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An Exploratory Study of Self-reported Quality of Life in Children with Autism Spectrum Disorder and Intellectual Disability

Erika Ikeda · Chris Krägeloh · Tineke Water · Erica A. Hinckson

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Abstract We examined the content validity of the Pediatric Quality of Life Inventory™ Young Child Self-report (PedsQL™-YC) in children with autism spectrum disorder (ASD) and intellectual disability and made recommendations for the development of a quality of life (QOL) measure. Ten children, 14 parents, and three teachers were recruited for focus groups and interviews. Focus groups and interviews were conducted to obtain their perceptions about the appropriateness of the PedsQL™-YC (Phase 1). Based on the results from Phase 1, recommendations for a QOL measure for children with ASD and intellectual disability were made (Phase 2). After piloting a QOL measure by children and subsequent interviews, further refinement was undertaken (Phase 3). Data from Phases 1 and 3 were analysed using thematic and content analyses. Findings suggest that a QOL measure for children with ASD and intellectual disability should be related specifically to the children's daily life and contexts. Due to the specific cognitive and behavioural characteristics of this population, the wording, response options and presentation style of the existing PedsQL™-YC would need refinement. Questions about social interactions with friends appeared less relevant to children with ASD. These recommendations address the wording and formatting issues needed for a QOL measure for use in children with ASD and intellectual disability identified through qualitative research methods. Further research is needed to include additional or modified questions in the social domain.

E. Ikeda (✉) · T. Water · E. A. Hinckson
Faculty of Health and Environmental Sciences, National Institute for Public Health and Mental Health Research, Centre for Child Health Research, Auckland University of Technology, Private Bag 92006, Auckland, New Zealand
e-mail: erika.ikeda@aut.ac.nz

C. Krägeloh
Faculty of Health and Environmental Sciences, School of Public Health and Psychosocial Studies, Department of Psychology, Auckland University of Technology, Private Bag 92006, Auckland, New Zealand

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1 Introduction

In the last few decades, the prevalence of autism spectrum disorder (ASD) has increased worldwide, and one very recent estimate places the global prevalence rate of ASD at one child out of 160 (Elsabbagh et al. 2012). ASD includes autistic disorder, Asperger disorder and pervasive developmental disorder-not otherwise specified (American Psychiatric Association 2013). The core defining attributes of ASD are impaired social interactions, impaired communication, repetitive behaviours, and restricted interest (American Psychiatric Association 2013). ASD is also associated with impaired cognitive abilities and high rates of various types of child psychiatric comorbidities, such as anxiety disorder and attention deficit hyperactivity disorder (ADHD) (Elsabbagh et al. 2012; Farley et al. 2009; Simonoff et al. 2008). Differentiation between ASD and intellectual disability is blurred because of the attribute of diagnostic overlap between psychiatric symptoms and cognitive impairment (Simonoff et al. 2008). According to the Centers for Disease Control and Prevention, 31 % of children with ASD aged eight years were diagnosed as intellectual disability (IQ<70) (Centers for Disease Control and Prevention 2014). Both ASD and intellectual disability significantly impact on personal development as well as social, psychological, and physical well-being in children, such as school activities, education, and peer relationships (Simonoff et al. 2008; McIntyre et al. 2004; Schalock 2004; Ministry of Health 2011).

The importance of quality of life is widely accepted in many areas such as medicine, economics and social sciences (Cummins 2005; WHOQOL Group 1995). Quality of life can be defined as “individuals’ perception of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (p.1405) (WHOQOL Group 1995). Health-related quality of life is more specific to health and medical contexts (Drotar 2004; Eiser and Morse 2001). Health-related quality of life has received great attention as an outcome measure in the evaluation of treatment efficacy among paediatric populations, and is viewed as a gold standard against which other health outcomes need to be assessed (Eiser and Morse 2001; Coghill et al. 2009; Upton et al. 2008; Cummins 2005).

A number of generic quality of life (QOL) and health-related quality of life (HRQOL) instruments including self- and proxy-report versions have been used in children with ASD, such as the Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Core Scales (Kuhlthau et al. 2010; Limbers et al. 2009; Sheldrick et al. 2012; Shipman et al. 2011; Varni et al. 2012) and the World Health Organization Quality of Life Instrument, Abbreviated Version (WHOQOL-BREF) (Jennes-Coussens et al. 2006; Kamp-Becker et al. 2010). The PedsQL™ is the most commonly used HRQOL instrument in children with ASD, and would be favourable to this population due to a clear structure, the length of the measure, and availability of various versions for different age groups (Ikeda et al. 2014). The reliability and validity of the PedsQL™ self-reports have been established in children with and without chronic and mental health conditions (Coghill et al. 2009; Danckaerts et al. 2010; Dey et al. 2012; Varni et al. 2003; Limbers et al. 2011). The PedsQL™ self-reports in children and adolescents with high-functioning autism have demonstrated high internal consistency reliability, low to moderate correlations with parent proxy-reports, moderate to high construct validity, and moderate concurrent validity (Sheldrick et al. 2012; Shipman et al. 2011; Potvin et al. 2013).

