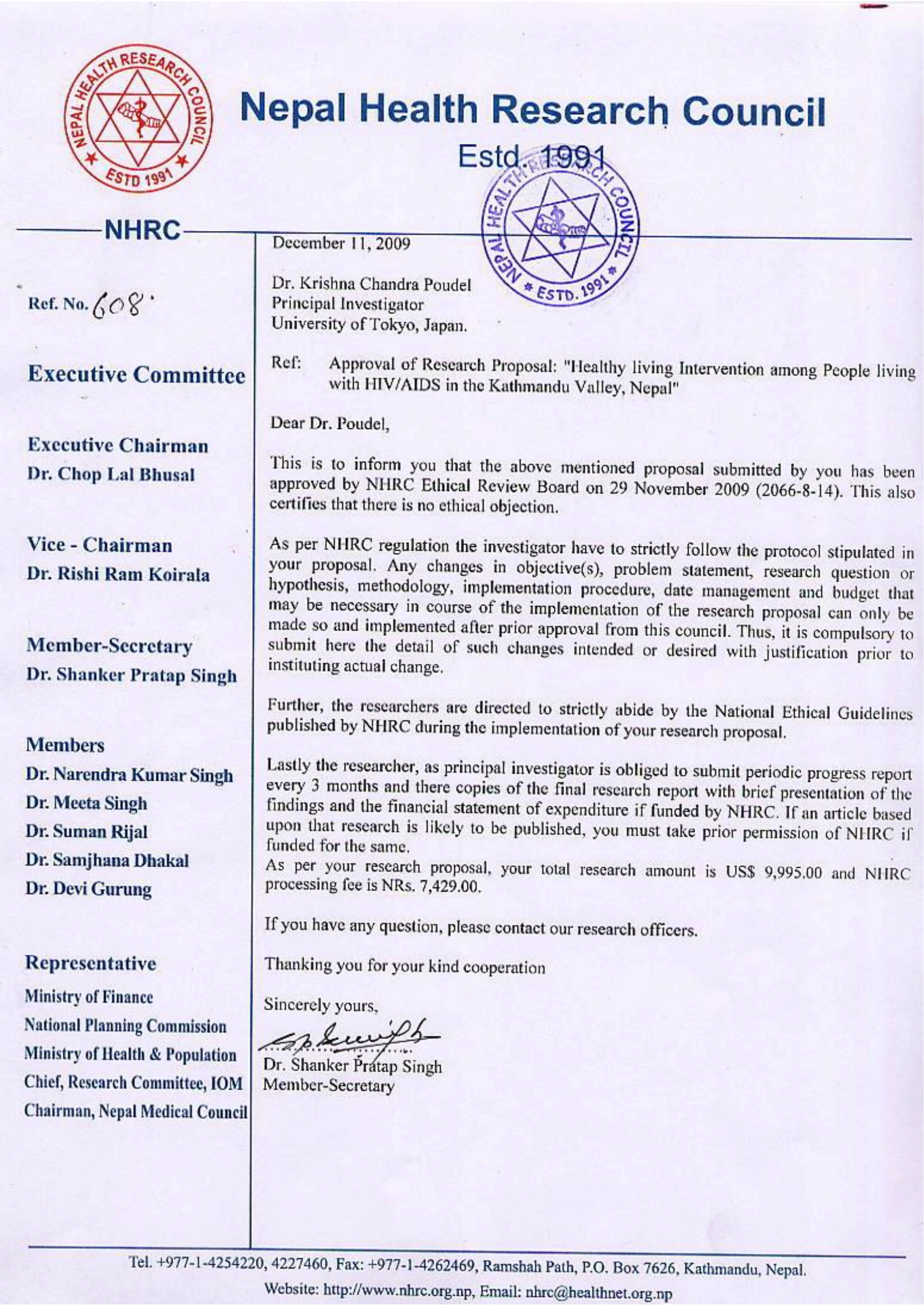
Appendices

Appendix 1: Map of the study area



Appendix 2: Ethical approval from the Nepal Health Research Council



Nepal Health Research Council
Estd. 1991

NHRC

Ref. No. 608

December 11, 2009

Dr. Krishna Chandra Poudel
Principal Investigator
University of Tokyo, Japan.

Ref: Approval of Research Proposal: "Healthy living Intervention among People living with HIV/AIDS in the Kathmandu Valley, Nepal"

Dear Dr. Poudel,

This is to inform you that the above mentioned proposal submitted by you has been approved by NHRC Ethical Review Board on 29 November 2009 (2066-8-14). This also certifies that there is no ethical objection.

As per NHRC regulation the investigator have to strictly follow the protocol stipulated in your proposal. Any changes in objective(s), problem statement, research question or hypothesis, methodology, implementation procedure, date 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 here the detail of such changes intended or desired with justification prior to instituting actual change.

Further, the researchers are directed to strictly abide by the National Ethical Guidelines published by NHRC during the implementation of your research proposal.

Lastly the researcher, as principal investigator is obliged to submit periodic progress report every 3 months and there copies of the final research report with brief presentation of the findings and the financial statement of expenditure if funded by NHRC. If an article based upon that research is likely to be published, you must take prior permission of NHRC if funded for the same.
As per your research proposal, your total research amount is US$ 9,995.00 and NHRC processing fee is NRs. 7,429.00.

If you have any question, please contact our research officers.

Thanking you for your kind cooperation

Sincerely yours,

Dr. Shanker Pratap Singh
Member-Secretary

Tel. +977-1-4254220, 4227460, Fax: +977-1-4262469, Ramshah Path, P.O. Box 7626, Kathmandu, Nepal.
Website: http://www.nhrc.org.np, Email: nhrc@healthnet.org.np

Appendix 3a: Information sheet for participants (English)

Study Information for Participants

Research title: Healthy Living Intervention Among People Living With HIV/AIDS in the Kathmandu Valley, Nepal

Introduction:

This document explains the details of the above-written study, in which we are requesting your cooperation as a voluntary participant. Therefore, please read the following information carefully so that you are fully aware of the research process. If necessary, we may also read this sheet aloud to you. There may be some words in this text with which you are unfamiliar. If so, please feel free to ask about such words or anything else that may be unclear to you.

Objectives of the study:

The overall objective of this intervention study will be to a) improve the HIV-related knowledge, attitudes, and practices, including safer sexual behaviours, b) reduce the prevalence of sexually transmitted infections, and c) explore the health status, mental health status, nutritional status, and smoking status among the HIV -positive people in the Kathmandu Valley, Nepal.

Research Methods:

If you decide to participate in this study, we will contact you 4 times over the next 1-year period. In the first contact (today), we will request roughly 60 minutes of your time. During that time, we will ask you several questions about yourself and your background, including basic sociodemographic characteristics, information pertaining to your HIV diagnosis and current antiretroviral (ARV) regimen, alcohol and drug use, and feelings about your life, physical condition, and emotional state.

We will ask a series of questions as detailed above and record your answers manually in a questionnaire. We will not record your name on the questionnaire. In place of personal identifying information, we will assign one identification code number to each participant. Thus, please be assured of the confidentiality of any information you may provide.

