

The Relationship among Perceived Satisfaction from Social Support, Hope and Quality of Life (QOL) of People Living with HIV/AIDS (PLWHA): A Case Study from Nepal

Sushil Yadav YAMAMOTO*

Abstract

This cross-sectional study investigates the relationship among perceived satisfaction from social support, hope and quality of life of people living with HIV/AIDS (PLWHA). A sample of 160 HIV infected persons receiving treatment, care, and support from eight non-governmental organizations (NGOs) were interviewed. Quality of life (QOL) was assessed using the World Health Organization's (WHO) quality of life tool (WHOQOL – 26) and perceived satisfaction from social support was assessed by using a modified Sarason's Social Support Questionnaire. A hope assessment scale was also developed. The PLWHA had less stigma and they disclosed their HIV status to receive support. Perceived satisfaction from social support, hope and QOL correlated with gender, but did not correlate with other demographic factors. Non-family support network was greater than family support network. Overall perceived satisfaction from social support and hope was significantly correlated with QOL. The greatest effect of perceived satisfaction from social support was on environmental functioning and the lowest was on social relationships. Emotional support was a lesser predictor of social relationship than other types of supports. Perceived satisfaction from informational and tangible support was the best predictor of hope and QOL. Furthermore, there was a significant positive relationship among perceived satisfaction from social support, hope and quality of life. The results of the study have implications for providing social support including care and treatment to foster hope and enhance the quality of life of PLWHA.

Keywords: perceived satisfaction from social support, hope, quality of life (QOL), people living with HIV/AIDS (PLWHA)

1. INTRODUCTION

The aim of this study is to assess the impact of social support on perceived satisfaction from social support, hope and quality of life (QOL) of people living with HIV/AIDS (PLWHA). The present article is based on the following definitions of perceived satisfaction from social support, hope and quality of life. Caplan (1974) & Cobb (1976) have defined perceived satisfaction from social support as

* Doctoral student, Graduate School of International Development, Nagoya University Japan.

a perception that leads people to believe that they are part of a network of communication and mutual obligation to be: 1) cared for and loved to mobilize their psychological resources in order to deal with emotional problems; 2) in a position to access to information about the environment; and 3) provided with instrumental aid (money, material, skills, and advice in order to help them to deal with particularly stressful situations that they are exposed to). Dufault and Martocchio's (1985) have defined hope as a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good, realistically possible and personally significant. The process of hopping consists of two spheres. One sphere is generalized hope, which has positive value and is beyond a time limit, and the other is particularized hope and has a specific time value and goal oriented. Ferran (1990) has defined quality of life as "the sense of well-being that stems from satisfaction or dissatisfaction with aspects of life that are important to an individual... [which] encompasses the interaction of the dimensions of health and functioning of life, socioeconomic and psychological."

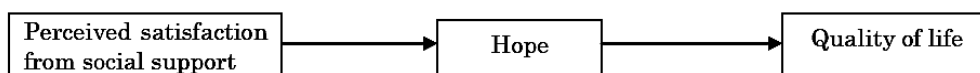
This article does not measure the level of social support itself. Rather, the measurement is the perceived satisfaction from social support. It examined one-to-one relationship among perceived satisfaction from social support, hope and quality of life using correlation method with respect to actual support by NGOs. The current paper is different from a previous study (Yadav, 2010), using multiple regression method in which I examined the combined additive effect of perceived satisfaction from social support and hope on quality of life.

The development of anti-HIV medicine has led to significant increase in life expectancy and quality of life for PLWHA. The average number of years PLWHA live after treatment with combination antiretroviral therapy is estimated to be 20 to 35 years (Antiretroviral Therapy Cohort, 2008). This tends to transform HIV to a chronic disease (Kucera, 1998). Chronic traits of a disease increase demand for care, support and treatment for PLWHA. In order to fulfill the demand for care and treatment, family, friends and communities can be major sources of support (Greenberger, *et al.*, 2000). A number of research studies have indicated that there is a significant relation between perceived satisfaction from social support and quality of life (Ashton, *et al.*, 2005; Bastardo & Kimberlin, 2000; Chesney, *et al.*, 2003; Friedland, Renwick, & McColl, 1996; Ichikawa & Natpratan, 2006; Jia, *et al.*, 2004; Koopman, *et al.*, 2000; Ncama, *et al.*, 2008; Swindells, *et al.*, 1999).

Hope is an under-researched concept in the social science of HIV care and treatment (Bernays, Rhodes, & Barnett, 2007). The concept has been explored minimally within the context of HIV and AIDS (Kylma, Vehvilainen-Julkunen, & Lahdevirta, 2003). Many researchers have examined hope among patients who are terminally ill, especially in cancer patients (Cutcliffe, *et al.*, 2002; Felder, 2004; Herth, 1989; Hong *et al.*, 2007; Miller, 1989). In the field of HIV/AIDS, most of the studies on hope have focused on the meaning of hope, dynamics of hope in the process of caring PLWHA (Kylma, 2005), maintaining hope while coping with end-stage AIDS, fostering hope, and its impact on

improving quality of life of the individual living with AIDS (Akinsola, 2001). However, thorough research on factors that are associated with the relationship between perceived satisfaction from social support and quality of life on PLWHA is unavailable. Therefore, the assumption made in this study is that there is significant relationship among perceived satisfaction from social support, hope and quality of life (Figure 1).

Figure 1 : Relationship model among perceived satisfaction from social support, hope and quality of life.



Furthermore, while many of the previous studies have been limited to specific risk factor groups or specific age groups, such as the elderly, gay, injecting drug users and people with AIDS, but this study focuses on PLWHA with different risk factors for HIV infection. In terms of risk factor for HIV Infection, It is plausible to argue that this study is reflective of the general HIV population in Nepal. It is also expected that the findings of this study will contribute to knowledge of health and community workers in understanding the continuum of care for better quality of life of PLWHA.

The rest of the paper is organized as follows. Section 2 explains methodology and measurement for the current research. Section 3 presents the concepts of social support, hope and quality of life in cancer to develop the framework for this research. This is followed by discussion on previous research studies in HIV, which is expected to further justify the framework for this research. Section 4 presents the findings of secondary data to look into the activities of NGOs. Section 5 focuses on the results of the field research. Section 6 discusses the findings followed by conclusion in section seven.

