INTERNALISED STIGMA AND QUALITY OF LIFE IN PEOPLE LIVING WITH HIV

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ABSTRACT

HIV/AIDS is recognised as a highly stigmatized disease which negatively influences the well-being of people living with HIV/AIDS. In the present study, an attempt has been made to compare the quality of life across different high, moderate and low levels of internalized HIV-stigma. In this cross-sectional study, a total number of 100 HIV-infected individuals already enrolled in ART centre, Sir Sundar Lal Hospital, Banaras Hindu University, Varanasi, India, were taken as subjects. The Internalised Stigma Index and Hindi version of WHOQOL-BREF were used to assess the quality of life in high, moderate and low levels of internalized stigma among HIV infected individuals. One-way analysis of variance followed by post hoc tukey test was used to compare the effect of internalised stigma categories on each domain of quality of life. It was found that physical quality of life, psychological quality of life, and environmental factor differed significantly across various internalised stigma level. Whereas, social relationship domain of quality of life differ significantly only in low and high internalised stigma category and no significant difference was found between low and moderate internalised stigma category. The finding of the present study conveys an encouraging message to HIV-infected individuals to rise above their feeling of self-hatred and lead a better life.

Keywords Stigma, HIV, AIDS, Quality of life

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INTRODUCTION

Since the discovery of AIDS in 1981, it has been recognised as disease associated with fear, denial, discrimination and stigma (Parker & Aggleton, 2003). HIV/AIDS is perhaps the most stigmatized medical condition in the world (Crawford, 1996; Peters, den Boer, Kok, & Schaalma, 1994). HIV/AIDS-related stigma is prevalent in the lives of people living with HIV. It’s almost a universal phenomenon, although they manifest differently and in varying degrees in different cultural setting.

Discussion of stigma, particularly in relation to HIV/AIDS often begins with Goffman’s (1963) definition of an attribute that is “significantly discrediting”. Herek et al. (1998) defines HIV stigma as a socially shared knowledge about the devalued status of people living with HIV. It is manifested in prejudice, discounting, discrediting and discrimination directed at people perceived to have HIV/AIDS, and the individuals, groups and communities with whom they are associated. Studies on HIV/AIDS stigma highlights different forms of stigma as experienced by people living with HIV/AIDS: Enacted stigma, Perceived stigma (Berger, Ferrans & Lashley, 2001; Scambler & Hopkins, 1986; Steward et al., 2008), Vicarious stigma (Steward et al., 2008) and Internalised stigma (Berger, Ferrans & Lashley, 2001; Lee, Kochman, & Sikkema, 2002; Steward et al., 2008).

Each of these forms of stigma are differently related to psychological, behavioural, and health outcomes (Earnshaw & Chaudoir, 2009). Among these kinds of stigma internalized stigma may have even more severe consequences than perceived or enacted stigma. Internalized stigma includes negative beliefs, views and feelings towards HIV/AIDS and oneself (Lee, Kochman, & Sikkema, 2002). In this case individual’s self concept becomes congruent with the stigmatizing responses of others and they accept their discredited status as valid (Jones et al., 1984; Herek, 2008) results in feeling of self-hatred. Lee, Kochman, and Skikema (2002) found that internalized stigma is experienced by majority of people living with HIV/AIDS. Results of studies showed that internalized stigma is likely to make HIV-infected individuals more sensitive towards both actual and anticipated rejection and stigmatization by others, which deters them from disclosing their serostatus to others (Chesney & Smith, 1999), discourage people living with HIV/AIDS (PLWHA) from seeking care (Malcolm et al., 1998) and may increase the levels of their loneliness compared to the general population (Vance, 2006; Ware, Wyatt, & Tugenberg, 2006).

PLWHA who feel stigmatized also feel anxiety, depression, and alienation, and these feelings of anxiety, depression, and alienation are associated with disruptions in normal social relationships (Crandall & Coleman, 1992). All these are likely to affect HIV-positives ability to effectively manage their disease.

With the introduction of antiretroviral therapy HIV infected men and women are living longer, hence enhancing quality of life (QOL) is an important area of
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Concern for both, health care provider and researchers. Quality of life is a term that is popularly used to convey an overall sense of well-being and includes aspects such as happiness and satisfaction with life as a whole. Quality of life is a multidimensional concept that refers to the individual’s perception of their position in the context of culture and value system in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging complex context shaped by an individual’s physical health, psychological health, social relationships and environmental factor (WHO, 1995). This definition reflects the view that quality of life refers to subjective evaluation, which is embedded in a cultural, social and environmental context.

