Three Sides of a Coin in the Life of People Living with HIV (PLWH)

Deepika Cecil Khakha1, Bimla Kapoor2, Manju1, Singh K Sharma3

1Lecturer, College of Nursing, All India Institute of Medicine Sciences (AIIMS), New Delhi, 2Former Director and Professor, Indira Gandhi Open University, New Delhi, 3Prof. and Head Department of Medicine, All India Institute of Medical Sciences, New Delhi, India

ABSTRACT

Background: Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) is a global epidemic, a major challenge as a health care problem of modern times. As the survival of life increases from the time of an HIV-positive diagnosis, growing concern for the quality of the life has been extended. Objectives: To assess and correlate the coping, social support and quality of life. Materials and Methods: A descriptive cross-sectional study was conducted at antiretroviral therapy (ART) clinic of AIIMS, New Delhi. The sample comprised people living with HIV/AIDS (PLWHA) who were seropositive for last six months. The tools used to assess the coping, social support and quality of life were BREF COPE, MOS social support survey and WHO QOL-HIV BREF, respectively. Permission was taken from the authors of the tools. The ethical permission was taken from the center. The coping, social support and quality of life were assessed and their association was observed. Data were analyzed using SPSS 17. Results: The most commonly used coping styles were acceptance and religion. The social support used by most of PLWHA was tangible support and affectionate support, while the least used support was positive social interaction. The lowest quality of life is seen in social relations, followed by physical quality of life. There was positive association seen between coping and quality of life as well as social support and quality of life. Conclusion: There was positive association between coping, social support and quality of life. Keywords: Coping, people living with HIV (PLWH), quality of life (QOL), social support

Introduction

Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) is a global epidemic, a major challenge as a health care problem of modern times. As the survival of life increases from the time of an HIV-positive diagnosis, growing concern for the quality of the life has been extended.(1)

The physical manifestations, psychological well-being, coping strategies, social support systems, antiretroviral therapy (ART), spiritual well-being and psychiatric co-morbidities are important indices of quality of life (QOL) in this population as suggested by existing data. Health care professionals are encouraged to become familiar with the full spectrum of predictors of Health-related QOL (HRQoL), which may eventually contribute to the development of multiple entry points for interventions in promoting QOL in these patients.(2,3)

The reaction to the diagnosis of HIV is an excessively traumatic event in the life of people living with HIV/AIDS (PLWHA). In the first phase of the disease, coping becomes an important parameter, which determines the patient outcome. There are studies that have examined whether an ‘acceptance’ style of coping, as opposed to a ‘mental disengagement’ style, selectively influencing the first stages of the processing of neutral, emotional and HIV-related information.(4,5) Consequently, research on the QOL of people diagnosed with HIV is of great importance.

Access this article online

Quick Response Code:

Website: www.ijcm.org.in
DOI: 10.4103/0970-0218.164385

Address for correspondence:
Deepika C. Khakha, Lecturer, College of Nursing, All India Institute of Medical Sciences, New Delhi -110029, India
Email: dckhakha@gmail.com

Received: 16-06-14, Accepted: 27-02-15
An increasing number of studies have also focused on the association between psychosocial factors (e.g., coping, social support and depressive symptoms) and outcome of patients' QOL. However, there is a dearth of information about the interaction of these traits with cognitive abilities to influence behavioral and emotional adjustment.

The negative views of HIV leading to discriminatory behavior along with community avoidance of HIV powerfully affected the mental health of people living with HIV (PLWH). The ongoing distress, in addition to, the limited support, leads to a life in which many PLWH silently endure their pain in silence and experience profound loneliness.

There has been increasing attention being focused on AIDS-related stigma in the literature, but there is lack of information available regarding the devastating impact it has on Indian rural women living with AIDS (WLA) the more are the AIDS symptoms, higher level of felt stigma experienced by WLA. This leads fewer adherence strategies and lower support for ART adherence were also associated with avoidant coping. Thereby, the results of the study promote the apparent need for support and resources for rural Indian WLA.