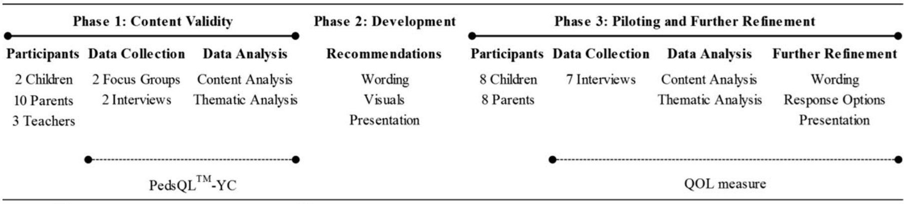
It is also crucial to consider the issue of using self- as opposed to proxy-reports. As (health-related) quality of life is essentially subjective and reflects an individual's perception of their life, self-reports are preferred over proxy-reports to obtain the child's perspective (Coghill et al. 2009; Ravens-Sieberer et al. 2006). Some researchers have questioned the extent to which children with mental health problems are able to provide reliable self-reports on their (health-related) quality of life (Coghill et al. 2009; Varni et al. 2005). Coghill et al. (2009) found that children with mental health problems have more difficulty completing self-reports because of slower cognitive development in language, memory, and recall, as well as disorder-specific impairments. For example, children with ASD may have difficulties reporting on peer relationships due to their impaired social competence (Danckaerts et al. 2010). In order to address the need for an ASD-specific QOL/HRQOL measure that may be applicable to a broader functioning range of children with ASD, the development of an ASD-specific module or version is important because it will likely enhance responsiveness to treatment and interventions (Coghill et al. 2009; Ravens-Sieberer et al. 2006). In this regard, the necessary first step is to explore the content appropriateness of a generic QOL/HRQOL self-report inventory for use in a broader functioning range of children with ASD including intellectual disability. The present study reports on an examination of the content validity of the PedsQL™ Young Child Self-report (PedsQL™-YC) for use in children with ASD and intellectual disability as an initial phase in order to guide further development of a self-reported QOL measure for children with ASD.

2 Methods

The present qualitative descriptive study involved three phases: content validity of the PedsQL™-YC in children with ASD and intellectual disability (Phase 1); recommendations for a self-reported QOL measure for children with ASD and intellectual disability (Phase 2); and piloting and further refinement of a QOL measure in a wider functioning range of children with ASD (Phase 3) (see Fig. 1). During Phase 1, focus groups and interviews with children, parents, and special school teachers were conducted to obtain their perceptions and opinions about the PedsQL™-YC. Based on the results from Phase 1, Phase 2 included recommendations for the wording, format, and layout of a self-reported QOL measure to be appropriate for children with ASD and intellectual disability. Phase 3 involved further development of an ASD-specific QOL measure based on qualitative analyses.

2.1 Sampling and Recruitment

Using convenience and purposive sampling, ten children with ASD and intellectual disability (approximate IQ>50), 14 parents, and three teachers of a special school were recruited. The characteristics of the participants in Phases 1 and 3 are shown in Table 1.



PedsQL™-YC Paediatric Quality of Life Inventory™ Young Child Self-report

Fig. 1 Qualitative descriptive research design and development of a QOL measure

Phase 1 involved two focus groups with two children (1 boy, 1 girl, age 13–14 years), eight parents (1 male, 7 females) and three teachers (1 male, 2 females), and two individual interviews with two parents (all females). Phase 3 consisted of seven individual interviews with eight children (all boys) and parents (1 male, 7 females). Four parents from Phase 1 also participated in Phase 3. Types of children's disability included ASD, ADHD and global developmental delay. The diagnosis and severity of ASD and intellectual disability were reported by parents or special school teachers as assessed by specialists, such as paediatricians, psychiatrists, or clinical psychologists.

Participants were recruited through a special school, a mainstream school with a special needs unit, and via two service providers for children with ASD within the Auckland region of New Zealand. Interested parents were sent information sheets that outlined the purpose and procedure of the present study. All parents provided signed informed consent to participate, and children provided written informed assent when possible. In both phases, recruitment finished when content saturation had been reached. This study was approved by the authors' institutional ethics committee.

2.2 Health-related Quality of Life Measure

In Phase 1, the Paediatric Quality of Life Inventory™ 4.0 Generic Core Scales Child Self-report for *young child* aged 5–7 years (PedsQL™-YC) was utilised. Some researchers and therapists with experience in the ASD field have deemed the PedsQL™-YC self-report version to be the most appropriate and comprehensible, particularly for children with lower cognitive ability (Riley 2004; Cremeens et al. 2006). The PedsQL™-YC comprises 23 items assessing four distinct dimensions: physical functioning (eight items), emotional functioning (five items), social functioning (five items), and school functioning (five items) (Varni et al. 2001). The PedsQL™-YC contains a three-point rating scale: "not at all", "sometimes", and "a lot" (Varni et al. 2001). The PedsQL™-YC Total Scale Score demonstrated high internal consistency (Cronbach's alpha=0.86–0.87) and construct validity with medium to large effect sizes (0.46–0.75) in comparisons between healthy and chronic health condition groups (Varni et al. 2007).

2.3 Focus Groups (Phase 1) and Interviews (Phases 1 and 3)

The combination of focus groups and individual interviews were used. Focus groups were conducted to gain comprehensive data based on shared views (Morgan 1996).