2. METHODOLOGY

2.1 Study design and participants

The study is descriptive and cross-sectional in design, focusing on adults living with HIV/AIDS in Nepal. The selection of participants was based on PLWHA receiving care, support and treatment, PLWHA with at least 18 years old, and PLWHA who were physically able to answer the questionnaire. The data collection was done by the author with the help of hired professionals from the National Health Research Council with field survey experience and trained as interviewers for this study.

The participants were contacted on monthly support meeting, and a voluntary convenience sampling was used and consent was obtained prior to the interviews. The purpose of the study was explained to the participants and they were informed that their names and addresses would not be included in the questionnaire as well as in research paper. During the one-to-one interview,

structured questionnaires of social support, hope, quality of life and socio-demographic status were administered. Five participants were reluctant to answer about their sexual activity item in the quality of life tool.

A total of 160 participants out of 169 with a history of drug use, housewives, and males who have sex with sex-workers completed the one-to-one interview. Five participants were unable to complete the questionnaire because of poor health and four participants refused to disclose their HIV status in front of the interviewer.

Support activities of NGOs were based on secondary data. The data collected was for the purpose of understanding the impact of actual support provided by the NGOs on perceived satisfaction from social support, hope and quality of life at micro level. The selection of NGOs to obtain secondary data and for empirical study was based on criteria that included NGOs providing care, support and treatment to PLWHA; registered under HIV/AIDS support organization; NGOs accountable to the Ministry of Women, Child and Social Welfare to cross check NGOs activities information for validity of data; and NGOs receiving funding from the governmental or international NGOs.

The data for the NGOs was from 2005 to 2008. This time specification was due to the Global Fund to Fight against Aids Tuberculosis and Malaria (GFATM) provided grant to Government of Nepal in 2004 to establish HIV care continuum from health care services to community based care, treatment and support with the cooperation with NGOs and other community based organizations. At the beginning of 2005 the Government of Nepal introduced the national action plan. The main objective of the action plan was to coordinate governmental institution, civil society, community based organization, and NGOs in providing care, treatment and support to PLWHA.

NGOs registered in Nepal under the HIV support organization and receiving funding from the Governmental or international NGOs are required to report their yearly expenditure and activities to the Ministry of Women, Child and Social Welfare. The validation of data was done by cross-checking NGOs information with the Ministry of Women, Child and Social Welfare.

There are currently close to 100 NGOs working in the area of HIV/AIDS in Nepal, but only eight NGOs provide the care, treatment and other support for PLWHA in Nepal. All of the eight NGOs were selected based on the above criteria for this study. The following NGOs provided data: Sparsha Nepal, Nava Kiran Plus, Sahara Plus, Srijanshil Samaj, Jesis Society, Sneha Griha, Mahila Samuha and Prerna. Three NGOs were located in Kathmandu, two NGOs in hilly area (east of Kathmandu valley) and two NGOs in central part of Nepal (Chitwan) and one NGO in the western part Nepal near the Indian border (Nepalgunj).

2.2 Measurements

The purpose of administering the questionnaires was to get information regarding socio-demographic status, respondents' types and sources of support, and the influence of sources and types

of support on being hopeful for future and on quality of life.

The first socio-demographic questionnaire was developed based on Nepalese context. The second hope scale, social support and quality of life tool were translated into Nepali language by independent translator at Trivubhan University in Nepal.

2.2.1 Socio-demographic status and hope scale

The socio-demographic questionnaire was administered to gather information regarding age, gender, type of religion, educational level, employment status, mode of transmission, duration of living with HIV, stigma and health related outcome as self reported CD4 + count (blood level).

The hope scale was developed particularly for this study. The construct of the scale was based on the meaning of hope explained by 25 PLWHA in this study during in-depth interview. The “hope scale” consists of seven items and they measure perceived hope. The first item measures hope from engaging in meaningful life. The second item relates to hope from personnel willpower. The third item focuses on the level of hopelessness due to discrimination by others. The fourth item is about perceived hope from family love and care. The fifth item measures perceived hope because of help from friends, counselors or health and community workers. The sixth item examines perceived hope from others` help with material and caring spouses. The seventh item assesses perceived hope from belief in religion or God. The scale showed good internal reliability yielding Cronbach’s alpha .88. The scale is on five-point value ranging from “not at all” to “extremely hopeful”. A higher score indicates better hope.

2.2.2 Social support questionnaire

The social support scale was adapted from the shorter Sarason’s Social Support questionnaire (SSQ-S) developed by Sarason *et al.* (1983). The SSQ-S is a 12 – items instrument that measures two aspects of perceived satisfaction form social support. The six odd numbered items count social support network and the number of people in the individual’s social support system. The total number of people in the individual’s social support system is further divided into family network and non-family network support (doctors, nurses, volunteer and other NGOs’ staff). The six even numbered items measure perceived satisfaction from social support network. Swindells *et al.* (1999) suggested that social support should not be conceptualized simply in terms of availability, but in its perceived adequacy, and social support may not be considered useful unless the individual perceives it as supportive. It has been proposed that the qualitative components (perceived satisfaction) of social support may be more important than the quantitative aspects of social support. Perception is generally a better predictor of health outcome than the receipt of social service (Wethington & Kessler, 1986). The overall satisfaction from specific support is based on a six-point scale ranging from very satisfied to very dissatisfied.

The modified HIV specific social support questionnaire for this study consisted of 14 items scale. The modified and added items were: 1) to whom they depend on when they need information for Anti-

HIV or other medications and HIV specific counseling; 2) to whom they depend on when they need information regarding spousal help, vocational training, and other legal activities; 3) to whom they depend on when they need for help for their spouses, living arrangement, food, transportation and others; 4) to whom they depend on when they need help to get anti-HIV medication, other infections medicine, vitamins or minerals to increase immunity of body and other medications; 5) to whom they depend on when they are under pressure; 6) to whom they depend on when they think there is no way of life; and 7) who accepts their worst and bad point regardless of what is happening to them.

Furthermore, a factor analysis of the seven items in social support questionnaire showed three different factors, and each corresponds to different types of support. The first is tangible support (providing an individual with money, material, skills, medication for opportunistic infection or anti-HIV medicine and counseling). The second is about informational support (information regarding available sources of support from their surrounding environment to received medication or other help). And the third is emotional support (linking, loving, and understanding the patients). Each of the domains in the Nepali version of scale showed good internal reliability, yielding Cronbach's alpha of .89 for emotional, .86 for informational, .82 for tangible and .87 for overall support.