The present study was done to find out coping social support and QOL of PLWHA and the relationship between these variables (social support, coping and quality of PLWHA).

**Materials and Methods**

**Study design**
Cross-sectional, descriptive, co-relational study was conducted at All India Institute of Medical Sciences (AIIMS, New Delhi).

**Study population**
The study population conveniently selected 200 PLWHA consenting to be a part of the study who met the inclusion criteria (Patients who are HIV positive for more than six months and willing to participate in the study, who are above 18 years of age, attending ART clinics of AIIMS, New Delhi, and can speak and understand Hindi/English).

**Methods**
All the subjects filled the self-administered questionnaires.

**Instruments**
The Brief COPE scale (Carver, 1997), a 28-item self-report measure of both adaptive and maladaptive coping skills was used.

**Medical outcome study social support survey (MOSSSS)**
All study subjects completed MOSSSS for assessing the variable of social support consisting of four functional support scales (emotional/informational, tangible, affectionate and positive social interaction) and the construction of an overall functional social support index.

**WHO QOL-HIV BREF**
For assessing the variable of QOL, WHO QOL-HIV BREF consisting of six domain scores was used. It has only one item to present each facet. Included in these, there are two items that examine general QOL. Hence there are 31 items, representing the 30 facets. Five of these facets are specific to HIV/AIDS. The individual items are rated on a 5-point Likert scale where 1 indicates low, negative perceptions and 5 indicates high, positive perceptions.

**Statistical analysis**
Data were analyzed with SPSS 17 for Windows. The baseline variables were assessed using descriptive statistics of mean and frequency percentages. The variables were correlated by using Pearson’s correlation. ‘t’ test was used for comparing the variables. The association between multivariate variables and coping, social support and QOL was done by one-way ANOVA.

**Ethical consideration**
The permission for collecting data was obtained from the Ethics Committee, AIIMS. A written informed consent from each study subject to participate in the study was obtained before the start of work with assurance of confidentiality of the data.

**Results**

**Socio-demographic characteristics of PLWHA**
The mean age of PLWHA was 39.8 ± 8.1, ranging from 21 to 61 years. The majority of PLWHA were males (76%). Total 39% of PLWHA were educated up to till class 10. In all, 75% of PLWHA were married and majority (76%) had income between 5,000 and 10,000/- per month [Table 1].

As evident from Figure 1, the most commonly used coping styles were acceptance and religion. The least used coping methods are self-blame, venting, humor, denial and substance use. This indicates that mostly adaptive coping strategies were used by PLWHA to face psychosocial and illness-related issues of HIV.

Table 2 shows that most of the PLWHA used tangible support and affectionate support, followed by emotional support, while positive social interaction was the least used support. This reflects the social distancing because of HIV infection.

As shown in Figure 2, the lowest QOL is seen in social relations, followed by physical QOL, which reflects the social implication of the disease. The psychological domain
of QOL was higher than the independence and spirituality domain. QOL in physical domain was largely dependent on discomfort reported arising from HIV-associated symptoms and treatment. The impact of HIV infection on the dimensions of QOL including physical and emotional well-being, social support systems, and life roles, emerged as a key issue for persons infected with HIV.

**Association of QOL with the coping and social support of PLWH**

The association between QOL and coping of PLWH is evident from Table 3.

As per Figure 3, as the physical domain of the QOL increased the emotional, tangible, affectionate and