Table 1 Descriptive characteristics of participants in Phase 1 and 3

Participants (n=27)	Gender	Age	Disability[b]	Phase 1			Phase 3
				Focus group 1	Focus group 2	Individual interview (2)	Individual interview (7)
Family							
1	F	50	–	◎			
	M	14	ADHD	◎			
2	F	47	–	◎			
	F	13	GDD, Epilepsy	◎			
3	M	42	–		◎		◎^{1}
	F	42	–		◎		◎^{1}
	M	6	ASD				◎^{1}
4	F	44	–				◎^{2}
	M	7	ASD, GDD, ADD, Epilepsy, Syringomyelia				◎^{2}
5	F	54	–			◎^{1}	◎^{3}
	M	16	ASD				◎^{3}
6[a]	F	49	–			◎^{2}	◎^{4}
	M	10	ASD, ADHD				◎^{4}
	M	10	ASD, ADHD				◎^{4}
7	F	49	–				◎^{5}
	M	14	ASD, Chromosonal Disorder				◎^{5}
8	F	38	–				◎^{6}
	M	6	ASD, ADHD				◎^{6}
9	F	48	–				◎^{7}
	M	15	ASD, ADHD				◎^{7}
Parent							
1	F	51	–	◎			
2	F	51	–	◎			
3	F	45	–		◎		
4	F	46	–		◎		
Teacher							
1	M	29	–	◎			
2	F	53	–	◎			
3	F	47	–	◎			

M male, *ADHD* attention deficit hyperactivity disorder, *GDD* global developmental delay, *ASD* autism spectrum disorder, *ADD* attention deficit disorder

[a] Twins

[b] ASD is the primary diagnosis, and the other diagnoses are comorbidities

Individual interviews were used to attain more specific and detailed opinions and feedback (Morgan 1996). Several guidelines were followed to decrease burden on participants. Venues were selected to be easily accessible for participants to feel comfortable to speak about their perceptions and opinions. A classroom at a special school, a meeting room at the authors' university, or individual interviews at the participants' home were organised. Each session began with informal conversation and *ice-breaking* activities to create a relaxing environment (p. 502) (Powell and Single 1996), followed by an outline of the procedure of the focus groups or individual interviews.

Focus groups and individual interviews were semi-structured and between 30 and 60 min in duration. Two researchers were present: one facilitator or interviewer, and one note taker to record behaviour, body language, and any noteworthy behaviour. Specific open-ended questions were asked to guide the discussion and interview, such as "*What did you think about this measure?*" and "*Which questions are likely to be unclear or confusing to the children? Why?*". The focus groups and interviews were audio-taped and transcribed by the first author, and each transcription and any notes were checked by the other researcher who was present in the focus groups/interviews.

2.4 Piloting of a Self-reported QOL Measure (Phase 3)

During Phase 2, a self-reported QOL measure for children with ASD and intellectual disability was developed based on the results from Phase 1, such as recommendations for item wording and the format and layout of a QOL measure. In Phase 3, a paper-and-pencil version of a QOL measure was completed by children with ASD or interview-administered in situations where a child was unable to read or write. If a child had difficulty interpreting a question, the researcher and the parent assisted the child by rewording the question or giving additional explanation. All conversations and further explanation that had been provided by the researchers and parents were recorded and analysed to determine further refinement of the measure.

2.5 Data Analysis

Content analysis was conducted to analyse the manifested and latent content of data reflectively and interactively, and yield a straight descriptive summary of the patterns of data (Neergaard et al. 2009; Sandelowski 2000). In order to move beyond description and produce an in-depth conceptual description and understanding the meaning of data, thematic analysis was employed (Neergaard et al. 2009; Sandelowski 2000). According to van Manen (1990), a "theme is the process of insightful invention, discovery or disclosure" (p. 88) of the data through interpretation and is not simply conceptual formulations or categorical accounts. Key themes that emerged through thematic analysis from Phases 1 and 3 embodied the meaning and interpretation of the data. The themes were associated with categories that were identified through content analysis in Phases 1 and 3, but were broader and deeper than the categories. Consequently, the themes from Phases 1 and 3 were demonstrated together as principles of the development of QOL/HRQOL self-reports for use in children with ASD and intellectual disability. The categories in Phases 1 and 3 were presented separately as a description of the content validity of the PedsQL™-YC and a QOL measure for use in children with ASD and intellectual disability.

2.5.1 Thematic Analysis

Thematic analysis was conducted for the data from focus groups and interviews in Phases 1 and 3 based on the selective or highlighting approach (van Manen 1990). The statement(s) or phrase(s) in transcripts that appeared specifically important to disclose perceptions of children with ASD and intellectual disability were highlighted. Similar statement(s) and phrase(s) were grouped together, and then subthemes and themes emerged through interpreting and seeing the meaning. The last process was collaboratively conducted by two of the authors, which included examination, articulation, re-interpretation, omission, addition, or reformulation of the themes (p. 100) (van Manen 1990). The collaborative analysis allowed the integrity of the findings to be scrutinised and improved research rigour (van Manen 1990; Neergaard et al. 2009).

2.5.2 Content Analysis

The data from focus groups and interviews in Phases 1 and 3 were analysed according to an inductive content analysis process (Elo and Kyngäs 2008). The process involved coding, categorisation, and summarising (Elo and Kyngäs 2008). Key words and phrases were identified and labelled into each meaning unit. The list of extracted codes then were grouped together to create subcategories and categories depending on similarities in the extracts. The categories were defined and described through interpretation of each category. All processes were conducted by the first author, and formulated categories and descriptions of each category were double-checked by one of the researchers to strengthen the credibility of the findings.

3 Results

3.1 Key Themes for the Development of QOL/HRQOL Self-reports in Children with ASD and Intellectual Disability

Three themes of *concreteness*, *relationships* and *perception* were identified through thematic analysis of data from Phases 1 and 3 (Table 2). The interpretation of the themes to discover thematic aspects of the experiences and situations which related to the life world of children with ASD and intellectual disability, and specific context will be also introduced with the findings.