At the second contact, we will organize a 2-day training for you in a small group setting. You will have the opportunity to attend either a risk reduction training (contents: HIV/AIDS-related knowledge, superinfection, self-efficacy, social support, etc.) or health promotion training (contents: mental health, ART, smoking, etc.).

At the third contact, we will contact you approximately 6 months after the training and ask the same questions as before. However, we will not collect your blood and urine this time. Finally, we will contact you approximately 12 months after the training and ask you similar questions. We will also collect your blood and urine samples for the tests we have described above.

Possible risks:

Some of the questions that we will ask may cause you discomfort or make you hesitate to answer. You are free to skip such questions or to withdraw yourself entirely from participation in the study at any time.

Benefits:

The information obtained from you will help us to understand more about this important topic. We hope that such information will be useful to design specific interventions to improve the lives of people living with HIV/AIDS. Besides, you will have the opportunity to learn about various issues pertaining to HIV/AIDS during the 2-day training. We will provide you NRS 100 and snacks each time/day for your participation in the survey and 2-day training. We will give you the results of all of your blood and urine test results for free. We will also provide you with free treatment if you test positive for syphilis, chlamydia, or gonorrhoea.

Confidentiality:

All the information collected during the study will remain confidential. Data will be stored securely and will be made available only to the concerned persons. We will not record your name in the questionnaire. Instead, we will use an identification code for every participant. Thus, your name will not appear in any of the reports we write or publish out of this study.

Funding:

This study is financially supported by the University of Tokyo.

Withdrawal from participation in the research:

You are free to withdraw yourself from the research at any time. Moreover, you are free to decide whether or not to participate in this research in the first place. You have the right to disagree to participate in this study, and it is guaranteed, even after entering the study, that you may quit at any time without facing any penalty.

Voluntary agreement:

If you understand fully what this study involves and agree to participate, you are welcome to join as a participant. If you do not wish to participate, you are free to decline and need not provide any information nor put your signature on any part of this or any of the attached documents.

After reading and fully understanding the contents of this sheet, you are free to offer your decision regarding participation in this study. If you decide to participate, you may indicate your consent by putting your signature on the attached consent form.

Should you have any further questions, please contact the following persons:

a) Dr. Krishna C. Poudel, Rachel M. Amiya, The University of Tokyo, Tokyo, Japan. Department of Community and Global Health, Graduate School of Medicine, The University of Tokyo, 7-3-1 Hongo, Bunkyo-ku, Tokyo 113-0033, Japan. Tel: 81-3-5841-3698; Fax: 81-3-5841-3422; email: krishna@m.u-tokyo.ac.jp, rachel.amiya@gmail.com

b) Dr. Basu Dev Pandey, Sukraraj Tropical and Infectious Disease Hospital, Teku, Kathmandu, Tel: 4253395; e-mail: drbasupandey2003@yahoo.com

Appendix 3b: Information sheet for participants (Nepalese)

अध्ययन वारे जानकारी

अध्ययनको शिर्षक: काठमाण्डौमा रहेका एच.आई.भी.तथा एड्स संक्रमित व्यक्तिहरुमा नियमित धुम्रपान र धुम्रपान त्याग्ने तत्पर्ता बारेको अध्ययन ।

परिचय:

यस लेखमा माथि उल्लेखित अध्ययनको वारेमा उल्लेख गरिएको छ । यहां हामी तपाईलाई यस अध्ययनमा स्वईच्छाले सहभागी भई सहयोग गरिदिनु हुनको लागि अनुरोध गरिरहेका छौ । त्यसकारणले तपाईलाई यो लेख राम्रोसग पढिदिनुहुनको लागि अनुरोध गर्दछौ । यदि तपाई पढ्न सक्नु हुन्न भने हामी नै यहा लेखिएका कुराहरु राम्ररी पढेर स्पष्ट पारिदिने छौ । यस लेखका कुनै शव्दहरु तपाईलाई वुझ्न गाह्रो भएमा कृपया हामीलाई सोध्नुहोस। तपाईले नवुझेका वा अन्य कुनै पनि प्रश्न भएमा पनि हामी तपाईलाई प्रष्ट पारीदिनेछौ।

अध्ययनको उद्देश्य:

यस अध्ययनवाट हामीले काठमाण्डौमा रहेका एच.आई.भी.तथा एड्स संकमित व्यक्तिहरुमा १) धुम्रपानको प्रयोग र धुम्रपान गर्नुका कारणहरु पत्ता लगाउने २) चिकित्सकबाट दिइने धुम्रपान सम्बन्धी सल्लाह र सुझावहरुको नियमितताको आँकलन गर्ने ३) धुम्रपान छोड्न चिकित्सकबाट दिइने सल्लाह र सुझावहरुको प्रभाव पत्ता लगाउने लक्ष्य लिएका छौ ।

अध्ययनको प्रकृया:

यदि तपाई यो अध्ययनमा सहभागी हुन मञ्जुर हुनुहुन्छ भने, हामी तपाईलाई जम्मा १ पटक सम्पर्क गर्ने छौं । सो सम्पर्क (आज) मा, हामी तपाईको ६० मिनेट लिने छौं । यो अवधिमा प्रश्नकर्ताले तपाईलाई व्यक्तिगत जीवन, तपाईको एच.आई.भी. सम्बन्धी केही जानकारीहरु, एच.आई.भी. संक्रमित प्रति हुने भेदभाव, तपाईको जीवन प्रतिको तपाईको धारणा, स्वास्थ्य सम्बन्धी समस्याहरु, औषधी सेवन, धुम्रपान र लागू औषधीको प्रयोगका बारेमा प्रश्नहरु गर्नुहुनेछ । हामी तपाईलाई प्रश्न सोध्ने छौं र तपाईको उत्तरलाई प्रश्नावलीमा टिप्ने छौं । तर हामी तपाईको नाम प्रश्नावलीमा लेख्ने छैनौं । हामी यसको लागि कोड नम्वरको प्रयोग गर्नेछौ । हामी तपाईलाई अन्य सहभागीहरुलाई जस्तै एउटा नम्वर दिनेछौ र प्रतिवेदनहरुमा यहि नम्वरको प्रयोग गर्नेछौं ।

सम्भाव्य खतराहरु:

हामीले सोध्ने केहि प्रश्नहरुको उत्तर दिन तपाईलाई केहि असजिलो लाग्न पनि सक्नेछ । तपाईलाई असजिलो लागेमा यस्ता प्रश्नहरुको उत्तर नदिन पनि सक्नुहुन्छ अथवा सम्पूर्ण अध्ययनवाट अलगिन पनि सक्नुहुनेछ ।

फाईदाहरु:

तपाईले दिनु भएको जानकारीबाट हामीलाइ यो विषयलाइ बुझ्ने अवसर मिल्नेछ । तपाईहरुले पु¥याउनु भएको सहयोगको कदर गर्दै सर्वेक्षण र तालिममा हामी तपाईहरुलाई रु १००/– (एक सय रुपियाँ मात्र) प्रति व्यक्ति प्रति दिन प्रदान गर्ने छौं साथै खाजाको पनि व्यवस्था गर्ने छौं ।