---

**Table 1: Socio-demographic profile of PLWHA N = 200**

| Variables          | Range/Range ± SD          |
|--------------------|---------------------------|
| Age                | 21-61 years/39.8 ± 8.1 years |
| Sex                |                           |
| Male               | 152 (76)                  |
| Female             | 48 (24)                   |
| Education          |                           |
| Illiterate         | 32 (16)                   |
| 1-5                | 39 (19.5)                 |
| 6-10               | 78 (39.0)                 |
| 11-12              | 21 (10.5)                 |
| Graduate and above | 30 (15)                   |
| Marital status     |                           |
| Single             | 19 (9.5)                  |
| Married            | 150 (75)                  |
| Separated          | 4 (2)                     |
| Divorced           | 2 (1)                     |
| Widowed            | 25 (12.5)                 |
| Income             |                           |
| <5000 Rs           | 20 (10)                   |
| 5000-10000         | 153 (76.5)                |
| Above 10,000       | 27 (13.5)                 |
| HIV status         |                           |
| Asymptomatic       | 139 (69.5)                |
| Symptomatic        | 59 (29.5)                 |
| AIDS converted     | 2 (1.0)                   |
| CD4 Count          |                           |
| <200               | 14 (7.0)                  |
| 200-400            | 97 (48.5)                 |
| 400-800            | 77 (38.5)                 |
| 800 above          | 12 (6.0)                  |
| Mode of transmission|                          |
| Unknown            | 45 (22.5)                 |
| Heterosexual contact| 123 (61.5)                |
| Injecting drug use | 24 (12.0)                 |
| Blood              | 8 (4.0)                   |
| When infected      |                           |
| Unknown            | 28 (14.6)                 |
| Before 2000        | 14 (7.3)                  |
| 2000-2006          | 69 (35.9)                 |
| 2006-2012          | 81 (42.2)                 |
| When tested        |                           |
| Unknown            | 28 (14.6)                 |
| Before 2000        | 14 (7.3)                  |
| 2000-2006          | 69 (35.9)                 |
| 2006-2012          | 81 (42.2)                 |

**Table 2: Baseline Social support among PLWHA**

| Domains                      | Mean ± SD |
|------------------------------|-----------|
| Emotional support (score ranges: 1-5) | 3.1±1.0   |
| Tangible support (score ranges: 1-5) | 3.2±1.1   |
| Affectionate support (score ranges: 1-5) | 3.2±1.2   |
| Positive social interaction (score ranges: 1-5) | 2.8±0.9   |

---

**Figure 1: Showing baseline coping strategies adopted by PLWH**

**Figure 2: Bar graph showing domains of QOL of PLWHA HIV/AIDS**

**Figure 3: Association of baseline QOL with the Social Support of PLWH**
positive social interaction also increased. PLWHA were able to positively interact with others as well as able to relate with others on affective and emotional level too. As PLWHA improved psychologically and were relatively stress-free, there was increase in their ability to interact with others on social, affectionate and emotional levels.

There was a positive significant association between the QOL of independence domain (mobility, work capacity, ability to do activities of daily living) and the emotional, tangible, affectionate and positive social interaction. Results also indicated that PLWHA were able to maintain personal relations and their social support improved as the spirituality domain of the QOL and positive social interaction increased.

Discussion

In the present study, the mean age ± SD of PLWHA was 39.8 ± 8.1 years. This was in accordance with the study by Tsevat et al., wherein the patients’ mean age was 43 years.
age was 44.8 (8.3) years. In reference to the HIV illness status, more than half (69.5%) reported themselves as asymptomatic, which is concordant with the results of the study conducted by Leiberich et al.,(10) in which 82% of PLWHA were asymptomatic. The authors explained their findings because of the study being conducted in the western part of the world where the socio-economical viability is more than their Indian counterparts.

Coping of PLWHA
In the present study, the most commonly used coping styles are acceptance and religion, which are congruent with the results of Trevino et al.,(11) giving implications for assessing religious coping and designing interventions targeting spiritual struggle in patients with HIV/AIDS.

Social support of PLWHA
The social support used by most PLWHA was tangible support and affectionate support, followed by emotional support, while the least(11) used support was positive social interaction.

QOL of PLWHA
The lowest QOL was seen in social relations, which is congruent with the study done by Miles et al.(7) The study by Basavaraj et al.,(9) stating the impact of HIV infection on the dimensions of QOL, including physical and emotional well-being, social support systems, and life roles, has emerged as a key issue for persons infected with HIV. This is also in agreement with the study by Côté et al.,(12) on psychosocial characteristics of treatment-adherent, successfully treated HIV patients and to examine the relationships between psychosocial variables.

