

Review Article

Measuring health-related quality of life of intellectually disabled children: a narrative review

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ABSTRACT

To identify currently available measures of Health-related quality of life (HRQOL) for intellectually disabled children and to describe their content. A comprehensive retrieval of the English literature from 2001 to 2021 was done in the PubMed and Google Scholar. The terms 'Intellectual disability', 'Differently abled', 'Special children', 'Differently challenged', 'Mental retardation', 'Health-related quality of life', 'Quality of life', 'Burden of intellectual disability' and 'India' were used to identify measures of HRQOL for children's with intellectual disability. Several tools were identified to measure HRQOL for children with intellectual disability. Many have parent proxy as well as self-report form with good validity and reliability. Though, they were often developed with minimal involvement from families, focus on functioning rather than wellbeing, and have items that sometimes may cause emotional upset. When children with different health problems are compared, the degree of their particular health condition should be measured. Furthermore, overlap of items seems not to be a problem when the HRQOL of children with intellectual disability is studied. Hence, HRQOL assessments are useful for collecting information beyond the clinical symptoms of a health problem thus improving quality of care.

Keywords: Quality of life, Health-related quality of life, Intellectual disability, Children, Literature review, Questionnaires

INTRODUCTION

Health-related quality of life (HRQOL) is a multidimensional model that includes physical, mental, emotional, and social functioning domains associated with an illness or treatment. The Centres for Disease Control and Prevention (CDC) defines HRQOL as an individual's perceived physical and mental health over time.¹ Health is fundamental to all human beings. WHO has defined health as "A state of complete physical, mental, and social wellbeing not merely the absence of disease or infirmity."² HRQOL is a subjective measure of one's health status, mostly based on the individual, and also focuses more on the impact of a perceived health state on the ability to live a fulfilling life.³ From a health (or disease) perspective, the term 'quality of life' refers to

patients' social, emotional, and physical well-being following treatment.⁴ HRQOL is a multidimensional concept which evaluates an individual's subjective perception about his/her effect of disease and treatment on physical, psychological, and social functioning domain. In medical practice, HRQOL instruments prioritize health problems as a support to take the clinical decision and to monitor responses to treatment.^{6,7} Hence this paper narrates the importance of measuring HRQOL of ID children with available literature in the scientific world.

METHODS

The necessary information regarding HRQOL and its importance among ID children were obtained through a review of literature in PubMed (including Medline) using

terms 'Quality of life', 'Health related quality of life', 'Disabled children', 'Intellectually disability', 'Mental retardation', 'Special children', 'Differently abled', 'Differently challenged' and 'Global and India burden of disability' were obtained. The unpublished data on HRQOL were also collected included. The reference period was from the year 2000 to 2020. Based on gathered references, the studies included in our paper was (1) studies that emphasis on ID children; (2) paper that was written in the English language; (3) paper that focuses on HRQOL measurements among ID children. The final preferred article was recently published in the scientific journal, the higher order of study designs (systematic reviews), and s multilateral agencies' publications. Analysis of the literature was synthesized into a narrative review report, highlighting our key findings by the following themes: Burden of ID, Importance of measuring HRQOL of ID children, tools to measure HRQOL.

THE BURDEN OF INTELLECTUALLY DISABILITY

WHO, claims that around 15% of population is living with a disability, and 110 million (2.2%) people have very significant difficulties in functioning. It is found that one in twenty children less than 15 years of age live with a moderate to severe form of disability.⁸ According to the rights of persons with Disabilities Act 2016, there are seven categories of disability. One of the categories is ID, formerly known as mental retardation (MR). The ID is a condition categorised by significant limitations, in intellectual functioning such as reasoning, learning, problem-solving, and adaptive behaviour, which includes a range of everyday activities. The ID comprises two broad categories: specific learning disabilities (SLD) and autism spectrum disorder (ASD).⁷

National Sample Survey Organization (NSSO), a wing of the Ministry of Statistics and Programme Implementation, Government of India on their 76th round during July 2018 to December 2018, found the prevalence of disability in India to be 2.2%, with 2.3% in the rural area and 2% in an urban area.⁹

IMPORTANCE OF MEASURING HRQOL

HRQOL is a multidimensional concept covering social, emotional, and physical functioning domain or wellbeing related to the patient's health condition. Measurement of HRQOL in individual with chronic health conditions can provide data on inpatient management and medical intervention to improve their health, resulting in increased survival rates and life expectancy.¹⁰ HRQOL can be measured by both self-report and proxy report tools.¹¹

Mary Law et al in 2017 did a longitudinal study to measure the HRQOL among locomotor disabled individual using parent proxy form of child Health questionnaire (CHQ) among 427 individuals in Canada.¹² They found significantly lower scores in the physical domain of health-

related quality-of-life than the psychosocial domain for children with physical disabilities.

Surender et al did a cross-sectional study in India to assess HRQOL among 100 children three to ten years of age with Cerebral palsy (CP). They found significantly impaired HRQOL in CP children. The degree of disability is associated with physical independence, mobility, clinical burden, and social integration dimensions.¹³

Shilpee Chaudhary et al in 2019 conducted a community-based cross-sectional study in the rural area of district Dehradun, India, to assess life quality among disabled persons. Two thousand six hundred people between 5-59 years of age were enrolled for the study. They concluded HRQOL domains had significant association with socio demographic characteristics.¹⁴

TOOLS TO MEASURE HRQOL

HRQOL is usually measured with 'instruments', which refers to patient questionnaires. HRQOL instruments are available as generic or disease-specific.¹⁵ The choice of HRQOL tool selection depends upon on researcher field of interest.