2.2.3 Quality of life tool

The WHOQOL-26 tool consists of 26 items and it is derived from the WHOQOL-100 items tool.¹ It consists of 26 items grouped into five domains related to quality of life. Physical functioning is defined as no physical pain hampers to perform daily activity, availability of medical treatment to function in life, energy to perform daily activities, physically to get around and to sleep, and satisfaction from daily living activities and work. Psychological functioning refers to enjoyment in life, perceived life to be meaningful, able to concentrate, able to accept bodily appearance, self-satisfactions and able to control negative feelings such as blue mood, despair, anxiety and depression. Social relationship is understood as having regard in gratifying relationship with others, interpersonal relationship and social role in life. Environmental functioning is defined as being able to feel safe in daily life, healthier physical environment, information available that is needed in their daily life, opportunities for leisure activities, satisfaction with living conditions, satisfaction with access to health service, and satisfaction with transport and other facility to receive service for their need (WHO, 1995). Global functioning defined as self rated overall quality of life and perceived satisfaction from current health status for health-related quality of life, combining together as global functioning (Kuyken, *et al.*, 1995). It includes seven items in the physical domain, six items in the psychological domain, three items in the social domain, eight items in the environmental domain and two items in global domain.

The findings of previous studies suggested relationship among four domains of quality of life and between domain and global functioning of life. Liang *et al.* (2000) found out that there were moderate to high correlations between physical functioning and psychological functioning, environmental

functioning, and social relationship domains of quality of life. Furthermore, physical, psychological, environmental functioning, and social relationship were positively correlated with the global functioning of life (Sakthong, *et al.*, 2007). Arnold *et al.* (2004) found the strongest correlation between social relationship and physical functioning ($r=0.41$, $p<0.01$), and psychological functioning ($r=0.32$, $p<0.01$), smaller correlation between global functioning and social relationship ($r=0.30$, $p<0.01$), physical functioning ($r=0.26$, $p<0.01$), and psychological functioning ($r=0.22$, $p<0.01$). The review of the findings from previous studies as above suggests that there is relationship among the four domains of quality of life and global functioning of life.

Patients were asked to rate their quality of life in the past two weeks. The item scores ranged from 1 to 5, with a higher score indicating a better quality of life. Since the numbers of items were different for each domain in WHOQOL-26, the domain scores were calculated by multiplying the average of the scores of all items in the domain by 4 to standardize all domain scores and make it comparable with other domains (Srisurapanont, *et al.*, 2001).

The WHOQOL-26 tool is translated in more than 10 different languages. The Hindi version consists of 26 items that show satisfactory psychometric properties and good internal reliability (Saxena, Chandiramani, & Bhargava, 1998). The reason behind adapting the Hindi version was that WHOQOL-Hindi was verified as a valid instrument for comprehensively assessing the quality of life in health care settings in India (Saxena, *et al.*, 1998). This was also due to the geographical proximity and historical relationship between India and Nepal. People from India and Nepal have a lot in common including culture, language, religion, and value systems. The Nepali version of WHOQOL-26 tool showed good internal reliability with Cronbach's alpha of .85.

3. SOCIAL SUPPORT, HOPE AND QUALITY OF LIFE IN CANCER AND HIV: REVIEW OF LITERATURE

3.1 Perceived satisfaction from social support

The roots of the concept social support are found in nineteenth century sociologists Durkheim (1984), who established the link between diminishing social ties and an increase in suicide (Rawls, 1997; Vaux & Harrison, 1985). As a concept, it has evolved over time starting with the term "social ties" as used by Durkheim (Vaux & Harrison, 1985).

Social support constitutes interactions and contacts to meet social needs, which can be either formal or informal with individuals or groups (Thoites, 1982; Wallston, *et al.*, 1983; Kaplin, *et al.*, 1983). Social support at the level of interpersonal transaction involves emotional concern, instrumental aid, information, and appraisal (House, 1981). Information from social support, for example, leads individuals to believe that they are cared for and loved, esteemed and valued, and they belong to a network of communication and mutual obligation (Cobb, 1976). The source of social support can come

in the form of emotional support from family, friends and peers, with social interaction in community, and interaction with environment (Brashers, 2002; Gottlieb, 1983; Greenberger, *et al.*, 2000).

3.2 Research on social support and hope in cancer

Hope has been defined in a number of different ways. Miller (2007) summarizes hope as “a state of being characterized by an anticipation of a continued good state, and improved state or a release from a perceived entrapment.” Cutcliffe & Herth (2002) define hope as “inspiration that involves the presence of another human being who demonstrates unconditional acceptance, tolerance, and understanding.” Hope has been found to help a person adapt to and provide meaning in illness, maintain a high level of well-being, and give direction and a reason for being (Saleh & Brockopp, 2001). Hope is also important in coping with various phases of illness (Cutcliffe & Herth, 2002; Herth, 2000). The high levels of hope were positively related to coping specially stress-reduction (Felder, 2004). There are several studies on people living with cancer, which suggested that the types of social support (instrumental, emotional and informational) enhance or inhibit hope, and these needs can be met by family, friends, nurses, doctors and other staff (Suominen, Leinokilpi, & Laippala, 1995).

Social support enhances the level of hope while at the same time absence of family members leads to decrease in hope (Hong & Ow, 2007). Social support can relieve distress and indirectly buffer the effects of stressful life events. Carlsson & Hamrin (1994) suggest that social support is critical for psychosocial functioning of cancer patient.

Sultan *et al.* (2004) stated that the availability of emotional and instrumental support had an impact on quality of life of cancer patients. Modification of perceived social support through clinical interventions could improve the survivorship (Karnell, *et al.*, 2007). The review of research on cancer patients shows that fostering hope by social support can enhance the quality of life of people living with cancer.

3.3 Research on social support and hope in HIV/AIDS

Herth (1990) examined hope fostering strategies on PLWHA which were defined as those sources that assist to install, support or restore hope in some way. Further strategies were categorized into seven domains: 1) interpersonal connectedness that mainly focus on love from family and friends; 2) spiritual base focusing on spiritual practice as a source of hope; 3) attainable aim direct to setting goals and maintaining independence; 4) affirmation of worth that focuses on positive relationship with professional careers; 5) light heartedness that centers on friendship with others who are suffering from same cause; 6) personal attribute which shows determination and being a fighter; and 7) uplifting memories that include recalling uplifting moments/times act as a hope fostering strategy.

