



## Quality of Life of People Living With HIV/AIDS in The Karnataka, Kerala and Tamil Nadu Aids Prevention Societies

### KEYWORDS

HIV/AIDS, Stigma, Discrimination, People Living with HIV/AIDS, Quality of Life.

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**ABSTRACT** *The Literature could not trace adequate evidences of emotional and family issues of PLHA as a result of Stigma and Discrimination as the Indian studies are focused more on fiscal, vulnerability and behavioural aspects. Hence it is important to understand and establish the effect of Stigma and Discrimination on the Quality of Life of PLHA. This mixed method research study with a sample size of 60, having 20 participants each across states, has used WHOQOL-BREF scale, Barbara Berger's HIV Stigma Scale along with in-depth interviews. The research study understanding the best practices in improving the Quality of Life proposes a 7-step Intervention Model which can be replicated across all Care Providing Societies of NACO.*

### INTRODUCTION

According to World Health Organization (2010), Human Immunodeficiency Virus (HIV) is a retrovirus that impacts immune system functioning and results in increased vulnerability to several other immune systems functioning and results in increased vulnerability to several other infections with the advancement of the illness. Acquired Immuno Deficiency Syndrome (AIDS) is the most advanced and final stage of the illness; the progression to the final stage can be slowed down with the help of ARV treatment.

### HIV/AIDS: STATISTICS AND RECENT TRENDS

HIV/ AIDS has assumed the nature of a global pandemic, taking the toll of approximately 2 million lives and with 2.7 million individuals being newly infected with HIV in 2008 across the globe (UNAIDS/WHO,2009). In India, statistical data estimate 2.27 million people to be living with HIV/AIDS with the prevalence rate being 0.29 per cent (NACO, 2016). On a more positive note, an analysis of statistical data over a period of 7 years from 2002 to 2008 suggests a downward trend in the estimated HIV-adult prevalence and decrease in the number of PLHA; with this trend expecting to continue in the future (NACO, 2009-10). The implementation of sustained intervention programmes with high-risk populations, increased accessibility to VCCTCs, and increased efficiency of community development initiatives and healthcare systems have paved the way for this declining trend.

In the context of HIV/AIDS, stigma has been defined by Herek *et al.* (1998) as "prejudice, discouraging, discrediting, and discrimination directed at people perceived to have AIDS or HIV and at the individuals, groups, and communities with which they were associated" (p.36) HIV/AIDS related stigma received worldwide attention when Mann (1987) emphasized on the three phases of the global pandemic: (a) The epidemic of HIV (b) The epidemic of AIDS, and (c) The epidemic of Stigma, Discrimination and Denial. HIV/AIDS related stigma has been instrumental in influencing rapid transmission of the epidemic and magnifying the negative impact associated with HIV/AIDS (UNAIDS,2005).

### QUALITY OF LIFE (QOL): AN IMPORTANT HEALTH-RELATED OUTCOME

Quality of Life (QOL) is an important indicator of the degree of satisfaction in various domains such as physical health, psychological well-being, social relationships and environment (Skevington. Lofty & O'Connell, 2004). In recent years, QOL, as an outcome variable, is being increasingly documented in several studies related to HIV/AIDS (Frain, Berven, Chan & Tschopp. 2008; Guertsen, 2005; Hudson, Kirksey & Holzemer. 2004) as a result of improvements in medication and treatment facilities, especially ART.

HIV stigma and discrimination adversely affect every aspect of life for People Living with HIV and their families. In many settings, an HIV diagnosis still can be as devastating as the illness itself, leading to job loss, school expulsion, violence, social ostracism, loss of property, and denial of health services and emotional support. People living in fear are less likely to adopt preventive behaviour, come in for testing, disclose their sero-status to others, access care and adhere to treatment (ICRW, 2010).