Association of QOL with coping
In the present study, the association between active coping and QOL domains of physical, independent, social relations and spirituality was positively statistically significant. This is in concordance with the results of Steglitz et al.,(13) in which religiosity was related to decreased avoidant coping and increased social support, which in turn were related to psychological distress. Spirituality was positively related to active coping and social support. The association between denial and QOL domains of independence, social relations and spirituality was significantly increased in independence, social relations and spirituality domains of QOL in the current study and it was consistent with the results of Kamen et al.,(14) where denial coping predicted an increase in QOL over time, though QOL remained low in those who practiced denial coping. There was a significantly negative association between substance use and environment. This is in agreement with the study by Leiberich et al.,(10) whose patients reported significantly worse physical and cognitive-emotional QOL than healthy subjects. The HIV-positive IV drug users with great distress showed significantly lower QOL scores. Association between instrumental support and physical, independence, social relations and environment domains of QOL was positive and had significant P value in the present study.

There was significant association between social relations and behavioral disengagement. This implies that as behavioral disengagement increases, the social relations increased too, which was contrary to the reports of Koopman et al.,(15) which indicated that HIV-positive persons who experienced the greatest stress in their daily lives were those with lower incomes, who disengaged behaviorally/emotionally in coping with their illness, and those who approached their interpersonal relationships in a less secure or more anxious style.

Association of baseline QOL with the social supports
There was a statistically significant positive association between the physical domain of QOL and social support domains of emotional support, tangible support, affectionate and positive social interaction in concordance with the results of Heckman et al.,(16) which revealed QOL strategies as the most promising included, ensuring that instrumental support and daily assistance is readily available, teaching HIV-affected persons coping and problem-solving skills and conducting weekly face-to-face support groups for persons living with HIV/AIDS. The association between the psychological domain of QOL and social support i.e., emotional support, tangible support, affectionate and positive social interaction was statistically significant. This is in agreement with study by Slater et al.,(17) in which emotional/informational support remained as a significant positive predictor and medical co-morbidities. There was a statistically significant association between the independence domain of QOL and social support, which was in concordance with the findings of Skevington et al.,(18) which revealed that increased positive feelings, social support and perceived improvements of access to health and social care improved QOL. Social inclusion increased perceived physical health indirectly through positive feelings. Better physical health leads to improved sex life, greater independence and better quality of life.

Conclusion
The most commonly used coping styles were acceptance and religion. The social support used by PLWHA was tangible support and affectionate support. The lowest QOL was seen in social relations, followed by physical
QOL. There was positive correlation seen between ways of coping (self-distraction, active coping, instrumental support, behavioral disengagement, venting, positive reframing, acceptance and religion and domains of QOL).

There was negative correlation between self-blame (coping styles) and physical, independence, social relations, environment and spiritual domains of QOL. There was significant negative correlation between substance use and environment domain of QOL. There was positive significant relationship between all the domains of QOL and of all four domains of social support.

**Implications of the study**

Health care personnel need to be prepared to manage the psychosocial implications of the disease as they play a major role in empowering PLWHA. Awareness regarding the issues faced and vulnerabilities of PLWH can be sensitized to the public. The caregivers can be educated on the importance of social support. The PLWH can be equipped to use effective coping strategies.

**Recommendations**

Similar studies can be conducted in different geographical areas with a larger sample size. Other outcomes such as level of disease burden, anxiety, depression, subjective wellness, stress related to disease condition can be assessed. The coping strategies to deal with the disease should be available to PLWHA as regular reinforcement and support. The impact of the coping device on the practices of PLWHA on coping and social support can be assessed.

**Acknowledgment**

We wish to express our gratitude to Dr. A Nyamathi, Professor, School of Nursing, UCLA, US for her direction and inputs. Our immense thanks go to PLWH for their cooperation and time.

