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EDITORIAL COMMENTARY

Health-Related Quality-of-Life Tools for Indian Infants and Toddlers

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Health-related quality of life (HRQoL) refers to patients' overall functioning and well-being in multiple domains like physical, psychological, and social domain. The main aim of treatment of any medical condition is not just to cure or control the disease but to improve the quality of life of an individual. The clinical indicators alone do not reveal the full impact of disease/intervention on the psychosocial well-being of a patient. Hence, HRQoL assessment has become a part of treatment of many conditions [1].

HRQoL assessment is difficult in younger children as they are not able to give their own opinion. The instruments to assess young children (< 3 y) are very few. None of the HRQoL instruments for infants are available in Indian languages [2]. Quality of life of the infant (QUALIN) is a recently developed parent-/caregiver-administered generic scale (not disease-specific) that is designed to assess an infant's HRQoL between the ages of 3-mo and 3-y. It was developed in France based on some spontaneous criteria that are used by parents or caregivers (pediatricians or nurses) when they think about the quality of life of a baby [3]. It has been translated, validated and applied widely in English, Italian, Spanish, Russian, and Armenian population with satisfactory psychometric properties [2].

In this issue of the Journal, Devi et al. have presented their study on the translation, adaptation, and validation of the Hindi version of QUALIN (Hi-QUALIN) [2]. They have used appropriate statistical methods to analyze, and enrolled adequate number of children. The authors concluded that Hi-QUALIN is a valid and reliable instrument with acceptable psychometric properties for HRQoL assessment in Indian children.

However, the Hi-QUALIN scale does not include any item related to participation or restriction of activity. Hence, it may not help in evaluating children with motor disabilities like cerebral palsy or strokes [4]. HRQoL is strictly a personal attribute and its dimensions change from person to person, from context to context and from culture to culture. Contextual factors like parent's coping of their child condition, and socioeconomic and cultural background may also influence the way relatives report the HRQoL of their child with disease/disability. The items of any HRQoL tool should consider the social environment of the patients or population. This is particularly significant for India as there is so much diversity in social, cultural, ethnic, economic, and linguistic aspects among various states. The customs, religious beliefs, health practices, literacy, and health awareness vary from region to region. Thus, the tools developed for Western populations or elsewhere cannot be utilized to study the HRQoL by mere translation into any of the Indian languages. This was clearly shown with respect to family environment subdomain having a high ceiling effect irrespective of health status in the Devi et al. study. Relevant changes in the content and construct of the tool are necessary according to the demography to assess the subjective perception [5]. Other limitations of this study include the lack of concurrent validity assessment due to nonavailability of validated instruments in Indian languages and its external validity. Hence, there is need to develop indigenous or culture-appropriate tools in different Indian languages for proper assessment of HRQoL in young children.

Declarations

Conflict of Interest None.

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