3.1.1 Concreteness

One of the themes in the present study was that most children with ASD and intellectual disability would struggle to comprehend abstract ideas. For example, using a child's name instead of "you" and his/her friends' names rather than "other kids" was more comprehensible. A parent from Phase 3 stated,

> "Yesterday was Tuesday."

Table 2 Themes through thematic analysis of focus groups and interviews in Phases 1 and 3

Theme	Definition of theme	Subtheme	Definition of subtheme	Examples of quotations
Concreteness	Something that is tangible, based on reality of specific events or experience and is often perceptible through the senses (Hobson 2012; Rosa et al. 2010).	Who / Whom	A description of a specific person or people in the measure.	“If possible, the use of ‘name of the child’ instead of ‘you’”; “Maybe it is better to ask questions about a specific friend rather than in general about friends”.
		When	The time or period that something is done or happens in a particular situation.	“Specifying a certain time or a certain day such as ‘Monday’ or ‘today’”; “At night time or during the day?”.
		Where	A particular place or part that is likely to be known by the child, or a variety of interpretations of context.	“It’s better to use ‘wide contexts’ rather than time, such as ‘at school’ or ‘at home’”.
		What	Particular information or details about the thing or things.	“Without particular reference to a specific sporting activity or exercise that the children like or try to participate in, it may not make sense”.
Relationships	A particular type of connection between individuals in the context of social, cultural and other influences, which varies from family or kinship relations, friendship or peer relationships to relations with neighbourhoods.	Social Interactions	The process of communication between two or more individuals and one or more types of behaviours in the context of an individual’s family, friends or peers.	“The children want to make friends, but at the same time they feel overwhelmed”; “The most important thing in his life is his family, you know, we spend a lot of time with extended family”; “They are much more comfortable talking to adults than they are with, you know, their peers”.
		Self	The state of not interacting with others.	“The children actually prefer to play alone and don’t necessarily want or desire the participation and interaction with other children”; “I just don’t usually hang out with people. I just hang by myself”.
Perception	The way we interpret or make sense of sensory input which is attained via five senses, namely sight, hearing, smell, taste and touch (Shaffer and Kipp 2007; White et al. 2010a). It directly influences or controls thoughts, feelings, behaviours or a combination of these.	Visuals	Pictures that are illustrated in the measure to make the meaning of each question clearer.	“The use of visuals would likely contribute to a better understanding of the questions by the children”; “Obviously kids with autism are very visual…pictures are good, too, because they are so simple”.

Table 2 (continued)

Theme	Definition of theme	Subtheme	Definition of subtheme	Examples of quotations
		Feelings	A child’s emotions that are aware through the mind and the senses, or emotional expressions that are demonstrated as pictures.	“Use visuals together with emotions such as smiley faces would be more easily understood”; “Use of emotive language may be difficult for some children to understand”; “Some people [with ASD] could be more the unexpected. Some might have bad temper, some might be a little distractive. And some can just have real bad meltdowns”.
		Behaviour	A particular way that a child answers the measure.	“He is still gonna say ‘happy’ because what he has been doing, it’s about a routine and a pattern that is responded to”; “He chose ‘a lot’ but he would probably choosing a smiley face”; “Most of the time he [the child] answers ‘yes’ for everything anyway”.

ASD autism Spectrum Disorder

The idea of *yesterday* was linked to a specific day such as *Tuesday* to help a child remember how the child felt and what the child did on that day. The way children with ASD and intellectual disability think concretely can become problematic when they deal with measures that involve abstract concepts. *Concreteness* is defined as something that is tangible, based on the reality of specific events or experience, and is often perceptible through the senses (Hobson 2012; Rosa et al. 2010). This is in contrast to the "abstract", which refers to something that cannot be perceived directly by the senses (Rosa et al. 2010). Moving from concrete to abstract thinking is one of the milestones of normal childhood development (White et al. 2010b). However, this cognitive transition from concrete to formal operational thinking is less likely to occur in children with ASD and intellectual disability. Young children and children with high-functioning autism and Asperger disorder, for example, find concrete words or factual knowledge easier to understand than abstract words (Church et al. 2000; Ropar and Peebles 2007).

QOL/HRQOL self-reports for use in children with ASD and intellectual disability may thus need to consider the possibility of tailoring certain aspects of the item content to the respondent's personal contexts. The concept of concreteness, however, indicates that one circumstance cannot be generalised to others. When the context of each question is precisely determined by specific information of person, time, and place, the measure may provide only a limited snapshot of a child's (health-related) quality of life in one particular situation.

3.1.2 Relationships

The findings showed that the concept of social relationships in children with ASD and intellectual disability was different from that of typically developing children, and that children specifically with ASD tend to interact more with family and adults including teachers and teacher aides, than with friends. A *relationship* refers to a particular type of connection between individuals in the context of social, cultural, and other influences, which ranges from family or kinship relations, friendship or peer relationships, to relationships within neighbourhoods. Characteristics of a *relationship* are determined by the content, quality, and pattern of interactions; the extent to which the interactions are reciprocal or complementary; and the level of cognitive and moral abilities (Hinde 1995). Compared to other children, children with ASD often have impairments in perceiving, producing, and understanding emotions as well as verbal and non-verbal communication (Filipek et al. 1999; Travis 1998). These impairments create obstacles to successfully engaging in social interactions and maintaining relationships (Travis 1998).

Children with ASD often prefer to engage in activities on their own. One participant with ASD from Phase 3 commented,

> "I just don't usually hang out with people. Just by myself go for walk, do my own thing. I'm not so interested in hanging out with them."