A number of studies that centred on the quality of life of HIV-positive individuals using different types of QOL measuring tools have shown that socio-demographic characteristics, such as age (Liu et al., 2006; Molassiotis, Callaghan, Twinn, & Lam, 2001), gender (Griffin, Rabkin, Remien & Williams, 1998; Mrus et al., 2005; Starace et al., 2002), marital status (Nojomi, Anbary, & Ranjbar, 2008), education (Murri et al., 2003; Wachtel et al., 1992), income (Wig et al., 2006), employment status (Liu et al., 2006; Nojomi, Anbary, & Ranjbar, 2008) and disease related variables such as disease stage (Griffin, Rabkin, Remien & Williams, 1998; Lubeck & Fries, 1997), opportunistic infection (Basavaraj, Navya, & Rashmi, 2010), CD4 count (Nirmal, Divya, Dorairaj & Venkateswaran, 2008) as well as the use of highly active antiretroviral therapy (HAART) (Liu et al., 2006) and side effect of these treatments (Burgoyne & Tan, 2008), were reported to have a significant impact on the quality of life of PLWHA. But, there is a great variability in the reported findings regarding these relationships.

The increase in number of symptoms and degree of severity has been identified as an important predictor of well-being of people living with HIV/AIDS (Bing et al., 2000; Lubeck & Fries, 1993). Apart from physical deterioration, HIV/AIDS patients also struggle with numerous psychosocial problems such as stigma, depression, substance abuse, and culture beliefs which can affect their quality of life (Aranda-Naranjo, 2004). In India, six important themes that emerged in the three centres i.e., Delhi, Banglore, & Chennai, as being important for quality of life were: Access to health care, stigma, sexuality issues, death, body image and spirituality (Chandra, Saxena & Kumar, 2000). Swindells et al. (1999) have found that health related quality of life in HIV-infected person is determined by satisfaction with social support, degree of hopelessness and coping style.

The literature has provided substantial evidence of the negative influence of internalized HIV/AIDS-related stigma in the lives of PLWHA. Despite the potential significance of internalized HIV stigma in the lives of PLWHA, this concept received less attention from both, researchers and programme planners (Brouard & Wills, 2006; Crandall & Coleman, 1992). A better understanding of the effects
of internalized stigma on PLWHA is required to reduce this and to minimize its deleterious effects on the QOL of people living with HIV/AIDS. Thus, the present study aims to assess the quality of life across different levels of internalized HIV-stigma (i.e., High, Moderate, and Low).

In lieu of this objective, it has been hypothesized that high internalized stigma category would score lower on all domains of quality of life than moderate and low internalized stigma category.

**METHODOLOGY**

**Sample**

This is a cross-sectional study. The study sample consisted of 100 HIV positive individuals enrolled at ART Centre, Sir Sundar Lal Hospital, Banaras Hindu University, Varanasi. The inclusion criteria included (1) documented status of HIV positive (2) on Highly Active Antiretroviral Therapy (HAART) for at least six months (3) minimum of 18 years of age (4) ability of writing, reading and speaking Hindi (5) having no history of drug abuse and alcoholism (6) having no history of psychiatric problems such as mental retardation (7) having no history of cognitive problems (8) willingness to provide informed consent and (9) willingness to spare the time for the interview.

**Tools**

**Hindi version of WHOQOL-BREF** (Saxena, Chandiramani & Bhargav, 1998). WHOQOL-BREF is a short version of the WHOQOL-100 and is a self-rating instrument. It includes 26 items in which 24 items cover the four main domains such as physical health (physical state), psychological health (cognitive and affective state), social function (interpersonal relationships and social roles in life) and environmental factors (relationships to salient features of the environment) and remaining two items measure satisfaction of overall health and overall quality of life. The physical domain includes three facets *i.e.*, pain and discomfort, energy and fatigue, and sleep and rest. The psychological domain includes five facets *i.e.*, positive feelings, negative feelings, learning and concentration, body image, and self-esteem. The social domain includes three facets *i.e.*, personal relationship, practical social support, and sexual activity. The environmental domain includes five facets *i.e.*, financial resources, healthcare availability, opportunities for acquiring new information and skills, opportunities for leisure, and transport. Each item uses a Likert-type five-point scale in positive direction (higher the score, higher the quality of life). The WHOQOL-BREF score demonstrated good discriminated validity, content validity, and test-retest reliability, and the questionnaire is considered a valid and reliable measure for assessing QOL profile in different populations, including patients sample (WHOQOL Group, 1998).
Internalised stigma index. Internalised stigma index is developed by Steward, Gregory, Ramakrishna, Bharat, Chandy, Wrubel and Ekstrand (2008). It is a 10-item index that assess the extent to which, being an HIV-infected, they should be treated in a discriminatory manner or be a target of stigmatizing beliefs. Responses were given on a 4-point scale running from 0 (not at all) to 3 (a great deal). The scale was translated in Hindi to administer on the Hindi speaking local population. Subjects having same frame of mind and speaks Hindi language require the tool in Hindi, thus the tool was transformed in Hindi by the translation method available. The translation was done by the present researcher, a bilingual expert, and a subject expert. The items were then systematically scrutinized in terms of the contents yielding generalization of human behaviour.