गोपनियताः

अध्ययनको क्रममा संकलन गरिएका संपूर्ण तथ्यांकहरु गोप्य राखिनेछन । यी तथ्यांकहरु अध्ययनमा संलग्न व्यक्तिहरु र अन्य सम्वन्धित व्यक्तिहरुले मात्र प्रयोग गर्नेछन । हामी सहभागीहरुसंग सम्वन्धित सवै प्रश्नावलीको नतिजा तयार गरीने कागजहरुमा कोड नम्वर नै प्रयोग गर्ने छौ । हामीले यस तथ्यांक प्रयोग गरी वनाउने वा छपाउने कुनैपनि प्रतिवेदनमा तपाईको नाम हुनेछैन ।

अध्ययनवाट हट्ने प्रावधानः

तपाईलाई यस अध्ययनमा भाग लिन मन नलागेमा भाग नलिन पनि सक्नुहुनेछ र भाग लिएर विचमा छोड्न मन लागेमा पनि कुनै पनि वेला छोड्न सक्नुहुनेछ । तपाईलाई यस अध्ययनमा सहभागी नहुने निर्णय गर्नको लागि पनि पूर्ण अधिकार छ। त्यसै गरी तपाई अध्ययनमा सहभागी भएर मन नपरेको खण्डमा कुनैपनि समयमा विनाकारण सहमती पत्र खारेज गरी यस अध्ययनबाट कुनै दण्ड जरिवना बिना नै सहभागीताबाट हट्न पनि सक्नुहुनेछ ।

कृपया यो अध्ययनको लागि तपाई सहमत हुनुहुन्छ भने मन्जुरीनामा पत्रमा दस्तखत गरीदिनुहोला ।

यदि तपाईंको केही प्रश्नहरु भएमा तलका व्यक्तिहरुलाई सम्पर्क गर्न सक्नु हुनेछ ।

१.) डा कृष्ण पौडेल, राचेल अमिया मारी, सामुदायिक तथा विश्व स्वास्थ्य विभाग, चिकित्सा संकाय, टोकियो विश्वविद्यालय, ठेगानाः ७–३–१ हंगो, बुन्क्यो कु, टोकियो ११३–००३३, जापान । फोनः ८१ ३ ५८४१ ३६८९ इमेलः krishna@m.u-tokyo.ac.jp, rachel.amiya@gmail.com

२) बासुदेव पाण्डे
शुक्रराज ट्रोपीकल तथा सरुवा रोग अस्पताल, टेकु, काठमाण्डौं, नेपाल । फोनः ४२५३३९५
इमेलः drbasupandey2003@yahoo.com

Appendix 4a: Informed consent form (English)

Informed Consent Form for Participants

To: The Dean of the Graduate School of Medicine, The University of Tokyo
Research Title: Healthy Living Intervention Among People Living With HIV/AIDS in the Kathmandu Valley, Nepal

---

I, Mr./Mrs./Ms. ……………………………, have agreed to participate in this research entitled "Healthy Living Intervention Among People Living With HIV/AIDS in the Kathmandu Valley, Nepal" as a participant.

The procedures I agree to are as follows:

a) Baseline survey: I will be asked questions by an interviewer questions about myself and my background, including basic sociodemographic characteristics, information pertaining to my HIV diagnosis and current antiretroviral (ARV) regimen, alcohol and drug use, and feelings about my life, physical condition, and emotional state. I will also be asked for blood and urine samples. The samples will be examined for syphilis, herpes, gonorrhoea, chlamydia, hepatitis C virus, CD4 cell count, haemoglobin, cholesterol, triglyceride, ALT/SGPT, and C-reactive protein. I will receive the results of my blood and urine tests. I will also receive free treatment if I am tested positive for syphilis, chlamydia, or gonorrhoea.
b) Intervention: I will have an opportunity to attend a 2-day training: either a risk reduction training (contents: HIV/AIDS-related knowledge, superinfection, self-efficacy, social support, etc.) or a health promotion training (contents: mental health, ART, smoking, etc.).
c) Post-intervention surveys: I will be contacted 6 month after the training and will be asked the same questions as before (baseline). Finally, I will be contacted again 12 months after the training and will be asked a similar set of questions as before. At this time, I will be also asked for blood and urine samples for the tests as before (baseline).

I give this consent voluntarily, after receiving a full explanation from the study team about confidentiality to protect my privacy (my rights will not be jeopardized) and the experimental procedure, including possible risks. I understand the potential benefits of the investigation for myself, for people living with HIV/AIDS, and for other community members. In addition, I understand that the data obtained in this study will be used in a manner consistent with the strict maintenance of confidentiality and personal rights.

Finally, I know that I can withdraw my consent and discontinue my participation at any time without facing any penalty.

Participant's identifying code: …………………………… Signature: …………………….

Witness name: ……………………………………………….. Signature: ……………………

Name of the person who obtained consent: ………………………………………..

Date: Year: ………… Month: ………… Day: ………

Appendix 4b: Informed consent form (Nepalese)

मञ्जुरीनामा पत्र

श्रीमान डीन ज्यु,

चिकित्सा शास्त्र संकाय

टोकियो विश्वविद्यालय

अध्ययनको विषयः काठमाण्डौमा रहेका एच.आई.भी.तथा एड्स संक्रमित व्यक्तिहरुमा नियमित धुम्रपान र धुम्रपान त्याग्ने तत्पर्ता बारेको अध्ययन

म, श्री/सुश्री/श्रीमती .... (नामको पहिलो अक्षर मात्र लेख्ने), काठमाण्डौमा रहेका एच.आई.भी.तथा एड्स संक्रमित व्यक्तिहरुमा नियमित धुम्रपान र धुम्रपान त्याग्ने तत्पर्ता बारेको अध्ययन मा एक सहभागीको रुपमा तल उल्लेखित विधि वा विषयहरुमा सहभागी हुन मञ्जुर छु। अध्ययनकर्ताहरुले मलाइ एक पटक सम्पर्क गर्नु हुनेछ। म निम्न कार्य गर्नका लागि सहमत छु :

सर्वेक्षणः मलाई प्रश्नकर्तावाट मेरो व्यक्तिगत जीवन, मेरो जीवन प्रतिको मेरो धारणा, स्वास्थ्य सम्बन्धी समस्याहरु, एच.आई.भी.तथा एड्स सम्बन्धि जानकारीहरु र धुम्रपान र लागू औषधीको प्रयोगका वारेमा प्रश्नहरु सोधिनेछ।

यस अध्ययनमा सहभागी भएर मैले बताएका कुराहरु अनावश्यक ढंगले तोडमोड तथा व्याख्या नगरी गोपनियता पनि भंग गरिने छैन भन्ने कुरा तथा यस अध्ययनको तरीका र संभाव्य खतराहरुसमेत मलाई अनुसन्धानकर्ताहरुले वताईसकेपछि मैले यो मञ्जुरीनामा स्वइच्छाले दिएको छु। यस अध्ययनबाट एच.आई.भी.तथा एड्स संक्रमित व्यक्तिहरुलाई तथा समुदायकै लागि फाईदा हुन्छ भन्ने कुरा पनि मैले वुझेको छु। त्यसैगरी यस अध्ययनमा सहभागी भएर मैले बताएका कुराहरुको गोपनियता भंग नगरीकन र मेरो व्यक्तिगत अधिकारको ख्याल गरी प्रयोग गरिनेछ भन्ने कुरा पनि मैले वुझेको छु।

अन्त्यमा, यदि मलाई मन नपरेको खण्डमा कुनैपनि समयमा विनाकारण यो सहमती पत्र खारेज गरी यस अध्ययनबाट कुनै दण्ड जरिवना बिना नै सहभागीताबाट हट्न पनि सक्नेछु भन्ने कुरा पनि मलाई राम्रोसंग थाहा छ।

सहभागीको कोड नं.: .... हस्ताक्षर : ....