3.1.3 Perception

Predominant visual dependence, impairments in emotional recognition and atypical behaviours in children with ASD and intellectual disability were identified as issues when conducting QOL/HRQOL self-reports. *Perception* including "recognition" and "identification" refers to the way we interpret or make sense of sensory input, which is attained via five senses, namely sight, hearing, smell, taste, and touch (Shaffer and Kipp 2007; White et al. 2010a). It also directly influences or controls thoughts, feelings, behaviours, or a combination of these.

All parents from Phase 1 consistently reported that the use of visuals was helpful to understand the meaning of each question. A parent from Phase 3 mentioned,

> "Pictures are definitely… are really helpful. The idea of visuals is of course to have less word and let the pictures do a talk."

Sensory peculiarities are considered as integral features of ASD and consequently affect the development of the perceptual system (Iarocci and McDonald 2006). The perceptual experience of individuals with ASD demonstrated that visual perception is likely to predominate in the integrated audio-visual sensory contexts (Iarocci and McDonald 2006). However, visuals in each question might cause misinterpretation because the children might not be familiar with the pictures, or the pictures might not represent their real situation.

Children with ASD generally struggled to recognise or reflect on their own feelings relevant to each question. Instead of responding to the content of each question, they might perceive the required task to consist of matching facial expressions in the response options to the pictures in the corresponding items, and thus their responses might not reflect their own feelings. Individuals with ASD have impairments in the cognitive processing of emotions, including problems in identifying and describing feelings, and difficulties in recognising feelings from the physical sensations of emotional arousal (Hill et al. 2004). Likewise, behaviours of repetition and preference in children with ASD might result in their habitually choosing the same option. One parent from Phase 3 described:

> "He's got a routine of clicking a happy box because that just it becomes a habit. It's about a routine and a pattern that is responded to."

Individuals with ASD tend to have a particular interest or activity and frequently engage in repetitive and stereotypic behaviours (Church et al. 2000; Ozonoff et al. 1991). Thus, one-by-one presentation of each question is important for engaging the children in the measures and helping them understand questions.

3.2 Content Validity of the PedsQL™-YC in Children with ASD and Intellectual Disability

Five categories of *rewording*, *responses*, *presentation*, *irrelevance* and *omission* were identified (Table 3). *Rewording* refers to the wording in the PedsQL™-YC that needs to be changed into different words or phrases or even a new sentence. Parents reported that children with ASD and intellectual disability might struggle understanding a word or phrase that has multiple meanings and tend to interpret the meaning of each word literally. For instance, the word "hard" might be interpreted as referring to "something that is difficult to bend or break" instead of "difficult to do, understand or answer". This

Table 3 Categories through content analysis of the PedsQL-YC™ in Phase 1

Category	Definition of category	Subcategory	Examples of quotations[a]
Rewording	The wording in the PedsQL-YC™ that needs to be changed into different words or phrases or even a new sentence	Physical Functioning	“‘Hard’ would be seen as ‘physically hard”’ (Q1-6); “Use of the word ‘hard’ could be difficult for some children to understand” (Q1-6).
		Emotional Functioning	“‘Angry’ instead of ‘mad’” (Q3); “‘Trouble’ may be a difficult word to understand in the context of sleeping” (Q4).
		Social Functioning	“‘Get along with’ would be perhaps changed to ‘to be friends with”’ (Q1); “The word of ‘tease’ would be changed to ‘friendly’ or ‘unfriendly’ perhaps” (Q3); “The children might struggle with ‘keep up’” (Q5).
		School Functioning	“It may be useful to separate ‘classwork’ from ‘homework’ in terms of keeping up with ‘schoolwork’” (Q3).
Responses	An answer to a question in which options such as dichotomous or rating scales are included	Yes-No	“‘Hard for you’ would be changed to ‘Can you…?’”; “The question ‘Is it hard for you…?’ could be reworded to ‘Do you…?’”.
		Order	“Mixing up the smiley face answers between questions so there is less risk of the children simply selecting the same face as an answer.”; “Need to mix things up so that the smiley is not always on the left.”
Presentation	The way in which the PedsQL-YC™ or each question is shown or described to children	One-by-One	“One question at a time”; “Presenting questions as individual questions”.
		Declarative Sentence	“Presenting questions as sentences, for example, ‘[NAME] is happy when he/she runs’”.
Irrelevance	An item that is not important to or associated with a child	Social Functioning	“These questions are not relevant for low-functioning children with autism because they don’t want to play. However, children with Asperger’s want to have friends”.
		School Functioning	“Are they supposed to remember things?” (Q2).
Omission	Elements that are important to a child’s (health-related) quality of life but are not included in the measure	Social Functioning	“If a questionnaire were to be designed from scratch, it would have a question about ‘sense of belonging’”.

PedsQL-YC™ Paediatric Quality of Life Inventory™ Young Child Self-report, *Q* question

[a] Question numbers refer to the ones in the PedsQL-YC™ (see Fig. 2)

tendency of literal thinking is related to the theme of *concreteness*, and would be a major obstacle to comprehending metaphorical terms in the PedsQL™-YC. Therefore, it is suitable for children with ASD and intellectual disability to use simple statements with clear and detailed explanations.

A *response* represents an answer to a question in which options such as dichotomous or rating scales are included. The PedsQL™-YC has three response options: "not at all", "sometimes", and "a lot". Some parents suggested that "yes-no questions" may be more reasonable for children with ASD and intellectual disability. All questions in the PedsQL™-YC arrange response scales in the same location, that is "not at all" on the left side, "sometimes" in the middle, and "a lot" on the right side. Referring to the theme of *perception*, children with ASD may have a tendency towards repetitive behaviours, which may influence their response selection and create response sets. Parents reported that the order of the response options needed to be altered from question to question in order for the child not to simply select the same response option each time.

