Quality of Life in People Living with HIV (PLWH)

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Abstract
A cross-sectional, descriptive study was conducted to assess Quality of life (QOL) of people living with HIV (PLWH) at ART clinic at a tertiary care centre. The study population conveniently selected comprised of 200 PLWH consenting to be a part of the study who met the inclusion criteria. The ethical permission was taken from the centre. The lowest quality of life is seen in social relations, followed by physical quality of life. There was positive association of age with physical domain, independence and spiritual domain of quality of life and significant p value. Positive association was seen between marital status, education and income and quality of life.

Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) is a major health care challenge of modern times. As the longevity is increasing with current prophylactic and therapeutic strategies, the growing concern for the quality of life (QOL) has been extended. Thus, while searching for the cure for AIDS and methods of its prevention and control, there is also an apparent need to develop strategies within health and social systems to facilitate adjustment and enhance well-being.

Health care professionals are encouraged to become familiar with the full spectrum of predictors of health related QOL, which may eventually contribute to the development of multiple entry points for interventions in promoting QOL in these patients.

Objectives
The objectives of the study were:
1. To assess quality of life (QOL) of people living with HIV (PLWH).
2. To find out the association of quality of life with demographic profile of PLWH.
3. To find out the association of quality of life with HIV-related profile of PLWH.

Review of Literature
A cross-sectional study on 399 HIV positive women to examine their physical, psychological, and social factors associated with QOL indicated that age, race and time of HIV diagnosis showed significant association with QOL. In another study it was concluded that one cannot confine solely on the individual, but must also focus on the local community and society as a whole to improve the quality of life and health of PLWH.

Acute and chronic life stressors have a detrimental effect on the health of people living with HIV. Psychosocial resources such as mastery, coping and social support may play a critical role in moderating the negative effects of stressors on health-related quality of life. Longevity is achievable with current prophylactic and therapeutic strategies for persons with HIV infection, QOL has emerged as a significant medical outcome measure and its enhancement has become an important goal. Anti-retroviral therapy, psychological well-being, social support systems, coping strategies, spiritual well-being and psychiatric comorbidities are important predictors of QOL in this population. Consequently, 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.

Methodology
Study design: It was a cross-sectional, correlational study conducted at All India Institute of Medical Sciences (AIIMS), New Delhi.

Study population: The study population was 200 PLWH who met the inclusion criteria (Patients who are HIV positive for more than six months and willing to participate in the study, aged 18 years or above, attending ART clinics of AIIMS, New Delhi, can speak and understand Hindi/English).
Instruments

Section I: Demographic data and HIV related data i.e, age, gender, educational status, marital status, income, HIV status, CD4 count, mode of transmission, time of infection and time of testing HIV.

Section II: WHO QOL-HIV BREF: WHO QOL-HIV BREF is a standardising tool consisting of six domain scores for assessing the variable of Quality of Life. Domain I: Physical - comprising of pain, discomfort, energy, fatigue, sleep and rest. Domain II: Psychological - constitutes positive feelings, thinking, learning, memory, self esteem, body image, negative feelings and appearance. Domain III: Level of independence - includes mobility, activities of daily living, work capacity. Domain IV: Social relations - encompass personal relationship, social support, and sexual activity. Domain V: Environment - which includes physical safety and security, home environment, financial resources, health and social care, participation in recreation/leisure activities. Domain VI: Spiritual - includes forgiveness and blame, concerns about future, death and dying.

The tools were in English and Hindi. The permission to use the tool was taken by the competent authority at WHO. Tool try out was done on 5 PLWHA in the month of May 2011 at Delhi Positive People Network, Neb Sarai, New Delhi. It took half an hour to complete the questionnaire by each PLWHA. There was no problem encountered by PLWHA.

Reliability of the tool: Test-retest reliability of the above said tools was done by the researchers. The reliability score obtained by Cronbach’s Alpha for the tools was 0.992.

Statistical analysis: Data was analyzed with SPSS 17. Descriptive and inferential statistics were used for counting and correlation. The baseline variables were assessed using descriptive statistics of mean and frequency percentages. The inferential tests used were student ‘t’ test and one way ANOVA.

Ethical consideration: Permission for collecting data was obtained from the Ethics Committee, AIIMS; a written informed consent was obtained from each study subject.

