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## Commentary

### Measurement of quality of life of HIV individuals: Perspectives & future directions

What does quality of life (QOL) mean? What does it denote? What parameters can be used to measure QOL? These must be the most telling and repetitive questions during the last decades. We all want answers to problems we have encountered. From such answers we synthesize new questions and further answers, leading to innovation and change.

With respect to the first question, QOL is a complex and multidimensional concept that is difficult to define and measure<sup>1-3</sup>. Consequently, various conceptual and operational definitions have been used in QOL<sup>4,5</sup>. Kohli *et al*<sup>6</sup> in their article in this issue have collected several definitions. QOL 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. World Health Organisation has defined QOL as 'individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, standards, expectations and concerns<sup>7</sup>.

Among patients, especially those who have chronic, incurable diseases, health-related quality of life (HRQOL) may be the most important outcome to be considered when assessing treatment effectiveness. Because the patient is the best source of information about his or her HRQOL, many practical tools have been developed that rely on patient self-ratings. The HRQOL has increasingly gained importance as an outcome measure in health care<sup>8,9</sup>, especially as regard interventions for patients with various chronic diseases<sup>10</sup>. The human immunodeficiency virus type 1 (HIV) infection induces a wide array of immunological alterations resulting in the progressive development of opportunistic infections and malignancy, which results

in AIDS. The HIV infection is also associated with different psychological and neuropsychiatric disorders. Today, there is no cure against HIV infection. Therapeutic management of patient is concentrated more on delaying the suppression of the immune system and on controlling and preventing opportunistic infections and cancer.

Recent estimates by the joint United Nations Programme on HIV/AIDS and the World Health Organization suggest that of the 34.3 million people currently infected with HIV, 95 per cent live in sub Saharan Africa and the developing countries of Asia and Latin America. With nearly 17,000 infections occurring every day, the estimate for the end of the twentieth century is more than 40 million infected people. Unless a cure is found or life-prolonging therapy can be made more widely available, the majority of people living with HIV or AIDS will continue to suffer with the disease, with serious impact on their quality of life. For this reason, development and implementation of a reliable and valid cross-cultural quality of life measure is necessary that can be used not only to assess the physical and medical needs of HIV/AIDS people, but also their psychological, social, environmental and spiritual areas of life<sup>11</sup>. This is particularly pertinent for use with those living in developing countries where medical care is currently unavailable and social support is at a minimum.

Assessment of QOL in individuals living with HIV/AIDS is becoming crucial to research and evidence-based practice in this area. QOL is currently considered essential for clinical trials in HIV infection, as commonly used end-points (CD4 level, viral load,

opportunistic diseases) are inadequate to catch the complexity of treatment outcomes. The World Health Organization has developed a standardized set of instruments to assess subjective QOL in different medical conditions, including HIV infection. Starace *et al*<sup>12</sup>, have reported evidence for the acceptability, reliability and validity of the Italian version of the WHOQOL-HIV. Recently an analysis of the WHOQOL HIV field test instrument was performed in patients from seven culturally diverse centres (Australia, Brazil, Italy, Thailand, Ukraine and two centres in India: Bangalore and New Delhi)<sup>13</sup>.

Kohli *et al*<sup>6</sup>, described the dimension of QOL among HIV infected patients to study their relationship with socio-demographic characteristics and the stages of disease progression and to examine changes in QOL over time. They modified the medical outcome study (MOS) core instrument to suit the Indian cultural setting and used. Of the 62 questions contained in the core instrument, 20 were selected for inclusion in the modified instrument. The language was modified and response categories were reduced in most of these questions. Some questions were clubbed so that they can be applicable to both sexes. One question resulted from the combination of two so that the instrument does not become very long, whereas another one was split for the clarity of responses. Because some of the activities of daily routine were different in Indian population, the authors had modified some questions with relevant activities.

In addition, different questions were regrouped under different domains according to previous studies<sup>14-16</sup> about the QOL of HIV positive individuals. Besides, opinion of experts in social science research, physicians working in the field of HIV/AIDS, and HIV patients was taken into consideration in order to modify items suitably for Indian cultural setting. The authors considered that domains on food and appetite and sexual activities would be relevant and in consequence they were added to the instrument. Finally, items on stigma and discrimination were also incorporated.

The modified MOS QOL instrument displayed items on QOL related to health among infected persons. It consisted of 29 structured questions in 10 domains: physical health, work and earnings, daily routine, social

activities, cognitive functions feelings and emotions, pain, food and appetite, sleep and sexual life.

The modified MOS QOL instrument used in this study was found to be appropriate and suitable for assessing the quality of life in HIV infected person in India. The scale was reliable with Cronbach alpha value more than 0.70 for all the domains. The validity of the instrument was also supported by the observed relationship between QOL scores and CD4 counts and stages of clinical disease. Besides, the HRQOL scores changed over a period of time as was evident from the follow up observations. The association between the different demographic and clinical parameters and the QOL scores showed that there existed differences between men and women with respect to QOL scores with women having significantly lower scores in many domains than men. These results agree with those obtained in previous studies performed in two centres in India (Bangalore and New Delhi)<sup>13</sup> and with the ones observed by other investigators<sup>17-19</sup>.

In conclusion, although considerable work has been done in this field, little has been done in clinical setting in India for the purposes of quality improvement. The modified medical outcome study (MOS) instrument for QOL assessment in HIV infected individuals proposed by Kohli *et al*<sup>6</sup> undoubtedly provides a new set of opportunities for studying the problem of QOL assessment in HIV individuals in India.

The modified medical outcome study (MOS) instrument<sup>6</sup> is a valid measure of quality of life in the HIV infected population in India and is therefore likely to be useful in future clinical trials in the region. These findings suggest a need to incorporate new methods for improving the knowledge of chronic pathologies. This work will eventually have an impact in clinical research in India and will help medical community in further investigations on this topic.

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