Presentation refers to the way in which the PedsQL™-YC or each question is shown or described to the children. The PedsQL™-YC presents all of its 23 questions on one page. Two parents pointed out that it is preferable for children with ASD and intellectual disability to be presented with one question at a time. Additionally, a parent recommended that items be shown as declarative rather than interrogative sentences.

The PedsQL™-YC was designed for children with and without acute and chronic health conditions, but not specifically for those with ASD. The findings demonstrated that there were unrelated or missing aspects of their (health-related) quality of life in the PedsQL™-YC for a broader functioning range of children with ASD. *Irrelevance* refers to an item that is not important for children with ASD and intellectual disability, such as most of the questions in the domain of social functioning. In particular, children with low-functioning ASD and some with Asperger disorder were unlikely to interact socially with their friends.

Omission relates to elements that are important to a child's (health-related) quality of life but that are not included in the inventory. One parent highlighted that the significance of "sense of belonging" in a child's life was not included in the PedsQL™-YC. The general impression of the PedsQL™-YC, however, was favourable, as indicated by the feedback that it is "straightforward", "relatively easy", "not too long", and "good for New Zealand kids".

3.3 Development of a Self-reported QOL Measure

The findings from Phase 1 identified the need for recommendations of development of the PedsQL™-YC in order for it to be fit for a broader functioning range of children with ASD and intellectual disability. This QOL measure included the use of visual, as well as item rewording (Fig. 2). Pictures were included for each item, which is presented one by one on a page (see Fig. 3). Response options in this QOL measure consisted of three-point Likert scales with three distinct facial expressions, namely smiling, neutral, and sad faces that were presented below each item and picture.

PedsQL™-YC	**QOL measure**
PHYSICAL FUNCTIONING	**PHYSICAL FUNCTIONING**
1. Is it hard for you to walk	1. Yesterday walking was easy for [NAME]
2. Is it hard for you to run	2. Yesterday running was easy for [NAME]
3. Is it hard for you to play sports or exercise	3a. Yesterday kicking a ball was easy for [NAME] 3b. Yesterday throwing a ball was easy for [NAME]
4. Is it hard for you to pick up big things	4. Yesterday lifting heavy things was easy for [NAME]
5. Is it hard for you to take a bath or shower	5. Yesterday it was easy for [NAME] to take a bath or shower by [him/herself]
6. Is it hard for you to do chores (like pick up your toys)	6. Yesterday it was easy for [NAME] to help in the house
EMOTIONAL FUNCTIONING	**EMOTIONAL FUNCTIONING**
3. Do you feel mad	3. Yesterday [NAME] was angry
4. Do you have trouble sleeping	4. Last night [NAME] slept well
SOCIAL FUNCTIONING	**SOCIAL FUNCTIONING**
1. Is it hard for you to get along with other kids	1. Yesterday [NAME] liked to play with other kids
3. Do other kids tease you	3. Yesterday other kids were friendly/nice to [NAME]
5. Is it hard for you to keep up when you play with other kids	5. Yesterday other kids played in the same way as [NAME]
SCHOOL FUNCTIONING	**SCHOOL FUNCTIONING**
2. Do you forget things	2. Yesterday [NAME] remembered what [NAME] learned at school
3. Is it hard to keep up with schoolwork	3a. Yesterday [NAME] finished all of [his/her] schoolwork at school 3b. Yesterday [NAME] finished all of [his/her] homework at home

PedsQL™-YC Paediatric Quality of Life Inventory™ Young Child Self-report

Fig. 2 Selected example items of the PedsQL™-YC and corresponding items of a QOL measure

3.4 Piloting and Further Refinement of a QOL Measure in Children with ASD

The first items from each domain are presented as examples of a new QOL measure in Fig. 3. Four categories of *rewording*, *responses*, *irrelevance* and *omission* emerged during Phase 3 (Table 4). *Rewording* refers to the wording in this QOL measure that needs to be changed into different words or phrases or even a new sentence. A phrase of Question 6 in physical functioning, “to help in the house” was deemed to be too abstract and was rephrased by most parents to something like “to tidy up” or “to mop and vacuum”. Again, concrete concepts and description, referring to the theme of *concreteness*, are necessary for children with ASD.

A *response* refers to an answer to a question in which options such as dichotomous or rating scales are included. Following the first interview in Phase 3, the description of the response options were adjusted depending on the nature of the questions, such as “very easy”, “sometimes easy”, and “not easy”. The order of response scales was also altered for every question to minimise the likelihood of response sets.

Irrelevant and missing facets of the new QOL measure were clearly demonstrated in the interviews. *Irrelevance* refers to an item that is not important for the child, and *omission* stands for elements that are important to the child’s (health-related) quality of life but are not included in this QOL measure. Most children from Phase 3 went to special schools, and the majority of parents agreed that the children usually do not receive homework. Although the QOL measure separated ‘schoolwork’ into ‘schoolwork at school’ and ‘homework at home’ based on the finding through content analysis in Phase 1, an item about homework may not be necessary for children with ASD. Compared to the findings from Phase 1, more views on the unique characteristics of social interactions in children with ASD were attained. Consistent with the findings of the theme *relationships*, irrelevant aspects of the QOL measure were interactions with peers and friends, while questions about interactions with family and adults particularly teachers and teachers’ aides who are important persons for the child’s life were missing from the QOL measure. Clarifying the type of individual activities and