**References**

1. Cobb S, Erbe C. Social support for the cancer patient. Forum Med 1978;1:24-9.
2. Douaihy A, Singh N. Factors affecting quality of life in patients with HIV infection. AIDS Read 2001;11:450-4, 460-1, 475.
3. Basavaraj KH, Navya MA, Rashmi R. Quality of life in HIV/AIDS. Indian J Sex Transm Dis 2010;31:75-80.
4. Makoae L, Greeff M, Phetlhu RD, Uys LR, Naidoo JR, Kohi TW, et al. Coping with HIV-related stigma in five African countries. J Assoc Nurses AIDS Care 2008;19:137-46.
5. Novara C, Casari S, Compostella S, Dorz S, Sanavio E, Sica C. Coping and cognitive processing style in HIV-positive subjects. Psychother Psychosom 2000;69:316-21.
6. Salama C, Morris M, Armistead L, Koenig, LJ, Demas P, Ferdon C, et al. Depressive and conduct disorder symptoms in youth living with HIV: The independent and interactive roles of coping and neuropsychological functioning. AIDS Care 2013;25:160-8.
7. Miles MS, Isler MR, Banks BB, Sengupta S, Corbie-Smith G. Endurance and profound loneliness: Socioemotional suffering in African Americans living with HIV in the rural south. Qual Health Res 2011;21:489-501.
8. Nyamathi A, Ekstrand M, Zolt-Gilburne J, Ganguly K, Sinha S, Ramakrishnan P, et al. Correlates of stigma among rural Indian women living with HIV/AIDS. AIDS Behav 2013;17:329-39.
9. Tsevat J, Leonard AC, Szaflarski M, Sherry SN, Cotton S, Mrus JM, et al. Change in quality of life after being diagnosed with HIV: A multicenter longitudinal study. AIDS Patient Care STDS 2009;23:931-7.
10. Leiberich P, Engster M, Olbrich E, Schumacher K, Brieger M, et al. Longitudinal development of distress, coping and quality of life in HIV-positive persons. Psychother Psychosom 1997;66:237-47.
11. Trevino KM, Pargament KI, Cotton S, Leonard AC, Hahn J, Caprini-Faigin CA, et al. Religious coping and physiological, psychological, social, and spiritual outcomes in patients with HIV/AIDS. Cross-sectional and longitudinal findings. AIDS Behav 2010;14:379-89.
12. Côté J, Delmas P, Delpierre C, Sylvain H, Delon S, Rouleau G. In Process Citation. Open Nurs J 2009;3:10-7.
13. Steglitz J, Ng R, Mosha JS, Kershaw T. Divinity and distress: The impact of religion and spirituality on the mental health of HIV-positive adults in Tanzania. AIDS Behav 2012;16:2392-6.
14. Kamen C, Taniguchi S, Student A, Kienitz E, Giles K, Khan C, et al. The impact of denial on health-related quality of life in patients with HIV. Qual Life Res 2012;21:1327-36.
15. Koopman C, Gore-Felton C, Marouf F, Butler LD, Field N, Gill M, et al. Relationships of perceived stress to coping, attachment and social support among HIV-positive persons. AIDS Care 2000;12:663-72.
16. Heckman TG, Somlai AM, Kelly JA, Stevenson LY, Galdabini K. Reducing barriers to care and improving quality of life for rural persons with HIV. AIDS Patient Care STDS 1996;10:37-43.
17. Slater LZ, Moneyham L, Vance DE, Raper JL, Mugavero MJ, Childs G. Support, stigma, health, coping, and quality of life in older gay men with HIV. J Assoc Nurses AIDS Care 2013;24:38-49.
18. Skevington SM, Norweg S, Standage M. WHOQOL HIV Group. Predicting quality of life for people living with HIV: International evidence from seven cultures. AIDS Care 2010;22:614-22.

How to cite this article: Khakha DC, Kapoor B, Manju, Sharma SK. Three sides of a coin in the life of people living with HIV (PLWH). Indian J Community Med 2015;40:233-8.

Source of Support: Nil, Conflict of Interest: None declared.