साक्षीको नामः .... हस्ताक्षरः ....

मञ्जुरीनामा लिने व्यक्तिको नामः ....

मिति : ....

Appendix 5a: Study questionnaire (English)

Interview Questionnaire

Interviewer's name:______________________ Respondent No: ☐☐☐

Date of interview: ___________________ Interview starting time: ________________

Interview ending time: _______________ [Total time spent on interview: __________]

[Checked by supervisor: Signature ________________________ Date _________________]

Background characteristics	
1. Marital status	(1) Married (2) Unmarried (3) Divorced (4) Widowed
2. What is your level of education?	(1) Illiterate (2) Informal education (_____months) (3) Literate (___yrs of formal education) (4) Other (Specify: _________)
3. How much do you earn every month?	NRs_______
4. How many family members are currently living with you at your present residence?	________ persons
5. Have you disclosed your HIV status to any of the family members?	(1) Yes (2) No
6. Do you have any children?	(1) Yes (____ children) (2) No
7. How would you classify your sexual orientation?	(1) Heterosexual (2) Homosexual (3) Bisexual
HIV-related information	
8. When did you first come to know of your HIV-positive status?	Year: ___Month: ___Day: ___
9. Do you receive ART?	(1) Yes (2) No

10. When did you start taking ART?	Year: ___Month: ___Day: ___
Perceived family support (Nepali Family Support and Difficulty Scale)	
11. How much does your family show love and caring for you?	(0) Not at all (1) Sometimes (2) Often (3) All the time
12. How much do you feel disliked by your family?	(0) Not at all (1) Sometimes (2) Often (3) All the time
13. How much do you feel you have an important role in your family?	(0) Not at all (1) Sometimes (2) Often (3) All the time
14. How much do you feel (emotionally) distant from your family?	(0) Not at all (1) Sometimes (2) Often (3) All the time
15. How much are you involved in family decision making?	(0) Not at all (1) Sometimes (2) Often (3) All the time
16. How much are your basic needs (food and clothes) met in your family?	(1) Not at all (4) Sometimes (5) Often (6) All the time
17. How much support do you get from family when you are sick?	(0) Not at all (1) Sometimes (2) Often (3) All the time
18. How much has your family physically (beaten) hurt you?	(0) Not at all (1) Sometimes (2) Often (3) All the time
19. How much can you share your feelings with your family?	(0) Not at all (1) Sometimes (2) Often (3) All the time
20. How much does your family exploit you (such as for labor in the house and/or farming)?	(0) Not at all (1) Sometimes (2) Often (3) All the time

HIV/AIDS Internalized Stigma Scale

Please indicate whether or not you feel that the following statements apply to you.

21. It is difficult to tell other people about my HIV infection.	(1) Disagree (2) Agree
22. Being HIV-positive makes me feel dirty.	(1) Disagree (2) Agree
23. I feel guilty that I am HIV-positive.	(1) Disagree (2) Agree
24. I am ashamed that I am HIV-positive.	(1) Disagree (2) Agree
25. It is my own fault that I am HIV-positive.	(1) Disagree (2) Agree
26. I hide my HIV status from others	(1) Disagree (2) Agree
27. I sometimes feel worthless because I am HIV-positive.	(1) Disagree (2) Agree

Substance use

28. How often have you had a drink containing alcohol (a glass of beer, wine, a mixed drink, or any kind of alcoholic beverage) in the last 30 days?	(1) Daily (2) 3 or 4 times a week (3) Once or twice a week (4) 2 or 3 times a month (5) Once a month (6) Never
29. Have you ever used injecting drugs in your lifetime?	(1) Yes (2) No
30. Have you used injecting drugs in the past 6 months?	(1) Yes (2) No
31. Have you used marijuana in the past 6 months?	(1) Yes (2) No
32. Have you used any other illicit drug in the past 6 months?	(3) Yes (Indicate:_____) (4) No

Beck Depression Inventory (BDI)

During the past two weeks, including today, have you been feeling…

33. Sadness?	(0) I don't feel sad (1) I feel sad much of the time (2) I am sad all the time (3) I am so sad or unhappy that I can't stand it
34. Pessimism?	(0) I am not discouraged about my future (1) I feel more discouraged about my future than I used to be

	(2) I do not expect things to work out for me (3) I feel that my future is hopeless and will only get worse
35. Past failure?	(0) I do not feel like a failure (1) I have failed more than I should have (2) As I look back, I see a lot of failures (3) I feel I am a total failure as a person
36. Loss of satisfaction?	(0) I am not particularly dissatisfied (1) I am often dissatisfied (2) I usually dissatisfied with most aspects of my life (3) I am dissatisfied with every single aspect of my life
37. Guilty feelings?	(0) I don’t feel particularly guilty (1) I feel guilty over many things I have done or should have done (2) I feel quite guilty most of the time (3) I feel guilty all of the time
38. Punishment feelings?	(0) I don’t feel I am being punished (1) I feel I may be punished (2) I expect to be punished (3) I feel I am being punished
39. Self-dislike?	(0) I feel the same about myself as ever (1) I have lost confidence in myself (2) I am disappointed in myself (3) I dislike myself
40. Self-criticalness?	(0) I don’t criticize or blame myself more than usual (1) I am more critical of myself than I used to be (2) I criticize myself for all my faults (3) I blame myself for everything bad that happens
41. Suicidal thoughts or wishes? (During the past 2 weeks, have you thought about ending your life?)	(0) I don’t have any thoughts of killing myself (1) I have thoughts of killing myself, but I would not carry them out (2) I would like to kill myself (3) I would kill myself if I had the chance
42. Crying?	(0) I don’t cry any more than I used to (1) I cry more than I used to (2) I cry over every little thing (3) I feel like crying, but I can’t
43. Irritability?	(0) I am no more irritable than usual (1) I am more irritable than usual (2) I am much more irritable than usual (3) I am irritable all the time
44. Loss of interest?	(0) I have not lost interest in other people or activities (1) I am less interested in other people or things than before (2) I have lost most of my interest in other people or things