### SIGNIFICANCE OF THE STUDY

Not much research has been conducted in order to examine how the effect of Stigma and Discrimination on the Quality of Life and the method of use of specific coping strategies such as forgiveness, rumination, and coping in response to Stigma and Discrimination, influence QOL. As stated earlier, very few studies have examined the Quality of Life in the context of chronic illness, especially HIV/AIDS. Even though very few researches have shown that Stigma and Discrimination have major effect on the Quality of Life but the other aspects like Neglect and Unacceptance is common among PLHA and is often linked to the Quality of Life. Based on the theoretical frame described earlier, it is postulated that Stigma and Discrimination, forgiveness, rumination, and religious coping may interact with each other and all of them may predict different domains of QOL. The conceptual framework of research study has been schematically represented in

Figure 1.1

**Figure 1.1 Stigma and Discrimination, forgiveness, family support and healthcare as predictors of the four domains of Quality of Life (QOL).**

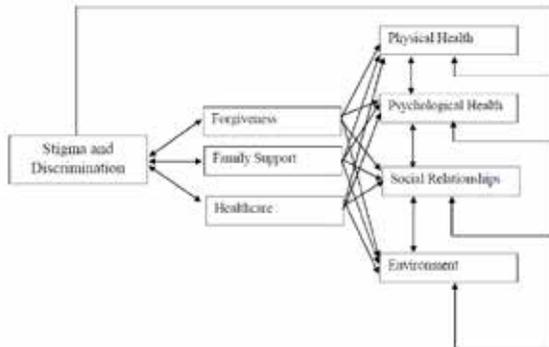


Figure 1.1 is generated as a figure by the author to establish the effects and relation between Stigma, Discrimination and the Quality of Life of PLHA. The figure clearly states that Stigma and Discrimination is reduced among the PLHA by the method of Forgiveness towards the spouses, provision of Family support to the PLHA from their respective families and easier access to Healthcare by all the PLHA in Care Giving Societies of NACO. All these three factors in turn, result in improving the Physical, Psychological, Social and Environmental Health of the PLHA which results in the overall improvement the Quality of Life of PLHA.

#### RESEARCH GAPS

The review of literature shows that number of researches conducted on HIV/AIDS has always been given minimal importance on Stigma, Discrimination and the Quality of Life of PLHA. High frequency of behavioural risk factors, together with unawareness, and very little health infrastructure, thus creating an impending risk for the rapid spread of HIV/AIDS (Singh, Harminder et. al,2010) which clearly states the importance to the access to healthcare system as a deficient factor towards Quality of Life. A statistically significant increase of psychosocial problem in orphans was observed during the follow-up (Bant D, Mahesh.V, Dattatreya and Geetha V Bathija, 2013). Such studies state the lack of studies done with a focus on the effect of Stigma and Discrimination. Severe forms of stigma and depression resulting for poor QOL (Charles et al, 2012) emphasizes the importance of Stigma as a method of analysing the Quality of Life.

#### RESEARCH METHODOLOGY

**Aim of the Study:** The study aims to study the Quality of Life of People living with HIV/AIDS in Kerala, Karnataka and Tamil Nadu AIDS Prevention Societies.

#### Objectives:

To understand the Socio-Demographic details of the participants.

To find the Stigma and Discrimination faced by PLHA.

To understand the Quality of Life of PLHA.

To find and understand the relation between Stigma, Discrimination and the Quality of life of PLHA.

To propose an intervention model to improve the Quality of Life of PLHA.

#### Hypothesis:

H1: There is a strong effect of the Stigma and Discrimination on the Quality of Life of the PLHA.

**Methodology:** A mixed method (qualitative and quantitative) study design has been undertaken to describe the state of affairs as they presently exist (Quality of Life of individuals receiving the interventions). An in-depth study was done with the clients (N=60, with 20 each across each state) at Govt. Medical Hospital, Alappuzha; St. Johns Hospital, Bengaluru and Kilpauk Medical College and Hospital, Chennai wherein subjects completed the questionnaire in natural setting and were also interviewed through Purposive Sampling.

**Process of data collection:** Two separate standardized questionnaires on Quality of Life and Stigma and Discrimination were used by the researcher for conducting this research at the respective State AIDS Prevention Societies at Kerala, Karnataka and Tamil Nadu for analyzing the Quality of Life of the PLHA at the respective State AIDS Prevention Societies.

#### Tools of data collection:

**WHOQOL-BREF Scale (1991):** To assess the overall Quality of Life of People Living with HIV/AIDS details a questionnaire comprising of 26 questions was administered which constituted of details about their physical, psychological, social and environmental well-being.