Procedure

Initially a proper rapport was established with the selected subject. Personal information of the subject was filled. Voluntary participation certificate was signed by the subject. Internalised Stigma Index and Hindi version of WHOQL BREF was administered one after other on the 100 HIV patients registered in the ART centre, Sir Sundar Lal Hospital, BHU. All HIV patients were on Highly Active Antiretroviral therapy at least for the last 6 months. Subjects were either in stage-I (i.e., Asymptomatic) or stage-II (i.e., Symptomatic), according to the WHO Disease Staging System for HIV Infection and Disease. All participants had completed primary education, which include reading, writing and speaking Hindi fluently. Subjects having a history of drug abuse, alcoholism, cognitive problems and psychiatric problems such as mental retardation were excluded.

Data Analysis

SPSS PC+ (Version 16.0) software was used for statistical analysis. The descriptive variables such as mean and standard deviations were used. A comparison between categories was calculated using one way ANOVA followed by post hoc Tukey test.

Ethical Approval

At the beginning of each interview, written informed consent was obtained from each participant. The ethical review committee of the Institute of Medical sciences, Banaras Hindu University, Varanasi, had approved the study.

RESULT AND DISCUSSION

In the present study, majority of the sample reported experiencing some level of internalized stigma related to their serostatus. Many subjects experienced high level of internalised HIV-stigma, but few also reported experiencing no internalised HIV-stigma at all. These results are similar to the findings of Crandall and Coleman (1992), Lee, Kochman, and Skikema (2002) and Steward et al (2008) that HIV-positives personally hold mixed views about the validity of the
HIV-stigma. Further, HIV-positive individuals experienced varying degrees of internalised stigma related to their illness, including some who experienced no internalised HIV-stigma at all.

One-way ANOVA was conducted to compare the effect of internalised stigma categories i.e., high, moderate & low levels on each domain of quality of life.

### TABLE 1

<table>
<thead>
<tr>
<th>Domains of Quality of Life</th>
<th>Internalised Stigma [Mean (SD)]</th>
<th>F-value (2, 97)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low</td>
<td>Moderate</td>
</tr>
<tr>
<td>Physical</td>
<td>27.31(2.92)a</td>
<td>24.53(3.93)b</td>
</tr>
<tr>
<td>Psychological</td>
<td>24.53(3.36)a</td>
<td>20.16(4.49)b</td>
</tr>
<tr>
<td>Social relationship</td>
<td>29.72(4.13)a</td>
<td>26.66(4.60)b</td>
</tr>
<tr>
<td>Environmental</td>
<td>10.56(1.85)b</td>
<td>9.91(1.84)b</td>
</tr>
</tbody>
</table>

***p<0.001

a,b,c = Common superscript shows no significant difference; Post hoc test using Tukey.

The table shows that internalised stigma level i.e., high(n=36), moderate (n=32), and low (n=32) differed significantly on physical quality of life \( \left( F_{(2,97)} = 36.22; \ p=0.001 \right) \), psychological quality of life \( \left( F_{(2,97)} = 46.98; \ p=0.001 \right) \), social relationships \( \left( F_{(2,97)} = 15.04; \ p=0.001 \right) \) and environmental factor \( \left( F_{(2,97)} = 25.51; \ p=0.001 \right) \). Post hoc comparison using tukey test indicate that the low internalized stigma category differ significantly in physical QOL, psychological QOL, environment factor than moderate internalised stigma category. However, no significant difference was found between these categories in social relationship domain of QOL. Further both, low and moderate internalized stigma categories differ significantly in all domains of QOL than high internalised stigma category. The probable reason behind this is those individuals who are ashamed of their infection or blaming oneself for the illness denies their usual supports (i.e., family and friends) that are available to them, according to social comparison theory (Davison, Pennebaker, & Dickerson, 2000). They also need to maintain secrecy about the illness by hiding their seropositive status to others (Chesney & Smith, 1999; Hays et al., 1993). Hiding ones status and self isolation preclude HIV-positives from both, their support network and its attendant benefits.

The present study had certain limitation such as it was done on small sample of HIV positive individuals attending a hospital setting and therefore does not represent the entire HIV positives community. Another limitation is due to the cross-sectional design of the study causal interpretations of the results cannot be made.
In conclusion, even with its limitation this study has shown that although HIV is highly stigmatized disease, there are individual differences in the level of internalized stigma that HIV-positive people experience related to their illness. Further, internalizing of stigmatized feeling accentuates the problem of stigma which negatively influences the quality of life in HIV-infected men and women. Thus, finding of present study convey an encouraging message to HIV-infected individuals to rise above their feeling of self-hatred which deters them from disclosing his or her HIV status and making them to suffer the consequence of denied support, emotionally, financially, physically and socially that helps to lead a better life. It also cautions researcher and programme planner, highlighting the need for more work in order to determine the factors that either mitigate or heighten the internalised stigma experience by people living with HIV as well as its negative effects. The findings also support the need to focus interventions on altering self stigmatizing attitudes and enhancing coping skills.

REFERENCES


Vol. 9, No. 1, September, 2014


