

Erika Ikeda – Quality of life and self-report in children and adolescents with cognitive disability.

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The purpose of this research was to initiate the development of a tool that could be used by children and adolescents with autism spectrum disorders (ASDs) or mild intellectual disability (MID) to communicate perspectives of their quality of life (QOL). This research gathered direct verbal responses and opinions from parents and children and adolescents with ASDs or MID to assess the content validity of QOL instrument, Pediatric Quality of Life InventoryTM (PedsQL) Child Self-Report. The PedsQL questionnaire is designed to measure QOL in children and adolescents based on multidimensional domains of physical, emotional, social and school functioning.

This research was qualitative descriptive and consisted of Phase one and two. By using sample of convenience and purposive sampling techniques, participants were recruited from a special school, a school with a special unit in Auckland region and via two private service providers, the Centre for Autism and Related Disorders and the Wilson Home Trust in each phase. Focus groups and individual interviews in Phase one and the interviews in Phase two were employed to obtain the participants' perspectives and feedback on the appropriateness of the PedsQL questionnaire. The questionnaire was presented in both phases, and completed by the children and adolescents in Phase two. Thematic and content analyses were conducted in both phases to discover key themes and categories.

The findings showed that the PedsQL questionnaire was inappropriate for children and adolescents with ASDs or MID in terms of: (1) a number of missing and irrelevant questions on social domain, (2) use of abstract concepts and words, and (3) monotonous formatting, response scales and presentation style. Cognitive and language ability and disease-specific symptoms such as impaired social relationships strongly influenced the comprehension and appraisal of the questionnaire. The modification of the PedsQL questionnaire was undertaken after Phase one including use of concrete wording, visuals, facial expressions and one-by-one presentation style, which assisted the children's and adolescents' understanding of and engagement with the questionnaire in Phase two. Thus, the development of the PedsQL questionnaire for children and adolescents with ASDs or MID may enhance the accuracy of their self-rating and obtain their unique perception of QOL. Based on this research, future research will explore further modification of the PedsQL questionnaire for use in children and adolescents with ASDs or MID as well as the use of different modes of administration such as qualitative interviews and electronic devices.