	(3) It's hard to get interested in anything
45. Indecisiveness?	(0) I make decisions about as well as ever (1) I find it more difficult to make decisions than usual (2) I have much greater difficulty in making decisions than I used to (3) I have trouble making any decisions
46. Body image?	(0) I don't feel I look any worse than I used to (1) I am worried that I am looking worse than I used to (2) I feel that I usually look unattractive (3) I feel that I am ugly or repulsive-looking
47. Work inhibition?	(0) I work as well as usual (1) I feel that I do not work as well as I used to (2) Working for me is very difficult (3) I cannot do any work at all
48. Change in sleeping pattern?	(0) I have not experienced any change in my sleeping pattern (1) I can't sleep as well as I used to (2) I wake earlier than I used to (3) I wake very early and it's impossible to fall back asleep
49. Weight loss?	(0) My weight has not changed (1) I have lost about 5 kilos (2) I have lost about 10 kilos (3) I have lost more than 15 kilos
50. Change in appetite?	(0) I have not experienced any change in my appetite (1) My appetite is somewhat less than usual (2) My appetite is much less than before (3) I have no appetite at all
51. Somatic preoccupation?	(0) I am no more worried about my health than usual (1) I am more concerned about my health than I used to be (2) I am so concerned about my health that it is hard to think about anything else (3) The only thing I can think about is my health and nothing else
52. Tiredness or fatigue?	(0) I am no more tired or fatigued than usual (1) I get tired or fatigued more easily than usual (2) I am too tired or fatigued to do a lot of the thing I used to do (3) I am too tired or fatigued to do most of the things I used to do
53. Loss of interest in sex?	(0) I have not noticed any recent change in my interest in sex (1) I am less interested in sex than I used to be

	(2) I am much less interested in sex now (3) I have lost interest in sex completely
HIV Symptom Index (HSI) The following questions ask about symptoms you might have had during the past 4 weeks. Please indicate the one response that best describes how much you have been bothered by each symptom.	
54. Fever, chills, or sweats?	(0) I don't have this problem (1) I have this problem and it does not bother me (2) I have this problem and it bothers me little (3) I have this problem and it bothers me (4) I have this problem and it bothers me a lot
55. Feeling dizzy or light-headed?	(0) I don't have this problem (1) I have this problem and it does not bother me (2) I have this problem and it bothers me little (3) I have this problem and it bothers me (4) I have this problem and it bothers me a lot
56. Pain, numbness, or tingling in the hands or feet?	(0) I don't have this problem (1) I have this problem and it does not bother me (2) I have this problem and it bothers me little (3) I have this problem and it bothers me (4) I have this problem and it bothers me a lot
57. Trouble remembering?	(0) I don't have this problem (1) I have this problem and it does not bother me (2) I have this problem and it bothers me little (3) I have this problem and it bothers me (4) I have this problem and it bothers me a lot
58. Nausea or vomiting?	(0) I don't have this problem (1) I have this problem and it does not bother me (2) I have this problem and it bothers me little (3) I have this problem and it bothers me (4) I have this problem and it bothers me a lot
59. Diarrhea or loose bowel movements?	(0) I don't have this problem (1) I have this problem and it does not bother me (2) I have this problem and it bothers me little (3) I have this problem and it bothers me (4) I have this problem and it bothers me a lot
60. Skin problems, such as rash, dryness, or itching?	(0) I don't have this problem (1) I have this problem and it does not bother me (2) I have this problem and it bothers me little (3) I have this problem and it bothers me (4) I have this problem and it bothers me a lot
61. Cough or trouble catching your breath?	(0) I don't have this problem (1) I have this problem and it does not bother me (2) I have this problem and it bothers me little

	(3) I have this problem and it bothers me (4) I have this problem and it bothers me a lot
62. Headache?	(0) I don't have this problem (1) I have this problem and it does not bother me (2) I have this problem and it bothers me little (3) I have this problem and it bothers me (4) I have this problem and it bothers me a lot
63. Bloating, pain, or gas in your stomach?	(0) I don't have this problem (1) I have this problem and it does not bother me (2) I have this problem and it bothers me little (3) I have this problem and it bothers me (4) I have this problem and it bothers me a lot
64. Muscle aches or joint pain?	(0) I don't have this problem (1) I have this problem and it does not bother me (2) I have this problem and it bothers me little (3) I have this problem and it bothers me (4) I have this problem and it bothers me a lot
65. Changes in the way your body looks, such as fat deposits or weight gain?	(0) I don't have this problem (1) I have this problem and it does not bother me (2) I have this problem and it bothers me little (3) I have this problem and it bothers me (4) I have this problem and it bothers me a lot
66. Hair loss or changes in the way your hair looks?	(0) I don't have this problem (1) I have this problem and it does not bother me (2) I have this problem and it bothers me little (3) I have this problem and it bothers me (4) I have this problem and it bothers me a lot
Suicidal ideation/attempts	
67. Have you ever thought about ending your life?	(1) Yes (2) No
68. Have you ever attempted suicide?	(1) Yes (2) No
69. How many times did you attempt suicide after knowing you were HIV+?	_____ times

Appendix 5b: Study questionnaire (Nepalese)

सहभागी नं

अन्तरवार्ताको लागि प्रश्नावली

अन्तरवार्ता लिने व्यक्तिको नाम :......................... सहभागीको जिल्ला : ....

Background characteristics	
1. वैवाहिक स्थिती :	(1) विवाहित (2) अविवाहित (3) पारपाचुके (4) विदुर
2. तपाईले कति पढ्नु भएको छ ?	(1) निरक्षर (2) प्रौढ कक्षाः (....महिना) (3) स्कूलको शिक्षाः(.....वर्ष) (4) अन्य (उल्लेख गर्ने ....)
3. तपाईले एक महिनामा जम्मा कति रुपैयां कमाउनु हुन्छ ?	रु ....
4. तपाई हाल बस्ने ठाउंमा तपाईंसंग तपाईको परिवारका सदस्यहरु कति जना बस्नुहुन्छ ?	..........जना
5. तपाई HIV संक्रमित भएको कुरा घरमा कसैलाइ बताउनु भएको छ ?	(1) छ (2) छैन
6. तपाईंको वच्चाबच्चीहरु छन्?	(1) छन (.........जना) (2) छैनन्
7. तपाई आफुलाई कस्तो प्रकारको यौनलिंगी भन्न मनपराउनुहुन्छ?	(1) विपरितलिंगी (2) समलिंगी (3) दुवै समुहसग यौन संपर्क गर्ने
HIV-related information	
8. तपाईले आफुलाई HIV भएको कहिले थाहा पाउनुभयो?	सालः २०.....महिनाः.........गतेः ....
9. HIV रोगको लागि तपाईले ART खाने गर्नु भएको छ ?	(1) छ (2) छैन
10. तपाईले ART कहिले देखि खान थाल्नु भएको हो ?	साल.............महिना................गते...........