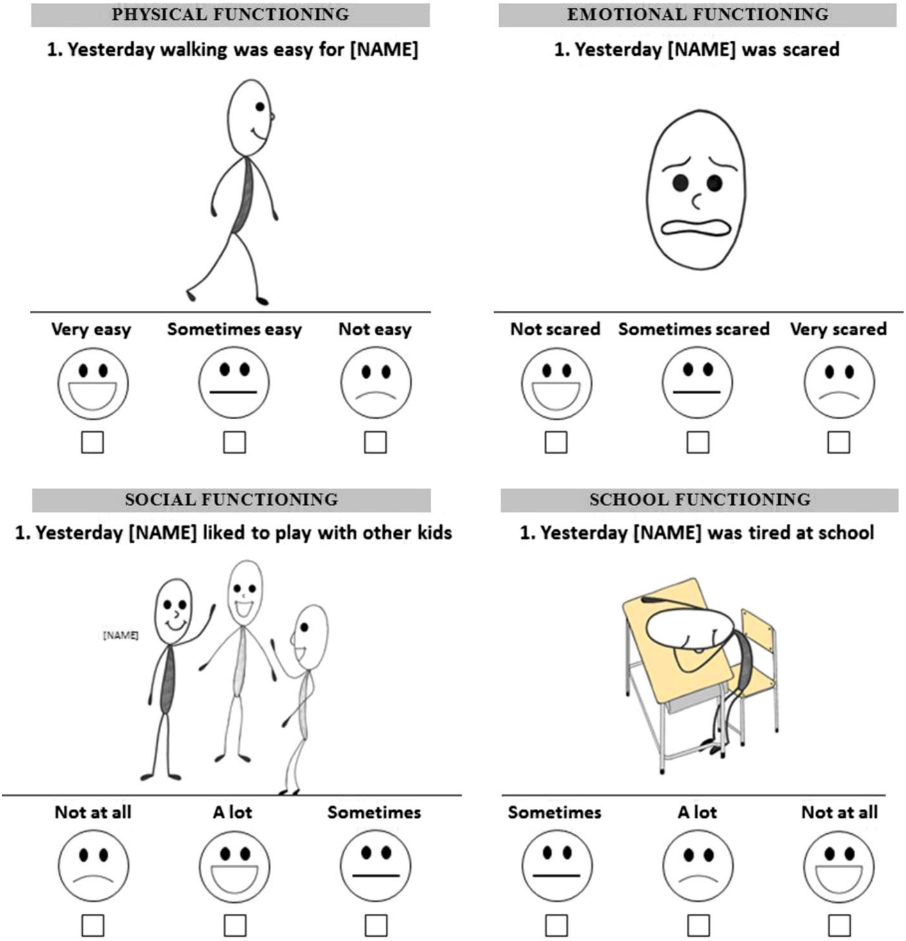


Fig. 3 Examples of a QOL measure

the level of activity and engagement were also viewed as a critical component of (health-related) quality of life in children with ASD in terms of social and physical perspectives.

Throughout Phase 3 of the interviews, enthusiastic impression and high satisfaction with the QOL measure were obtained such as "*pretty good*", "*straightforward*", "*just perfect*", and "*better than the original* [the PedsQL™-YC]". Parents reported that the QOL measure provided them with a new viewpoint on their children. One parent commented,

> "The first time I think [for the child] to complete [a questionnaire]… It [the QOL measure] gave me every information [of the child] as well. That is good."

Another parent remarked,

> "I was quite surprised that he [the child] could make time for what he likes and come and do this."

Table 4 Categories through content analysis of a QOL measure in Phase 3

Category	Definition of category	Subcategory	Examples of quotations[a]
Rewording	The wording in a QOL measure that need to be changed into different words or phrases or even a new sentence	Physical Functioning	The phrase of 'to help in the house' was rephrased to 'to tidy up', 'to make your own bed' or 'to mop and vacuum' by parents (Q6).
		Social Functioning	The word of 'friendly' was changed to 'nice' by a parent (Q3).
Responses Irrelevance	An answer to a question in which options such as dichotomous or rating scales are included	Yes-No	"The three categories are actually quite hard. Probably it would be easy 'yes' or 'no'".
		Varied Options	"The same answers [response options] for every question. It's easier but it doesn't mean that the children actually interpreting them"; "Obviously scale is the same [wording], right? Depending on the section, I think, differs some, right?".
		Alternative Options	Another option such as 'not applicable', 'cannot answer', 'do not want to answer', 'do not know', or 'maybe' were suggested by parents.
		Order	"I [the parent] think you changed the order of these all the time, didn't you? Definitely"; "It is better to swap the orders around"; "Can you change these order around, don't you? Actually it's a good point".
	An item that is not important to or associated with a child	School Functioning	"It's too stressful but well that's what they suggest is don't try and do homework with kids on the spectrum, it's all, the day is over, forget it, just have some down time"; "He [the child] doesn't have homework"; "There is no schoolwork at home" (Q3b).
Omission	Elements that are important to a child's (health-related) quality of life but are not included in the measure	Social Functioning	"What about interaction with adults in his world, teachers or other caregivers such an important persons in the child's life"; "Content of 'interaction with others' such as adults, teachers or teacher aides"; "I [the parent] don't think that there's actually nothing in there about 'family'"; "I [the parent] think if you do something on family as well like 'Do you have brothers or sisters?' and 'Do you play sports with [your family]?".
		Activity	"I [the parent] guess you could tailor it to the individual activities that the child likes doing"; "It should include 'how many times' to identify the level of activity and to ascertain how often the child is actually doing it"; "Probably something like 'What do you do in your spare time?' to make things a bit more interesting".