This HRQOL questionnaire is available as self-reporting forms and as parent reporting forms. In children, HRQOL includes the child's illness and family functioning impact.¹⁶ Self-reporting is the best standard of HRQOL measurements, but it is harder to get reliable information from children with a severe neurodevelopmental disorder.¹³

*Paediatric quality of life inventory 4.0 generic core scales (PedsQL)*¹⁷

PedsQL was developed by James Varni widely used to measure HRQOL for children and adolescents from 2-to-18 years of age. It consists of 23 items, namely Physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items) domain. PedsQL can be administered as a self-report form and parent proxy form.

*Child health questionnaire (CHQ)*¹⁸

The Child Health Questionnaire™ (CHQ) was developed in the US by Landgraf JM; Ware JE and widely used for measuring HRQOL for 5-18 years of age children. It consists of 11 domains with 87 items in Children form (CF87) and 98, 50, 28 items in CHQ- Parent form 50(CHQ-PF50), Parent form 28 (PF28) respectively.

*Child health and illness profile (CHIP)*¹⁹

The Child health and illness profile (CHIP) was developed in the US by Riley A; Starfield Band primarily used to access the health of children (Child Edition-CE) and adolescents (Adolescent edition-AE) ages 6 through 17

years. CHIP-AE has 183 items across four domains, CHIP-CE/CRF has 45 items across five domains, and CHIP-CE/PRF 76 items across five domains.

WHO Quality of life instruments (WHOQOL-BREF)²⁰

The WHOQOL-BREF instrument was developed by WHO, which consists of 26 items across four domains, namely physical (7 items), psychological (6 items), social relationship (3 items), and environment (8 items).

KIDSSCREEN Quality of life inventory²¹

KIDSCREEN 96, developed by Abel T et al assesses children's and adolescent subjective health and well-being. They were developed for all children from 8-18 years of age.

KIDSCREEN 52 version has 52 items across ten dimensions; KIDSCREEN 27 has 27 items across five dimensions, KIDSCREEN 10 with ten items.

KINDL-R²²

The KINDL-R (Revidierter KINDer Lebensqualitätsfragebogen) 97 developed by U Ravens-Sieberer, M Bullinger for measuring HRQOL from 4-16 years of age, it consists of a self-report form and parent report form with 24 items across six domains for 8-16 years of age and 12 items across four dimensions for 4-7 years of age.

The Netherlands organization for applied scientific research academic medical centre child QOL questionnaire²³

The Netherlands organization for applied scientific research academic medical center (TNO/AZL) the Netherlands developed child QOL Questionnaire (TACQOL) for 8-15 years of age with 56 items across seven dimensions.

The youth quality of life instruments-research version (YQOL-R)²⁴

The youth quality of life instruments- research version (YQOL-R) developed by Patrick DL et al was used to measure HRQOL for 12-18 years. It consists of 41 perceptual items scale and a 16-item short-form available, the YQOL-SF, developed with Rasch methodology.

Infant Toddler quality of life questionnaire (ITQOL)²⁵

Infant Toddler quality of life questionnaire (ITQOL) questionnaire was developed for two months to five years of age. It is a parent proxy form consisting of 43 items across twelve domains: physical functioning, growth, and development, bodily pain, general temperament /moods, general behaviour, getting along, general health, parental-emotional parental-time, family activities, family cohesion, change in health.

Warwick child health morbidity profile (WCHMP)²⁶

Warwick child health morbidity profile was developed in the UK by Spencer measuring HRQOL of children between 0-5 years of age.

It is a parent proxy form with 16 items across eight domains: general health status, acute minor illness status, behavioural status, accident status, acute significant illness status, immunization status, chronic illness status, functional health status, and health-related quality of life.

Behavioural, affective and somatic experience scale (BASES)²⁷

The behavioural, affective, and somatic experience scale (BASES) a disease-specific tool for measuring HRQOL in bone marrow transplant children from less than one year to twenty years of age. It is available as a parent, nurse, and self-report form. It has 38 items across six domains, somatic distress, compliance, mood/behaviour, interactions, activity, and miscellaneous items.

The paediatric oncology quality of life scale (POQOLS)²⁸

The paediatric oncology quality of life scale (POQOLS) was developed in the USA by Goodwin. It is disease-specific tool for measuring HRQOL among cancer children less than eighteen years of age. It consists of 21 items across three domains, namely physical function and role restriction, emotional distress, and reaction to current medical treatment.

Quality of life for children with otitis media (OM-6)²⁹

Quality of life for children with otitis media (OM-6) is a disease-specific tool for otitis media children between six to twelve years of age. It has six items across six domains, namely items. Physical suffering, hearing loss, speech impairment, emotional distress, activity limitations, and caregiver concerns

Haemophilia quality of life questionnaire (Haemo-QoL)³⁰

Haemophilia quality of life questionnaire (Haemo-QoL) was developed by a multinational group of experts that measures HRQOL among haemophilia patients with both parent and self-report form. It has short and long version with 21 to 77 and 8 items across ten domains: physical health, feeling, attitude, family, friends, other persons, sport and school, coping, treatment, and future.

Cystic fibrosis questionnaire revised³¹

Cystic fibrosis questionnaire revised form developed in Florida by Dr. Alexander Quittner for measuring HRQOL among cystic fibrosis patients from three to fifteen years of age. It consists of both self-report and parent proxy forms. It is a three items scale that includes nine quality of life

domains, namely physical, role/school, vitality, emotion, social, body image, eating, treatment burden, and health perceptions.

CONCLUSION

The field of HRQOL is growing as evidenced by a variety of definitions and the number of upcoming measures. Selection of a HRQOL measure for clinical or research commitments is also dependent on one's purpose and one's definition of HRQOL and the domains of interest to be studied.

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