Perceived family support (Nepali Family Support and Difficulty Scale)

पारिवारीक सहयोग

विगत १ वर्ष भित्रमा तपाईले निम्न लिखित कुराहरु कसरी महसुस गर्नु भएको छ कृपया बताइदिनु होला ।

11. तपाईको परिवारबाट तपाईले कत्तिको माया/हेरविचार पाउनु भएको छ ?	(0) पाएको छैन (1) अलिअलि पाएको छु (2) चाहिने जति पाएको छु (3) एकदमै धेरै पाएको छु
12. तपाईको परिवारबाट तपाईले कत्तिको घृणा/अपमान र भेदभाव भएको महशुस गर्नु भएको छ ?	(0) पाएको छैन (1) अलिअलि पाएको छु (2) चाहिने जति पाएको छु (3) एकदमै धेरै पाएको छु
13. परिवारमा तपाईको आफ्नो भूमिका कत्तिको छ जस्तो लाग्छ ?	(0) पाएको छैन (1) अलिअलि पाएको छु (2) चाहिने जति पाएको छु (3) एकदमै धेरै पाएको छु
14. तपाई आफ्नो परिवारबाट कत्तिको तिरस्कृत (मन नपराउने, अपहेलना गर्ने, टाढा रहने) भएको महशुस गर्नु हुन्छ ?	(0) पाएको छैन (1) अलिअलि पाएको छु (2) चाहिने जति पाएको छु (3) एकदमै धेरै पाएको छु
15. परिवारमा कुनै पनि कुराको निर्णय लिंदा तपाईलाई कत्तिको सोधखोज गरिन्छ ?	(0) पाएको छैन (1) अलिअलि पाएको छु (2) चाहिने जति पाएको छु (3) एकदमै धेरै पाएको छु
16. तपाईको परिवारमा तपाईले अन्य सदस्य सरह खाना खान पाउनु हुन्छ ?	(0) पाएको छैन (1) अलिअलि पाएको छु (2) चाहिने जति पाएको छु (3) एकदमै धेरै पाएको छु
17. तपाई बिरामी हुँदा परिवारको सदस्यबाट कत्तिको स्याहार पाउनु हुन्छ ?	(0) पाएको छैन (1) अलिअलि पाएको छु (2) चाहिने जति पाएको छु (3) एकदमै धेरै पाएको छु
18. तपाईको परिवारको सदस्यले तपाईलाई कत्तिको कुटपिट गर्नुहुन्छ ?	(0) पाएको छैन (1) अलिअलि पाएको छु (2) चाहिने जति पाएको छु (3) एकदमै धेरै पाएको छु
19. तपाई आफ्नो परिवारलाई मनको कुरा (खुसी, पिर, मर्का कत्तिको भन्नु हुन्छ ?	(0) पाएको छैन (1) अलिअलि पाएको छु

	(2) चाहिने जति पाएको छु (3) एकदमै धेरै पाएको छु
20. तपाईको परिवारले तपाईलाई कत्तिको शोषण (कामको बेला मात्र प्रयोग गर्ने, गरेको कामको जस नदिने, बढी काम गराउने गरेको महशुस गर्नुहुन्छ ?	(0) पाएको छैन (1) अलिअलि पाएको छु (2) चाहिने जति पाएको छु (3) एकदमै धेरै पाएको छु
HIV/AIDS Internalized Stigma Scale तलका प्रश्नहरुमा तपाईं सहमत वा असहमत के हुनुहुन्छ बताइदिनु होस् ।	
20. अरु व्यक्तिलाई आफु HIV संक्रमित भएको कुरा भन्न गाह्रो हुन्छ ।	(1) असहमत (2) सहमत
21. म HIVसंक्रमित भएको कारणले आफु अपवित्र भएको महसुस् हुन्छ ।	(1) असहमत (2) सहमत
22. म नराम्रो महसुस गर्छु कि म HIVसंक्रमित छु ।	(1) असहमत (2) सहमत
23. HIVसंक्रमित भएको कारणले म लज्जित छु ।	(1) असहमत (2) सहमत
24. आफ्नो गल्तिको कारणले म HIV संक्रमित भएँ ।	(1) असहमत (2) सहमत
25. म HIV संक्रमित भएको कुरा अरु संग लुकाउँछु ।	(1) असहमत (2) सहमत
26. म HIV संक्रमित भएको कारण कहिलेकाहीँ मेरो कुनै मुल्य छैन जस्तो महसुस हुन्छ।	(1) असहमत (2) सहमत
Substance use	
28. तपाईंले बिगत ३० दिनमा कति पटक मादक पदार्थ पिउनु भयो ?	(1) दिन दिनै जसो (2) हप्तामा ३-४ पटक (3) हप्तामा १ -२ पटक (4) महिनामा २-३ पटक (5) महिनमा १ पटक (6) कहिले पनि पिइन
29. के तपाईंले आफ्नो जिवनमा अहिले सम्म सुइ मार्फत दिने लागु औषधि लागु प्रयोग गर्नु भयो ?	(1) थिएँ (2) थिइन
30. के तपाईंले सुइ मार्फत दिने लागु औषधि गत ६ महिना भित्रमा प्रयोग गर्नु भयो ?	(1) थिएँ (2) थिइन
31. के तपाईंले गाँजा गत ६ महिना भित्रमा प्रयोग गर्नु भयो ?	(1) थिएँ (2) थिइन
32. के तपाईले ६ महिना अगाडि कुनै दुर्व्यसनीजन्य लागुपदार्थ सेवन गर्नुभएको थियो?	(1) थिए (खुलाउनुहोस........................) (2) थिइन