Hindrances to hope were defined as those factors that interfere or inhibit the possibility of

attaining or maintaining hope, which constitute: 1) abandonment and isolation, physical and emotional loss of significant others; 2) uncontrollable pain and discomfort; and 3) devaluation of personhood, being treated as a non-person having little value (Herth, 1990).

Another study on HIV suggested that hope is an important component of effectively dealing with HIV and AIDS. Potential sources for fostering hope are: 1) receiving support; 2) engaging in meaningful life experiences; 3) perceiving options; 4) receiving treatment; and 5) maintaining quality of life (Harris & Larsen, 2008).

One of the studies on PLWHA identified four major ways that hope was maintained: by miracles, religion, involvement in work, and support of family and friends (Hall, 1994). Specific ways of being in relationships with others include dealing with one's family, friendship group, helping others with HIV and developing a relationship with a higher power. In this case social support is the functional component of relationships, such as emotional and tangible assistance (Barroso, 1997). Tangible support seems to be more relevant to PLWHA (Gant, 1995). A study on HIV infected terminally ill persons indicates that there were significant differences in the level of hope according to diagnosis (Herth, 1990). A study by Phillips & Sowell (2000) on women infected with HIV found a significant positive relationship between hope and coping, hope and managing the illness, and between hope and spiritual activities. In addition, a negative relationship was observed between hope and inability to cope, while stigma was associated with less hope.

Promoting hope and acceptance of HIV-status enables to develop a positive therapeutic relationship with medication, which, in turn, promotes adherence to treatment. Treatment adherence is related to active participation in social networks (Nama, *et al.*, 2008). Facilitating hope appears to be an important therapeutic goal in newly diagnosed HIV-positive individuals and hope is connected to longer life (Harris & Larsen, 2008). Hope can help PLWHA deal with the HIV diagnosis, and it acts as an internal resource for helping to experience increased well-being (Heinrich, 2003).

There are two sources of social support that have been discussed in previous studies. The first is family and friends to receive emotional support, and the second from outside family and friends such as health care industry based support to receive medical support (Shippy, 2007). The support from friends and family is valuable to counter stigma (Andrews, *et al.*, 1995). The health care industry includes effective nursing practice (Cutcliffe, 1995). The role of peer counselors and health workers is important to provide referral information for livelihood in the process of fostering hope (Akinsola, 2001; Harris & Larsen, 2007).

3.4 Social support and quality of life in HIV

Quality of life is defined as a "fighting spirit" associated with longer life expectancies for individuals with HIV/AIDS (Leserman, Perkins, & Evans, 1992). Quality of life relates both to adequacy of material circumstances and to personal feelings about these circumstances and it includes

“overall subjective feelings of well-being that are closely related to morale, happiness and satisfaction” (Leserman, *et al.*, 1992; Rabkin, *et al.*, 1993).

Social support of PLWHA is significantly correlated with health related quality of life (Nunes, *et al.*, 1995). Research on PLWHA indicated that a supportive social environment, particularly friends and family acceptance, was significantly associated with quality of life (Friedland, *et al.*, 1996; Ichikawa & Natpratan, 2006). Alienation, rejection and isolation can threaten hope and well-being of PLWHA (Miller, 1989). Taking care of physical functioning, psychological functioning, and social relationship is important for maintaining quality of life (Srisurapanont, Sambatmai, & Jarusuraisin, 2001).

Social support was significantly associated with health related quality of life, with the exception of the physical functioning and bodily pain aspects (Bastardo & Kimberlin, 2000). Low level of social support leads to a worsening of physical function (Remor, 2002). Another study suggested that psychological and physical functioning were associated with a higher level of social support (Yang, *et al.*, 2003). Furthermore, type of social support influences the level of quality of life, as the high level of emotional support decreases physical distress, mental distress, activity limitation, depressive symptoms, anxiety symptoms, insufficient sleep, and pain (Strine, *et al.*, 2008). Social support from peers is critical for psychological functioning of PLWHA. However, in periods of crisis family support becomes a better determinant of psychological functioning (Crystal & Kersting, 1998).

In summary, the above discussion on perceived satisfaction from social support, hope and quality of life in cancer showed that fostering hope by social support could improve or maintain quality of life of people living with cancer. More specifically, the types and sources of support have influence on being hopeful for future, which leads to better quality of life.

Regarding the research on HIV, hope is an inner resource to experience well-being for long-term survival. Most of the research findings suggested the existence of relationship between social support and quality of life. Others pointed out relationships among hopelessness, depression, despair, coping, managing illness and quality of life. None of the studies explored the relationship among positive aspects of life, which are being “hopeful for future”, perceived satisfaction from social support, and quality of life. In addition, most of the tools used in previous research studies on HIV were specific to cancer. This research intends to fill the gaps in the conceptual approach of hope as having positive attributes from social support and tools to measure hope and perceived satisfaction from social support specific to HIV.

4. HIV/AIDS IN NEPAL: AN OVERVIEW

4.1 Status and Trend

The first case of HIV/AIDS in Nepal was reported in 1988. As can be seen from Table 1, by February 2009 over 13,263 cases of HIV infection were officially reported by the National Center for

AIDS and Sexually Transmitted Diseases Control (NCASC) with two times as many men reported to be infected as women. Table 1 indicates the higher prevalence of HIV among those men who had sex with sex workers followed by injecting drug users (IDUs). Housewives were the highest prevalence group followed by female sex workers (FSWs). Other ways of infection included mother to child transmission, men having sex with men (MSM) and blood and organ recipients. However, given the limitations of Nepal's public health surveillance system, the UNAIDS (2008) estimated that 75,000 people were living with HIV at the end of 2008.