**Barbara Berger's, Berger Scale (1996):** To understand the level and effect of Stigma and Discrimination on the People Living with HIV/AIDS, this questionnaire was used which details a questionnaire comprising of 40 questions. It helped to understand whether Stigma and Discrimination had an effect on the Quality of Life of the participants and the relation it had with the Quality of Life as a variable.

#### Limitations:

The emotional state and the stress level of HIV/AIDS patients while filling or responding to the questionnaire.

Confusion in the participants (Understanding the level and type of Stigma faced).

Time and the Non-participation of the participants/centers (Only 20 patients were interviewed per state.)

#### RESULTS AND DISCUSSIONS

40 percent of the participants fall in the age category of 41 – 50 years. 56.67 percent of the participants are married. 41.66 percent of the participants are having Secondary level of Education. 48.33 percent of the participants have reported to have Good Health Status. 66.67 percent of the participants are having moderate levels of Stigma where participants have reported statements as '*HIV is a sin; Area of work; Denial of HIV/AIDS; Blame of Infidelity; Brothers not telling sisters knowing the health status; Divorce; Broken Marriages ...*'. 48.33 percent of the participants have low levels of Discrimination. *My employer threw me out of the Job; Bad Omen to the Organization; Looking for flaws in the character; I am discriminated for no fault for mine; Born orphan, I don't want to die orphan; Fear of disclosure; Lack of trust; Separate food, gifts and clothes ...*'. 78.33 percent of the participants have moderate level of Quality of Life. There is a negative and significant relation between QOL and Stigma with a p-value= -.510. There is a negative and significant relation between QOL and Discrimination with a p-value= -.506. There is

no significant difference between the three states in terms of QOL with a  $p$ -value = .221. Kerala reported highest mean value of 83.13 where Anonymous Groups stands as the best practice to QOL with participants reporting that Anonymous Groups have helped to have a *Positive Outlook*, a feeling that *I am not the only one*, gets an *Emotional Support* and helped to *Resume job*, while Karnataka stands second with a value of 82.15 where the Counsellor – Counselee relation stood as the best practice where participants reported that Counsellor- Counselee helped them to add *Strength and Meaning to Life*, provided them *Insight*, build *Support and Quality to Life* while in Tamil Nadu which stood the least with 80.43 it was the Doctor-Client Relation which was found as the best practice with participants reporting that it has helped them in *Giving up on Alcohol and Drugs*, gifted them with *Satisfaction in Life* and has enhanced *Family Support*.

### Suggestions:

Counseling sessions on a weekly basis needs to be conducted for the PLHA by the counsellors. For a more gender based role, male and female counsellors should be present in the hospital for better services to the PLHA. Marital counseling can be provided to reduce the social tension in the participants' life in collaboration with the government Family Welfare and Marital Counseling centre located in the respective cities and States. Session should be focusing the problems of Ruminant as well as that behaviour still is prevailing among 2% of the participants. Attending Anonymous groups once every week should be made compulsory to all the PLHA irrespective of their date of admission into the centres. This shall facilitate their coping strategy and enable them to enhance the quality of life. The spouses and children of the PLHA can be included in the Doctor-Client Interactions and also on a regular basis Family Therapy can be conducted for the families of the PLHA. Workshops on life skills and employment skills can be provided to facilitate them and help them find better employment options. Life skills training to the PLHA with the structured Intervention Model will assist them to enhance the Quality of the Life of the PLHA and also of the family and other care givers (relatives, friends and colleagues).

### CONCLUSION

This study would be of a great help as there are very less number of studies conducted in this respective area. The PLHA across the regions have been benefitted by different intervention methods that are used in the respective Care Providing societies. More number of researches has been conducted focusing on Stigma and Unacceptance social hazards while Discrimination and the Intervention methods best practised have always been given minimal importance in the Indian Context. This study helped to understand the interdependency and independency of the different Care Givers and accordingly formulate a plan of intervention including the different stakeholders of the PLHA in the Care Giving Societies of NACO and would definitely make their lifestyle happier, healthier and enjoyable for a better future, thereby increasing the Quality of Life.

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