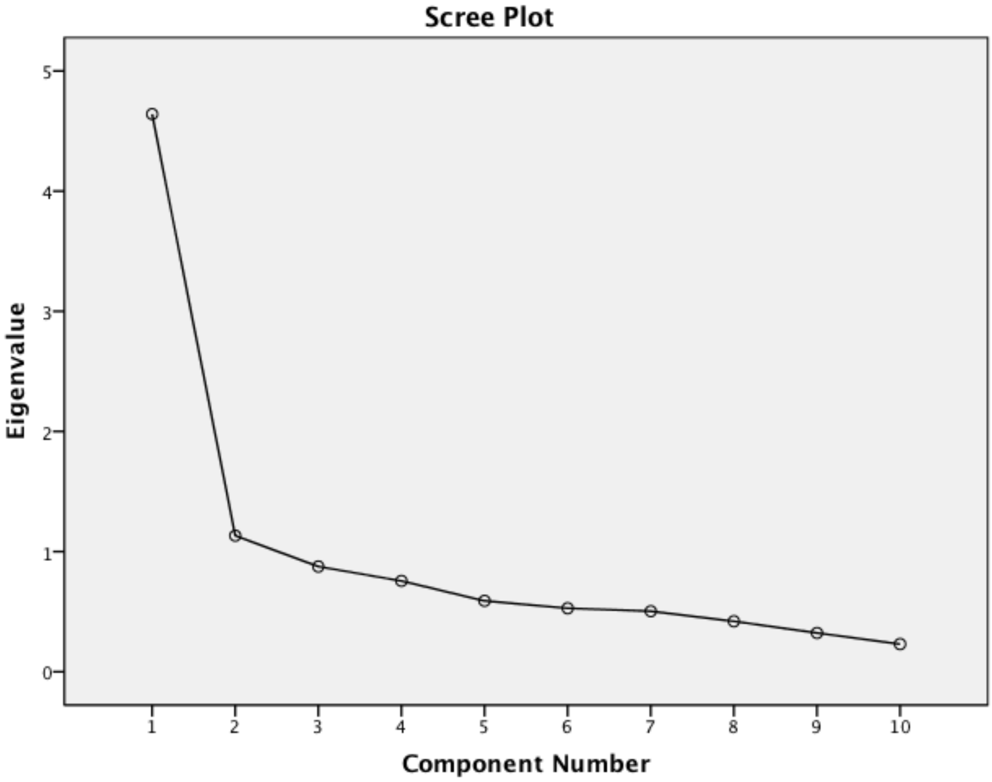
Beck Depression Inventory (BDI) कृपया ति लक्षणहरुले तपाईलाई गएको २ हप्तामा कत्तिको पिरल्यो राम्ररी सोचेर जवाफ दिनु होला ।	
33. गएको दुई हप्तामा तपाई कत्तिको उदास हुनुहुन्थ्यो ?	(1)कहिल्यै भईन (2)प्राय भएँ (3)सधैं जसो भएँ (4)असह्य भएको थियो
34. गएको दुई हप्तामा तपाई कत्तिको निराश हुनु भयो ? (जस्तै आफ्नो भविष्यको बारेमा सम्झेर)	(1)कहिल्यै भईन (2)प्राय भएँ (3)सधैं जसो भएँ (4)असह्य भएको थियो
35. गएको दुई हप्तामा तपाईलाई आफ्नो जिवनमा कत्तिको असफल भएजस्तो लाग्यो?	(1)कहिल्यै लागेन (2)प्राय लाग्यो (3)सधैं जसो लाग्यो (4)पूर्णरुपले असफल भए जस्तो लाग्यो
36. गएको दुई हप्तामा तपाई आफ्नो जिवन देखी कत्तिको असन्तुष्ट हुनुभयो ?	(1)कहिल्यै भईन (2)प्राय भएँ (3)सधैं जसो भएँ (4)जिवनको हरेक कुरामा असन्तुष्ट भएँ
37. गएको दुई हप्तामा तपाईले आफ्नो जिन्दगीको लागि आफुलाई कत्तिको दोषि ठान्नुभयो ?	(1)कहिल्यै ठानिन (2)प्राय ठानें (3)सधैं जसो ठानें (4)जिवनको हरेक कुरामा दोषि ठानें
38. गएको दुई हप्तामा तपाईले आफ्नो जिन्दगीमा कत्तिको दुख या सास्ति भोग्नु भयो ?	(1)कहिल्यै भोगिन (2)प्राय भोगें (3)सधैं जसो भोगें (4)जिवनको हरेक कुरामा सास्ति भोगें
39. गएको दुई हप्तामा तपाईलाई, आफुदेखी आफुलाई कत्तिको वाक्क लाग्यो ?	(1)कहिले लागेन (2)धेरैजसो लाग्यो (3)सधैं लाग्यो (4)आफुलाई नैं घृणा लाग्यो
40. गएको दुई हप्तामा तपाई आफ्नो गल्तिहरु प्रति कत्तिको जिम्मेवार हुनुभयो?	(1) जिम्मेवार भईन (2) गल्ति र कमजोरीको लागि उत्तरदायी भएँ (3) कमजोरीहरुको निन्दा गरेको थिएँ (4) हरेक नराम्रा कुराप्रति जिम्मेवार भएँ
41. गएको दुई हप्तामा तपाईले आफुलाई कत्तिको हानी पुचाउन चाहनु भयो ?	(1) आफुलाई कुनै पनि हानी पुचाउन चाहीन (2) हानी पुचाउन चाहें तर केही गर्न सकीन (3) म आफुलाई नै मार्न चाहन्थे (4) मैले मौका पाएको भए आत्महत्या गर्थे
42. गएको दुई हप्तामा कत्तिको रुनु भयो ?	(1) पहिले भन्दा बढी रोइन (2) पहिले भन्दा बढी रोएँ

	(3) हप्तै भरी रोएँ (4) चाहेर पनि रुन सकिनं
43. गएको दुई हप्तामा तपाईलाई कत्तिको झर्को लाग्यो?	(1) कहिले लागेन (2) प्राय लाग्यो (3) सधैं जसो लाग्यो (4) असह्य भएको थियो
44. गएको दुई हप्तामा तपाईलाई अरुसँग कत्तिको हाँसखेल गर्न मन लाग्यो ?	(1) हाँसखेल गर्न मन लाग्यो (2) पहिले जस्तो गर्न मन (3) लागेन बोल्न पनि मन लागेन (4) कसैको कुनै वास्ता राख्न मन लागेन
45. गएको दुई हप्तामा तपाईले आफ्नो जिवनमा कत्तिको निर्णय लिन सक्नुभयो ?	(1) सकें (2) पहिले जस्तैसकीन (3) निकै गाह्ते भयो (4) कुनै पनि निर्णय लिन सकीन
46. गएको दुई हप्तामा तपाईलाई, तपाई आफु कत्तिको राम्रो भएँ जस्तो लाग्यो ?	(1) पहिले भन्दा नराम्रो भईन (2) म नराम्रो हुँदै गइरहेको जस्तो लाग्यो (3) म सधैं नराम्रो नैं भईरहे (4) म कुरुप वा घिन लाग्दो देखिएको थिएँ
47. गएको दुई हप्तामा तपाईले कत्तिको काम गर्न सक्नुभयो ?	(1) पहिले जत्तिकै सकें (2) पहिले जस्तो सकीन (3) एकदम गाह्ते भयो (4) केही पनि काम गर्न सकीन
48. गएको दुई हप्तामा तपाई कत्तिको सुत्नु भयो ?	(1) पहिले जत्तिकै सुतें (2) पहिले जस्तो सकीन (3) पहिले भन्दा अगाडी बिउँझिन्थें र निदाउन सकीन (4) एकदमै चाँढै बिउँझिन्थें र निदाइन
49. गएको दुई हप्तामा तपाई कत्तिको थाक्नु भयो ?	(1)थाकिन (2)पहिला भन्दा बढी (3)जे गर्दा पनि थाक्दथें (4)एकदमै थाकेर केहि पनि गर्न सकीन
50. गएको दुई हप्तामा तपाईलाई खाना कत्तिको रुचीभयो ?	(1)पहिले जत्तिकै रुची भयो (2)पहिले जति रुची भएन (3)एकदमै कम रुची भयो (4)पटक्कै रुची भएन
51. गएको दुई हप्तामा तपाईको तौल कत्तिको घटेको थियो ?	(1)घटेको थिएन (2)५ के जी भन्दा बढी घट्यो (3)१० के जी भन्दा बढी घट्यो (4)3.१५ के जी भन्दा बढी घट्यो
52. गएको दुई हप्तामा तपाईलाई आफ्नो स्वास्थ्यको चिन्ता कत्तिको लाग्यो ?	(1) पहिला भन्दा बढी चिन्ता लागेन (2) दुखाई र पिडाले गर्दा चिन्तित थिएँ (3) स्वास्थ्यको कारणले गर्दा अरु केहि सोच्न सकीन (4) स्वास्थ्यको कारणले केही होश नैं भएन
53. गएको दुई हप्तामा तपाईले आफ्नो जिवन साथीको	(1) पहिला जत्तिकै सोचें (2) पहिला जत्तिकै सोचीन