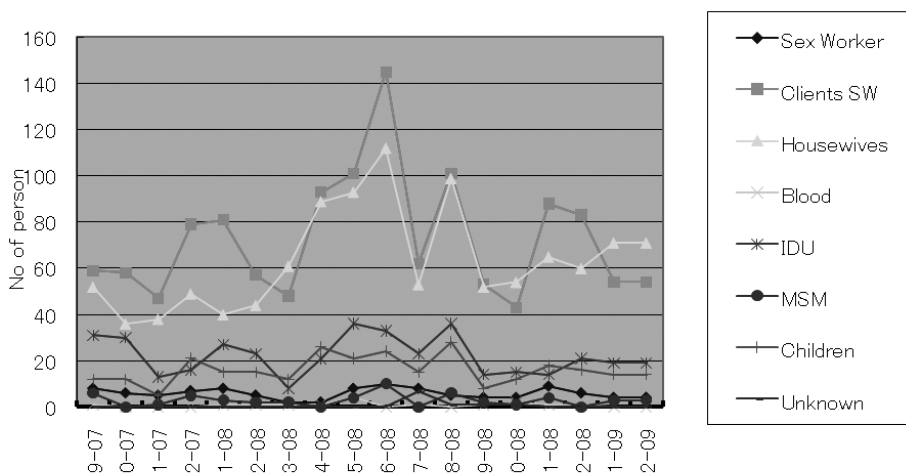
Table 1. Cumulative HIV and AIDS situation of Nepal (2009, Feb)

Sub-groups	Male	Female	Total
Sex Workers (SW)	3	792	795
Clients of SWs/STD	5,832	104	5,936
Housewives		3,160	3,160
Blood or Organ recipients	27	11	38
Injecting Drug Use	2,350	46	2,396
Men having Sex with Men (MSM)	74		74
Children	473	314	787
Sub-group NOT identified	53	24	77
Total	8,812	4451	13,263

Source: Ministry of Health and Population, National Centre for AIDS and STD Control

As Figure 2 shows, HIV spreads from this bridge population to the general population including wives, partners of sex worker's clients and new born child of infected women. IDUs and MSM are also considered a high-risk group as they may be married and engaged in unprotected sex, which may consequently infect their wives as well. Though small in number, blood or organ recipients also

Figure 2 : Trend of HIV in Nepal (2007/Sep-2009/Feb)



Source :Ministry of Health and Population, National Centre for AIDS and STD Control,Nepal

expose themselves to the risk of HIV infection.

The interaction of these high-risk groups with a much larger and low-risk general population through unprotected sex has the potential to cause an explosive epidemic that may, in future, affect the economically productive-age population in the age group 15–49 (see Table 2).

Table 2. Cumulative HIV infection by age group and gender (2009, Feb)

Age group (Years)	Male	Female	Total
0 - 4	190	112	302
5 - 9	216	155	371
10 - 14	78	51	129
15 - 19	246	252	498
20 - 24	1,165	785	1,950
25 - 29	2,014	1,050	3,064
30 - 39	3,604	1,517	5,121
40 - 49	1,049	419	1,468
50 - above	250	110	360
Total	8,812	4,451	13,263

Source: Ministry of Health and Population, National Centre for AIDS and STD Control

4.2 Activities of non-governmental organizations (NGOs)²

In Nepal a number of NGOs have been working since the 1970s to provide care, support and rehabilitation for persons who have faced social exclusion because of leprosy, tuberculosis, drug abuse and trafficking. After the first case of HIV in 1998 and further spread of HIV infection in different layers of society, most of the NGOs transformed themselves into HIV/AIDS NGOs. These NGOs are funded by international non- governmental organizations (INGOs).

NGOs provide support to HIV/Aids patients to achieve the following objectives:

- 1) Ensure that every person living with HIV and AIDS in Nepal to provide care, support and treatment;
- 2) Universal access to Anti-HIV medication;
- 3) Access to easy and affordable treatment and care programs;
- 4) Able to support themselves and those who depend upon them; and
- 5) Able to live in an open society without a fear of stigma and discrimination.

The NGOs involved in care, treatment and support for PLWHA provide counseling or rehabilitation to injecting drug users and others based on acknowledged risk factor. The duration of counseling or rehabilitation is two to nine months which is provided as course. The NGOs also provided palliative care for those who are terminally ill, prevention of onward transmission (mother to child transmission), protection from stigma and discrimination, information to receive anti-HIV medicines as referral system, hospice and food for newly diagnosed HIV infected person to complete the counseling or rehabilitation course to and spousal help for those PLWHA unable to support their

HIV infected family members.

NGOs activities data presented in Table 3 mainly explain the general support for PLWHA and their spouses included, the number of people who contacted NGOs (new case of HIV), death, number of people who received medical support, anti-HIV medicine, and referral for anti-HIV medicine on that particular year. Besides, it includes counseling, housing, food, transportation, spousal support and social function (such as rituals, wedding, religious function).

Table 3. New case of HIV, death from AIDS and General support for HIV infected person and their sponse by NGOs

Year	New case of HIV	Death	General medication	Receiving anti-HIV medicine	Referred for anti-HIV medicine	Counseling & rehabilitation	Housing	Food	Transport	Spouse help	Social function
2005	928	245	368	189	398	525	135	135	47	30	3
2006	1,233	204	520	217	692	764	269	269	78	49	13
2007	1,727	119	635	260	727	984	295	295	86	79	15
2008	2,250	32	691	432	922	1,036	368	368	126	89	19

Source: NGOs; Sparsha Nepal, Nava Kirm Phus, Sabara Phus, Srijanashil Samaj, Jesis Society, Sneha Griha, Mahila Samuha, Phrusa and Ministry of Women, Child And Social Welfare. (Note* Numbers indicates number of persons. *single entry in each year)

Table 3 indicates that PLWHA are disclosing their HIV status and they are receiving support. The data shows a positive trend to disclose and a decline in death rate. Medical support for anti-HIV medicine showed that 52.5% in 2005, 68.7% in 2006, 64.3% in 2007 and 53.2% in 2008 (number of people referred for anti- HIV medication year minus number of people received anti-HIV medication in each year) of PLWHA did not receive anti-HIV medications in each year (Table 3).

In Nepal the counseling to PLWHA is provided on first diagnosis of HIV during the voluntary counseling and testing (VCT) by NGOs involved in prevention of HIV. The main objective of counseling by care, treatment and support NGOs is to rehabilitate injecting drug users from drug abuse. The majority of the HIV infected people who contacted NGOs received counseling. Table 3 shows that 56.5% in 2005, 61.9% in 2006, 56.9% in 2007 and 46% in 2008 of PLWHA received the counseling. Therefore, it is no wonder to see that all HIV infected people contacted NGOs did not received the counseling because they might have received counseling during VCT site. Housing, general medication for opportunistic infection, food, transportation, spousal help, vocational training, family-counseling, home-based care and functional activities go hand in hand with the increase in funding in every year (Table 4).