Results

As seen from Table 1, the mean age of PLWH was 39.8 ±8.1 years, ranging from 21 to 61 years. The majority of PLWH were male (76%); 39 percent of PLWH were educated up to till class 10; 75 percent of PLWH were married and 76 percent had income between Rs. 5000-10,000/- per month.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Mean ±SD</th>
<th>Range</th>
<th>Mean percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domain 1 (Physical)</td>
<td>53.4±9.4</td>
<td>28-72</td>
<td>74.1</td>
</tr>
<tr>
<td>Domain 2 (Psychological)</td>
<td>58.7±9.4</td>
<td>32-80</td>
<td>73.3</td>
</tr>
<tr>
<td>Domain 3 (Independence)</td>
<td>56.8±13.0</td>
<td>20-80</td>
<td>71</td>
</tr>
<tr>
<td>Domain 4 (Social relation)</td>
<td>53.2±13.5</td>
<td>20-80</td>
<td>66.5</td>
</tr>
<tr>
<td>Domain 5 (Environment)</td>
<td>114.6±23.8</td>
<td>48-156</td>
<td>73</td>
</tr>
<tr>
<td>Domain 6 (Spiritual / religious beliefs)</td>
<td>56.9±10.9</td>
<td>20-80</td>
<td>71.1</td>
</tr>
</tbody>
</table>
Table 2 shows the lowest QOL in social relations, followed by physical, reflecting the social implication of the disease. QOL in physical domain was largely dependent on discomfort reported arising from HIV-associated symptoms and treatment suggesting that PLWH experience discomfort from symptoms associated with HIV. QOL in psychological domain is largely explained by perceived stress, positive thinking, self-esteem, body image and appearance. This implies that PLWH experience less stress than the issues encountered by them in the independence domain.

As evident from Table 3, as age increased the PLWH demonstrated more self dependence. PLWH who were single scored highest in the psychological domain, implying that they were stress-free as they did not have responsibilities to run the family and take care of others. Illiterate PLWHs were found to be more dependent on others probably because they go into social exclusion and their ability to establish personal relation was seriously affected. The score in environment domain of illiterate PLWHs was lowest and had serious consequences in their lives. Educational status played a role in social viability of PLWH.

Table 4 shows that the asymptomatic PLWHs had significant p-value in independence social relations, environment and spirituality domains of QOL, indication they were more proactive.

In independence domain of QOL CD4 counts PLWHs had counts with p-value 0.001. The PLWH with CD4 counts more than 800 had high level of independence. As CD4 is the indicator of health status, so the PLWH with above 800 would be symptom free, hence they would be more independent. In social relations domain of QOL CD4 counts, PLWH had p-value 0.001. The PLWH with CD4 counts 400-800 had high score in social relations. The PLWH with CD4 counts more than 800 had high level of spirituality domain. There was significant association between physical domain of QOL and mode of transmission. The PLWHs who got infected through blood and parenteral route had high QOL at physical domain.
The present study indicated the lowest QOL in domains of social relations; this is congruent with the study by Miles. They explored how community responses to HIV contribute to distress PLWH and found that community avoidance of HIV, negative views of HIV, and discriminatory behaviour powerfully affected the distress of PLWH. Cote J & Molassiotis A also stated that social relations are most affected in HIV. Basavaraj KH, et al stated the impact of HIV infection on the dimensions of QOL including physical and emotional well-being, social support systems, and life roles.

In the present study, there was significant association between age and physical domain of QOL. This is in disagreement to Skevington SM in which older HIV adults had better QOL than expected highlighting the extent of poor QOL in younger adults. There was association between age and independence domain. This indicates as age increases, the person becomes more independent. There is significant association of age with spiritual domain implying that ageing increases the PLWH spirituality. This is congruent with the study by Khumsaen N et al, where the results revealed that age, education level, employment status, monthly income, living in own house, living with family member, social support, spiritual well-being, and coping style and adaptation process were related to QOL.

There was significant association between the psychological domain and marital status. This is in agreement with Subramanian T et al, findings showing that gender and marital status had significant association with quality of life.

**Implications**

Nurses need to be prepared to manage the psychosocial implications of the disease as they play a key role in empowering PLWH. Nurses should give emphasis to illiterate PLWHs as their psychosocial resources are not adequate to cope with the disease. Nurses can sensitise the public regarding the vulnerabilities of PLWH. Holistic health services can be organised for PLWH in the community. More Psychosocial Support to be given to newly diagnosed PLWH as the resilience is poor as evident from the study.

**Recommendations**

Similar studies can be conducted in different geographical areas with a larger sample. Other outcomes like level of disease burden, anxiety, depression, subjective wellness, stress related to disease condition can be assessed.
The lowest QOL was seen in social relations, followed by physical QOL. There was positive association of age with physical, independence and spiritual domain of QOL. There was significant association between the psychological and environment domain with the marital status. There was positive association seen between education of the PLWH and physical, independence and environment domain of QOL.

References