ABSTRACT

Being diagnosed with a life-threatening illness such as HIV or cancer can be often traumatic. It can also have other devastating impact on a person’s life. Earlier researches on Persons Living with HIV (PLHIV) have found that HIV infection is a medical and existential crisis. PLHIV go through psychological trauma as well as social problems such as depression, stigma, poverty and marginalization in India and elsewhere. In India there has always been report of prejudice, exclusion and stigmatization of PLHIV. As a consequence PLHIV tend to isolate themselves, or go into a hiding. It is already known that both in India and in other parts of the world HIV infection has a wide range of psychological, physical and social consequences which the infected individuals and their families may have to face. Stigmatization worsens this impact. Due to all these it has been found that PLHIV and their families have to cope with a multitude of stressors.

It is also known that when individuals experience tragedies or setbacks in their life, they respond to it in an adaptive way by ascribing positive meaning to their experience that may enable them to restore their psychological functioning or even exceed it. This is known as meaning based coping. It means that when people go through an illness such as cancer or AIDS, that threaten their integrity they are found to forma coping strategy or plan to deal with the consequences of illness’ threat to one’s health and thereby one’s life. Search for meaning and finding positive meanings are important themes around which such adaptations occur. This has already been established in health psychology and positive psychology. The meaning-based psychological growth and wellbeing among PLHIV, however, has not been adequately explored in this country. This sets the background for an exploration of the different ways in which PLHIV ascribe meaning to and make sense of the experience of living with HIV. Therefore the current study was undertaken with the aim of exploring the idiosyncratic meaning-making themes of PLHIV in Kerala and how they perceive their illness and its influence on their psychological wellbeing and cognitive coping.

The current study has adopted a Mixed Method Convergent Parallel Design to explore the meaning that the participants attribute to their experience. The participants comprised of 37 persons for the qualitative strand and 232 persons for the quantitative who were recruited using purposive sampling method. They were between the ages of 18
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and 70 years, who have known their HIV status for at least a year and all residing in Kerala State at the time of the study. Apart from the demographic data sheet and a semi-structured interview schedule, standardized tools such as the Meaning in Life Questionnaire, the Illness Perception Questionnaire-Revised, the Cognitive Emotion Regulation Questionnaire-Short Form and The Psychological Wellbeing Scale were used to collect data.

Analysis of the interviews with the participants identified 12 representations of HIV which were the ways in which HIV is perceived and the life with HIV is lived by the participants. In the analysis of the quantitative data it has been found that majority of the participants find no meaning in their present life. On Illness Perception Questionnaire (IPQ) majority fell under the normal category while a quarter of participants scored high on all domains. It was also found that majority of the participants did not have a sense of control over their illness. An average of 25% of the participants scored high on all the domains of the psychological wellbeing scale. Majority of the participants ruminated about their illness while 28% viewed their illness as catastrophe. The results have also identified a few important association between gender, marriage, counselling with illness perception, coping and psychological wellbeing.

The significance of the current study lies mainly on the fact that there has not been an in-depth exploration of the lived-experiences of PLHIV in India. Some of the learning of this study, such as pre-test counselling is associated with the rumination in PLHIV, can be made use of by the counsellors providing HIV/AIDS counselling to shift from focusing on the dangers of the infection to positive living with HIV diagnosis. The qualitative findings such as ‘HIV as the spoiled identity’ and ‘HIV as isolation’ highlights that stigma is the worst experience in being infected with HIV. Measures could be taken to increase the awareness of HIV so as to reduce stigma even by including discussion on HIV infection as part of the school curriculum in India. The results also indicate to the fact that there is a need for more facilities that would provide psychological care for PLHIV together with ART centers to ensure PLHIV’s psychological wellbeing in this country.

Keywords: HIV, AIDS, meaning-making, illness perception, coping, psychological wellbeing, lived-experience