Table 5 shows that one out of three (number of new cases of infection divided by number of people received home based care) PLWHA received home-based care in 2005, and by 2008 it improved to one out of two. Pertaining to the family counseling, only one out of 11 (number of new cases of infection divided by number of family received counseling) family of PLWHA consistently received counseling for the four years, and one out of four (number of new cases of infection divided by number of people received vocational training) PLWHA received vocational training.

Table 6 shows yearly data on the number from previous year plus new counselors and other

Table 4. Expenses for support by NGOs

Year	Medical	Referral & rehabilitation	Counseling	Vocational training	Spouse support	Food and others	Total
2005	1,997.77	648.6	337.8	1,262.37	110	4,023.49	8,380.03
2006	2078.26	1,539.5	403	2,119.3	140	4,213.92	10,493.99
2007	3,190.67	999.54	693.6	3,814.8	120.5	5,708.59	14,527.7
2008	4,872.85	1,746.2	1,275.56	4249	161	9,077.898	21,382.51

Source: NGOs; Sparsha Nepal, Nava Kiran Plus, Sahara Plus, Srijanshil Samaj, Jesis Society, Sneha Griha, Mahila Samuha, Prema and Ministry of Women, Child And Social Welfare. (Note* Number indicates Nepalese rupee in thousands. *single entry in each year)

Table 5. Home based support, family counseled and vocational training

Year	Home based care	Family counseling	Vocational training
2005	352	72	117
2006	453	90	181
2007	1,553	136	320
2008	1,555	281	630

Source: NGOs; Sparsha Nepal, Nava Kiran Plus, Sahara Plus, Srijanshil Samaj, Jesis Society, Sneha Griha, Mahila Samuha, Prema and Ministry of Women, Child And Social Welfare (Note* Number under home based care indicates as number of persons. Number under family counseling indicates as number of families. Number under vocational training indicates number of persons. *single entry in each year)

Table 6. Human resource in NGOs

Year	Infected counselor	Non-infected counselor	Medical staff	Home-based staff
2005	26	17	6	6
2006	36	12	11	20
2007	50	13	14	29
2008	70	7	28	67

Source: NGOs; Sparsha Nepal, Nava Kiran Plus, Sahara Plus, Srijanshil Samaj, Jesis Society, Sneha Griha, Mahila Samuha, Prema and Ministry of Women, Child And Social Welfare (Numbers indicates numbers of persons. *single entry in each year)

medical and home-based care staff. The non-infected counselors were replaced by PLWHA as counselors. The number of home-based care staff increased as the need of home-based care increases every year.

5. RESULTS

Statistical analysis was performed using statistical analysis software SPSS version 17.0. The respondents' demographics status was presented as mean and percentage. Scores of quality of life, social support and hope scale were presented as mean, standard deviation and range.

The socio-economic and clinical characteristics of the study sample are summarized in Table 7. Out of 160 HIV infected patients included in the study, 68.7% were male and 31.3% were female. In terms of age, 20% of them were between 18 and 25 years old, 44.4% were between 25 and 32, 26.8% were between 33 and 40, and 8.8% were over 40 years old. In addition, 54% were married, 26% were single, 14.4% were widow, and 5% were divorced. It was also found out that 83.8% of the respondents were Hindu, 9.4% were Muslim, 5% Christian and 1.3% were Buddhist. In terms of education, 19.4%

Table 7. Characteristics of study participants

Characteristics	Number of person	%
Age:		
18-25	32	20.0
25-32	71	44.4
33-40	43	26.8
over 40	14	8.8
Gender:		
male	110	68.7
female	50	31.3
Marital status:		
Unmarried	42	26.3
Married	87	54.3
Widow	23	14.4
Divorced	8	5.0
Religion:		
Hindu	134	83.8
Buddhist	3	1.8
Muslim	15	9.4
Christian	8	5.0
Education:		
Uneducated	30	18.7
Primary school	54	33.7
High school	45	28.2
Graduate	31	19.4
Employment:		
Employed	35	21.9
Unemployed	96	60.0
Social Work	29	18.1
Duration of living with HIV:		
This year	40	25.1
2-4 Years ago	52	32.5
5-8 Years ago	11	6.9
More than 8 years ago	57	35.5
Acknowledge risk factors:		
Injecting Drug User (IDU)	70	43.8
Sex with other	35	21.8
From husband/wife	55	34.4
Medical outcome (CD4 count)		
< 200	43	26.9
>200	117	73.1

had higher education, 28.2% of respondents had high school education, 33.7% received primary education, and 18.7% were uneducated. The data on occupation showed that 21.9% were employed, 60% were unemployed and 18.1% were involved in social work in NGOs. Time since diagnosis showed 35% were infected more than 8 years ago, 6.9% were between 5 and 8 years, 32.5% were infected in the last 2 to 4 years.

Pertaining to the duration with HIV, 25.1% were diagnosed with HIV during 2008 – 2009, with an acknowledge risk factor (perceived mode of infection informed by the participants of this study) showing 43.8% injecting drug users, 21.8% had infection because of sex with others besides their

partners, 34.4% were infected by their husbands, 26.9% had less than 200 cells/ μ L CD4 count blood level and 73.1% had more than 200 cells/ μ L.³

The socio-economic characteristics of the participants of the this study showed that HIV infection has been spreading in different layers of society including male, female, uneducated to educated, persons with different religions, professional and non-professional, married (specially housewives), unmarried and different age groups in which most of them fall under the productive-age group (18–40 years old).

The mean, standard deviation and range of score for the social support, hope and quality of life scale is presented in Table 8. The mean score of 5.15 for overall satisfaction from social support shows that average participants were satisfied from their support network. The average participants were moderately hopeful and the mean score was 3.87. The mean score for physical functioning was 14.01 and for psychological functioning it was 14.36. In addition, the mean scores for social relationship, environmental functioning, and global functioning of life were 12.48, 13.66, and 6.73, respectively.