Q question

[a] Question numbers refer to the ones in a QOL measure (see Fig. 2)

4 Discussion

The aims of this research were to examine the content validity of the PedsQL™-YC for use in children with autism spectrum disorder (ASD) and intellectual disability, and to make recommendations for the development of a self-reported QOL measure that could be used for children with ASD. The overall findings identified that the PedsQL™-YC did not address their unique nature of social dysfunction, cognitive and language impairments, and deficits in emotional recognition for children with ASD and intellectual disability. These findings were congruent between children, parents and teachers. Iarocci and McDonald (2006) demonstrated that characteristics of ASD, including peculiar use of language and memory for specific things, may limit the ability of individuals with ASD to accurately report and have insight into their sensory experiences. Furthermore, individuals with ASD have impaired central coherence or the ability to integrate information from a variety of cognitive processes to draw higher levels of meaning (Iarocci and McDonald 2006). In spite of this limitation, the goal of obtaining children's own perspectives from self-reports needs to be prioritised as children's rights to express their opinions should be respected, protected, and fulfilled (Cremeens et al. 2006; United Nations Chidren's Fund 2005).

Through content analysis of the focus groups and interviews from Phase 1, we recognised the necessity for the development of a new QOL measure. Phase 2 made recommendations for the wording, format, and presentation style of the PedsQL™-YC to meet the needs of children with ASD and intellectual disability. In Phase 3, the QOL measure was piloted with children with ASD, and interview data of children and their parents were analysed. The categories of *rewording*, *responses*, and *presentation* were related to impairments in cognitive functioning and language in children with ASD and intellectual disability. In Phase 1, parents reported that multiple information and complex structures used in the PedsQL™-YC would be distracting and hard to comprehend for children with ASD and intellectual disability. In particular, it was proposed that sentences be shown in a declarative rather than in the interrogative manner of the PedsQL™-YC; fewer response scales be practical; and one item be shown at a time instead of listing many items on one page.

Regarding linguistic issues, it was suggested that words and phrases be used in a literal manner which means the "defined" or "normal" meaning of the terms without implication and inference. Bell (2007) recommended that questionnaires for children should be short in length, consist of short sentences, use straightforward language, present in direct and specific manner, and avoid using complex structure and negative formulations. It is also evident that individuals with ASD were not able to use language in a flexible manner (Church and Coplan 1995; Happe 1993). Carrington et al. (2003) found that a child with ASD had difficulty comprehending the words used in a question, and interviewers needed to prompt and reword the questions in most interviews. In the present study, the PedsQL™-YC was reworded and reformatted, and pictures were inserted in each item. After Phase 3, we recognised that a few phrases would still be required to be reworded because expressions of the phrases were not concrete enough for children with ASD.

In terms of *responses*, new ideas were proposed from parents, such as varied answers according to the type of questions, and alternative options if the question was "not applicable". Parents consistently reported that the type of "yes-no question" was more straightforward for children with ASD and intellectual disability. Nonetheless, it may be feasible to determine the need for yes-no questions or alternative options in combination with quantitative research methods to explore psychometric properties that include floor and ceiling effects of scores (Varni et al. 2007). In general, the QOL measure from Phase 3 was considered to be more appropriate than the PedsQL™-YC for children with ASD and intellectual disability; however, feedback from parents and children in Phase 3 demonstrated that the use of concrete wording and the type of response options may need further modification to increase the accuracy of responses from the children. Nevertheless, the PedsQL™ 4.0 Generic Core Scales is still useful for the benchmarking with typically developing children and children with other chronic health conditions using the parent proxy-report version and the child/teen self-report versions for children and adolescents with high-functioning autism.

The categories of *irrelevance* and *omission* emerged frequently in the domains of social functioning. Due to deficits in social interactions and relationships in children with ASD, the questions about social interactions with peers in the domain of social functioning were not regarded as relevant to the children. Instead, questions about interactions with family and teachers or teacher aides seemed to be more relevant and important to their lives. Moreover, non-interactive activities and their own time were pertinent aspects for children with ASD and were likely to affect their (health-related) quality of life. These findings indicated that the content of the PedsQL™-YC was not always relevant to (health-related) quality of life in children with ASD.

5 Conclusions

The main issues regarding the content validity of the PedsQL™-YC for use in children with ASD and intellectual disability were (1) a number of missing social functioning items and irrelevant social functioning items; (2) use of abstract concepts and terms; and (3) non-pictorial format and complex presentation style. The development of a self-reported QOL measure that is appropriate for children with ASD and intellectual disability may enhance communication of their perspectives on their QOL/HRQOL and the responsiveness of the measure. It would also allow parents to gain insights of their children by watching them complete such a QOL measure. However, pursuing an appropriate measure for this population may require a non-generic and, to some extent, a customised measure. For future studies, quantitative research methods will be required to determine the psychometric properties of a QOL measure, such as the one reported on here. It is also worthwhile to investigate different modes of administration such as the use of electronic devices. Considering that electronic devices such as tablet devices are frequently utilised as educational tools for children with ASD, it may be practical to collect data using such devices. While the present study focused on the content validity of the PedsQL™-YC and a QOL measure using content and thematic analyses, further research is needed to test the construct validity and reliability of a QOL measure. A QOL measure could be used to subjectively assess the child's perspective of health and wellbeing in studies such as Hinckson et al. (2013).

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