बारेमा कत्तिको सोच्नु भयो ?	(3) त्यति वास्ता नैं भएन (4) वास्ता नैं भएन
HIV Symptom Index (HSI)	
54. ज्वरो आउने, जाडो हुने वा पसिना आउने	(0) मलाई यस्तो समस्या छैन (1) यसले असर गर्दैन (2) यसले अलि अलि असर गर्छ (3) यसले असर गछ (4) यसले धरै असर गछ
55. रिंगटा लाग्ने वा टाउको हलुका हुने	(0) मलाई यस्तो समस्या छैन (1) यसले असर गर्दैन (2) यसले अलि अलि असर गर्छ (3) यसले असर गछ (4) यसले धरै असर गछ
56. ह्मत खुट्टा झम्झमाउने वा दुख्ने	(0) मलाई यस्तो समस्या छैन (1) यसले असर गर्दैन (2) यसले अलि अलि असर गर्छ (3) यसले असर गछ (4) यसले धरै असर गछ
57. सम्झन कठिनाइ हुने	(0) मलाई यस्तो समस्या छैन (1) यसले असर गर्दैन (2) यसले अलि अलि असर गर्छ (3) यसले असर गछ (4) यसले धरै असर गछ
58. टाउको दुख्ने वा बान्ता आउने	(0) मलाई यस्तो समस्या छैन (1) यसले असर गर्दैन (2) यसले अलि अलि असर गर्छ (3) यसले असर गछ (4) यसले धरै असर गछ
59. पखाला वा पातलो दिसा हुने	(0) मलाई यस्तो समस्या छैन (1) यसले असर गर्दैन (2) यसले अलि अलि असर गर्छ (3) यसले असर गछ (4) यसले धरै असर गछ
60. उदास हुने	(0) मलाई यस्तो समस्या छैन (1) यसले असर गर्दैन (2) यसले अलि अलि असर गर्छ (3) यसले असर गछ (4) यसले धरै असर गछ

61. आत्तिने	(0) मलाई यस्तो समस्या छैन (1) यसले असर गर्दैन (2) यसले अलि अलि असर गर्छ (3) यसले असर गछ (4) यसले धरै असर गछ
62. निदाउन कठिनाइ हुने	(0) मलाई यस्तो समस्या छैन (1) यसले असर गर्दैन (2) यसले अलि अलि असर गर्छ (3) यसले असर गछ (4) यसले धरै असर गछ
63. छालाको समस्या जस्तै रातो बिबिरा,सुख्खापन वा चिलाउने	(0) मलाई यस्तो समस्या छैन (1) यसले असर गर्दैन (2) यसले अलि अलि असर गर्छ (3) यसले असर गछ (4) यसले धरै असर गछ
64. खोकि वा स्वास फेर्न कठिनाइ	(0) मलाई यस्तो समस्या छैन (1) यसले असर गर्दैन (2) यसले अलि अलि असर गर्छ (3) यसले असर गछ (4) यसले धरै असर गछ
65. भोक नलाग्ने वा खानाको स्वादमा परिवर्तन	(0) मलाई यस्तो समस्या छैन (1) यसले असर गर्दैन (2) यसले अलि अलि असर गर्छ (3) यसले असर गछ (4) यसले धरै असर गछ
66. मांसपेशी वा जोंनी दुख्ने	(0) मलाई यस्तो समस्या छैन (1) यसले असर गर्दैन (2) यसले अलि अलि असर गर्छ (3) यसले असर गछ (4) यसले धरै असर गछ
Suicidal ideation/attempts *तपाई HIV पोजेटिभ हुनुभए पछि कहिल्यै यसरी सोच्नु भएको छ भने कृपया मलाई भन्नुहोसः*	
67. तपाईले आफ्नो जीवनको अन्त्य गर्ने भनेर कहिल्यै सोच्नुभयो?	(1) सोचें (2) सोचिन
68. तपाईले कहिल्यै आत्महत्या गर्ने कोशिस गर्नुभयो?	(1) गरें (2) गरीन
69. यदि हो भने, तपाईले आफ्नो HIV को बारेमा थाहा पाउनु भए पछि कति पटक कोशिस गर्नुभयो?	……पटक

Appendix 6: Scree plot and table of unrotated loadings for principal components analysis with oblimin rotation of two-factor solution of Nepali Family Support and Difficulty Scale



Component Matrix[a]

	Component	
	1	2
FS7: How much support when sick?	.798	.128
FS4: How much feel (emotionally) distant from family?	-.798	.228
FS1: How much does family show love and caring?	.774	.223
FS2: How much feel disliked by family?	-.769	.352
FS5: How much involved in family decision making?	.725	.339
FS3: How much feel have an important role in family?	.655	.306
FS6: How much basic needs met in family?	.645	-.089
FS9: How much can share feelings with family?	.608	.406
FS10: How much exploited by family?	-.502	.414
FS8: How much has family physically hurt you?	-.431	.581

Extraction Method: Principal Component Analysis.

a. 2 components extracted.

Appendix 7: Reliability analysis of 7-item version of the AIDS Internalized Stigma Scale

Case Processing Summary

		N	%
Cases	Valid	322	100.0
	Excluded[a]	0	.0
	Total	322	100.0

a. Listwise deletion based on all variables in the procedure.

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.745	.743	7

Item Statistics

	Mean	Std. Deviation	N
It is difficult to tell other people about my HIV infection	.69	.469	322
Being HIV positive makes me feel dirty	.44	.497	322
I feel guilty that I am HIV positive	.48	.500	322
I am ashamed that I am HIV positive	.45	.498	322
It is my own fault that I am HIV positive	.63	.483	322
I hide my HIV status from others	.67	.471	322
I sometimes feel worthless because I am HIV positive	.55	.498	322

Inter-Item Correlation Matrix

	It is difficult to tell other people about my HIV infection	Being HIV positive makes me feel dirty	I feel guilty that I am HIV positive	I am ashamed that I am HIV positive	It is my own fault that I am HIV positive	I hide my HIV status from others	I sometimes feel worthless because I am HIV positive
It is difficult to tell other people about my HIV infection	1.000	.329	.337	.404	-.063	.613	.277
Being HIV positive makes me feel dirty	.329	1.000	.590	.572	-.072	.343	.434
I feel guilty that I am HIV positive	.337	.590	1.000	.577	-.014	.366	.411
I am ashamed that I am HIV positive	.404	.572	.577	1.000	-.049	.391	.457
It is my own fault that I am HIV positive	-.063	-.072	-.014	-.049	1.000	-.030	-.016
I hide my HIV status from others	.613	.343	.366	.391	-.030	1.000	.287
I sometimes feel worthless because I am HIV positive	.277	.434	.411	.457	-.016	.287	1.000

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
It is difficult to tell other people about my HIV infection	3.22	3.524	.495	.412	.707
Being HIV positive makes me feel dirty	3.47	3.297	.593	.452	.683
I feel guilty that I am HIV positive	3.43	3.256	.614	.452	.677
I am ashamed that I am HIV positive	3.47	3.222	.641	.472	.671
It is my own fault that I am HIV positive	3.28	4.496	-.056	.010	.817
I hide my HIV status from others	3.24	3.486	.516	.415	.702
I sometimes feel worthless because I am HIV positive	3.36	3.465	.487	.271	.708

Scale Statistics

Mean	Variance	Std. Deviation	N of Items
3.91	4.615	2.148	7