Table 8. Quality of life, hope, social support and other profile (N=160)

Scale	Mean	SD	Range
Satisfaction with social support	5.15	0.5	2-6
Overall network	4.20	1.5	1-9
Overall male network	4.2		
Overall female network	2.9		
Family network	2.53	1.2	1-6
Non-family network	4.82	0.93	4-8
Hope	3.87	0.5	2.33-5.33
QOL Domain			
Physical functioning	14.01	2.12	7-20
Psychological functioning	14.36	1.87	7-20
Social relationship	12.48	1.95	4-16
Environmental functioning	13.66	1.82	9-19
Global functioning	6.73	1.82	3-9
Stigma	Yes		9.8%
	No		90.2%

Note: SD= Standard Deviation

The mean score of domains of quality of life showed that the respondents rated their psychological functioning higher than the other functioning of life, whereas social relationship was lower among other domains. In terms of global functioning participants perceived that their overall quality of life and perceived health status was good. In terms of stigma, 90.2% of participants reported that they did not have stigma.

A significant positive correlation was found between perceived overall satisfaction from the social

support and all domain of quality of life, physical capacity ($r = .296$, $p = .000$), psychological functioning ($r = .243$, $p = .001$), social relationship ($r = .152$, $p = .029$), environmental functioning ($r = .398$, $p = .000$) and global functioning ($r = .286$, $p = .000$).

Perceived satisfaction with informational, tangible and emotional support was a stronger predictor of physical functioning, psychological functioning, environmental functioning and global functioning of life than social relationship. The correlations obtained between perceived satisfaction from social support and the domains of quality of life are summarized in Table 9.

Table 9. Correlation between overall perceived satisfaction from social support, types of support and quality of life (N=160)

QOL-26	Overall satisfaction	Informational satisfaction	Tangible satisfaction	Emotional satisfaction
Physical functioning	.296**	.295**	.240**	.253**
Psychological functioning	.243**	.230**	.232**	.218**
Social relationship	.152*	.167*	.150*	.131*
Environmental functioning	.398**	.344**	.449**	.300**
Global functioning	.286**	.233**	.258**	.274**

Note: Numbers indicate Pearson r (* $P < 0.05$, ** $p < 0.01$)

A significant positive correlation was found between overall perceived satisfaction from social support and hope ($r = .296$, $p = .001$), satisfaction with informational ($r = .273$, $p = .000$), tangible ($r = .267$, $p = .000$) and emotional support ($r = .240$, $p = .001$). Perceived satisfaction with tangible and informational support was a stronger predictor of hope than emotional support. The results of the correlation are summarized in Table 10.

Table 10. Correlation between perceived satisfaction form social support and hope (N=160)

	Overall satisfaction	Informational satisfaction	Tangible satisfaction	Emotional satisfaction
Hope	.296**	.273**	.267**	.240**

Note: Numbers indicate Pearson r (** $p < 0.01$)

A significant positive correlation was found between hope and quality of life domain. Although hope was significantly correlated with all domains of quality of life, hope was a stronger predictor for the environmental functioning ($r = .445$, $p = .000$) than the other four domains of the quality of life. The result of the correlations is summarized in Table 11.

The relationship among demographic, health related variables and the main study variables (overall perceived satisfaction from social support, hope and quality of life) were investigated. Pearson correlations were calculated among the variables of age, gender, employment status, education, years

Table 11. Correlation between hope and quality of life (N=160)

QOL-26	Hope
Physical functioning	.375**
Psychological functioning	.357**
Social relationship	.352**
Environmental functioning	.445**
Global functioning	.313**

Note: Numbers indicate Pearson r (** $p < 0.01$)

of living with HIV, acknowledged risk factor, stigma, CD4+ count, overall perceived satisfaction from social support, hope, physical, psychological, environmental functioning, social relationship, and global functioning of life. Only gender was significantly correlated with overall satisfaction ($r = .174$, $p = .029$), hope ($r = .369$, $p = .000$), physical functioning ($r = .213$, $p = .007$), psychological functioning ($r = .256$, $p = .001$), social relationship ($r = .213$, $p = .007$), environmental functioning ($r = .312$, $p = .000$), global functioning ($r = .224$, $p = .002$) domain of quality of life. Differences by gender in the perceived satisfaction from social support, hope and functioning of life were also found to be significant. Female overall perceived satisfaction from social support, perceived hope and functioning of life were lower than male. The result of the correlation is summarized in Table 12.

Table 12. Socio-demographic and health outcome variables as correlates of perceived satisfaction from social support hope and quality of life (N=160)

	Overall satisfaction	Hope	Physical functioning	Psychological functioning	Social relationship	Environmental functioning	Global functioning
Age	.036	-.027	-.003	-.126	-.235**	.033	-.066
Gender	.174*	.369**	.213**	.256**	.213**	.312**	.244**
Employment	-.068	.030	.000	-.006	-.017	.133	.144
Education	-.051	.049	.066	-.004	.108	.122	.082
Year of living with HIV	.035	-.005	-.018	.049	-.029	.131	-.019
Acknowledge risk factor	.052	-.224**	-.147	-.170*	-.134	-.221**	-.183*
Stigma	-.142	-.167*	-.249**	-.264**	-.285**	-.148	-.225**
CD4+	.030	.072	-.061	-.007	.042	.067	.086

Note: Gender, Male=1, female=0, duration of living, four years=1, more than four years=0, acknowledge mode of transmission, sexual intercourse = 1, others= 0, stigma, feel stigma =1, no stigma= 0, occupation, employed=1, unemployed=0, CD4+ count, <200=1, >200=0. Numbers indicate Pearson r (* $P < 0.05$, ** $p < 0.01$)

In summary, most of the participants were young and they had family or non-family support network. The number of non-family network was higher than family network. A significant relationship was found between perceived satisfaction from social support, hope and quality of life.

6. DISCUSSION

The result of the correlation analyses showed that perceived satisfaction from social support was significantly correlated with all domains in the quality of life (Table 9). These findings support those found in previous studies that perceived satisfaction from social support was significantly correlated with physical functioning, psychological functioning, environmental functioning, social relationship and global functioning of life (Hirabayashi, *et al.*, 2002; Nunes, *et al.*, 1995; Swindells, *et al.*, 1999). The greatest impact of satisfaction from social support was on environmental functioning, whereas the lowest impact was on social relationship (Table 9).

In terms of types of support, the three major components of social support are informational, tangible and emotional support (Hays, Turner, & Coates, 1992). Furthermore, perceived satisfaction from informational and tangible support was a better predictor of all domains of quality of life than emotional support (Table 9). Overall perceived satisfaction from social support was significantly correlated with hope (Table 10), and this finding is similar to another existing study which showed that hope was positively associated with perceived social support (Zich & Temoshok, 1987). The finding was in line with research outcomes in cancer, which also suggested that there was a significant correlation between social support and hope (Hong & Ow, 2007).

Again, perceived satisfaction from emotional support was less of a predictor of hope than informational and tangible support. A similar finding was reported by Akinsola (2001), Barroso (1997), Gant & Ostrow (1995), and Hays *et al.* (1992), which indicated that instrumental or informational support seemed to be more relevant to PLWHA when they experience symptoms.

The finding of the current study showed that the mean score of family support network was less than non-family support network (Table 8), non-family network include to counselor, volunteer and other health personnel working at NGOs. Harris & Larsen (2008) suggested that non-family members such as health workers, counselors and volunteers have vital contributions in providing information and tangible support for livelihood and treatment.

Family support is a major source of emotional support (Crystal & Kersting, 1998; Shippy, 2007) and limited emotional support can inhibit social relationship (Strine, *et al.*, 2008). A study by Friedland *et al.* (1996) and Ichikawa & Natpratan (2006) suggested that family and friend acceptance was significantly related to social relationship.

Hope was significantly correlated with all domains of the quality of life (Table 11). This finding is collaborated by similar findings in which hope was found to be an important internal resource for increased functioning of PLWHA (Chammas, 1999; Heinrich, 2003). The greatest impact of hope was on environmental functioning and the lowest was on global functioning. The socio-economic status of participants showed that 18.1% of them were engaged as support provider (Table 7) and they were working as counselors or assisting in the referral system. This reflects mutual obligation of PLWHA

who are receiving support from NGOs and they are in turn providing support to others (Cobb, 1976).

They called themselves social workers, which put PLWHA in the company of others who are also infected with HIV. This is in line with the hope fostering strategy suggested by Herth (1990). The argument states that PLWHA who are active in care, support and treatment provision, and who have also HIVs and yet have been living long healthy lives serve as experience for other PLWHA that they may also have a long healthy life. This study's finding showed that not only having other PLWHA being around to HIV infected person, but also receiving various types of support from PLWHA was related to increasing number of new HIV cases to receive support which further foster hope and enhance better life. One of the important findings of this study is that PLWHA are able to work as peer counselors and can foster hope and improve quality of life of PLWHA around them. This is in line with the finding by Akinsola (2001) and Harris & Larsen (2007) that the role of counselor is vital to provide referral information (as informational support) for livelihood to receive counseling and medical treatments in the process of fostering hope. The finding of this study confirmed that there was a significant positive relationship among perceived satisfaction from social support, hope and quality of life.

The study also showed that there was statistically significant mean (male=4.2, female=2.9, $p=.003$) differences between male and female in terms of overall social network (Table 8). The correlation analysis revealed that female's overall perceived satisfaction from social support, perceived hope and functioning of life were lower than male (Table 12). Furthermore, the study result showed that HIV infected females (90% of female respondents were married or divorced) experienced less perceived satisfaction from social support (Table 8), which concurred the finding that HIV infected women received less social support (Klein, *et al.*, 2000). The finding of study showed that female participants had less hope, low physical, psychological, environmental, global functioning and social relationship.

The research outcome also suggested that in terms of types of support, source of support and perceived hope from social support and its impact on quality of life had similarities with previous research studies on cancer. The experience from care, support, and treatment to cancer patients could be important to foster hope and improve quality of life of PLWHA.

7. CONCLUSION

This study attempted to show that stated support of NGOs was positively related to the actual support provided to people infected with HIV. People infected with HIV were experiencing less stigma and disclosing their HIV status to receive support. This was based on the analysis of general support for HIV infected people and their spouses to home-based support, skill development, human resources, and expenses for support, the number of new HIV infected people every year approaches

to NGOs to receive care, support and treatment. The better the supportive environment to receive care, support and treatment, the less the stigma. This is related to people living with HIV, who will disclose themselves to receive support. However, an examination of medical support for anti-HIV medicine, less than 50% of PLWHA received the anti-HIV medication each year. This poses challenge for NGOs to align and maintain their support to the actual need for support by PLWHA in order to strengthen the positive outcome in terms of hope and quality of life.

The analysis in this study attempted to integrate perceived satisfaction and tangible support to PLWHA. Specifically, correlation analysis at the micro level showed that perceived satisfaction from social support was significantly associated with quality of life domains and hope. However, social relationship had less correlation than other domains. Emotional support was a lesser predictor of quality of life and hope. Community-based workers and health professionals should provide tangible support and inform HIV infected people (particularly females) about other social support from friends and family. The study outcome suggested that there was a significant relationship among perceived satisfaction from social support, hope and quality of life. The result of the study has implication for providing care, support and treatment for PLWHA, which uses hope as intermediary factor to influence the relationship between social support and quality of life. Furthermore, improving social support increased hope, which would improve their quality of life. Interventions to enhance satisfaction from various sources and types of social support and to foster hope may improve quality of life of people living with HIV/AIDS. Further research on the relationship between emotional support and social relationship with respect to family support is recommended.

Note

- 1 The WHOQOL-100 is lengthy scale with 100 items and its take long time to answer therefore researcher developed WHOQOL-26 tool an abbreviated 26 item version of the WHOQOL-100, and was developed using data from the field-trial version of the WHOQOL-100. The WHOQOL-26 is now available in over 20 different languages. The WHOQOL-26 instruments, by focusing on individuals' own views of their well-being, WHOQOL-26 measure the effect of the illness on individual's social relationships, physical functioning, psychological functioning, environmental functioning and global functioning
- 2 One limitation of this study is regarding the funding of the NGOs. Funding to each NGO is from different sources, and the mode and purpose of the funding agency can influence NGOs' support activities.
- 3 CD4 Cell: A normal CD4 count in Human blood without HIV infection will be approximately 400 to 1600 cells/ μ L, if HIV infected persons' CD4 count drops below 200, body's immune system is no longer strong enough to prevent other illness; a person is classified as having AIDS (Remington: The science and Practice Pharmacy, 1995)

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