

# Finding out what matters: validity of quality of life measurement in young people with ASD

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## Abstract

**Background** Compared with other conditions there has been a lack of focus on quality of life (QoL) as an outcome measure for children and young people with Autism Spectrum Disorder (ASD). This pilot study aimed to evaluate the validity of existing QoL questionnaires for use with children with ASD aged 8–12 years.

**Methods** A literature review (1990–2011) identified the PedsQL (Pediatric Quality of Life Inventory) and Kidscreen as robust measures used with children with neurodevelopmental disorders. These measures were completed by 10 children and 11 parents. In addition semi-structured interviews were conducted with 10 parents and four children to explore their experience of completing the QoL questionnaires.

**Results** Young people with ASD, and their parents, report lower child QoL compared with a normative sample. Framework analysis of the data highlighted six key themes which may affect the validity of generic QoL measures when administered within an ASD sample and which warrant further investigation.

**Conclusions** Our results indicate that a new condition-specific measure of QoL, grounded in ASD children's own perspectives of their lives, is needed and that such a measure should assess experiences of anxiety and access to special interests when measuring QoL of children with ASD. Active involvement of young people and their families is critical for the development of a theoretical framework for QoL within ASD, and any future development of an ASD-specific measure.

## Keywords

ASD, Asperger's syndrome, autism spectrum disorder, outcome measures, quality of life, validity

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## Introduction

The evidence base concerning interventions for children with Autism Spectrum Disorder (ASD) in early and middle childhood is growing (Rogers & Vismara 2008; Seida *et al.* 2009). However, compared with other conditions there has been a lack of focus on quality of life (QoL) as an outcome measure (Burgess & Gutstein 2007).

There is no universally accepted definition or model of QoL. This has resulted in great variability in the content of questionnaires that purport to measure the construct (Skevington *et al.*

2004). Felce and Perry's (1995) review of the QoL literature concluded that there are five core domains that should be included in measurement: physical well-being (health, fitness and physical safety); material well-being (possessions, income, transport and living environment); social well-being (interpersonal relationships, acceptance and support); emotional well-being (mood, satisfaction, self-esteem, status/respect and religious faith); and development and activity (independence, self-determination, education, leisure and productivity). There is a growing consensus that QoL is a multidimensional concept (Petry *et al.* 2005; White-Koning *et al.* 2008; Claes *et al.* 2009).

Solans and colleagues (2008) noted in their systematic review of generic and disease-specific instruments that the number of published Health Related Quality of Life instruments for children and adolescents increased dramatically between 2001 and 2006. Generic measures rose from 21 to 30 and disease-specific measures from 22 to 64. Despite this proliferation there remains limited agreement on a conceptual framework for QoL and limited evidence on psychometric properties (test–retest reliability, structural validity and sensitivity to change) of the measures used.

For children and adolescents with neurodevelopmental disorders, both condition-specific and generic paediatric QoL instruments have been developed. Three generic and 11 condition-specific QoL instruments were reviewed by Waters and colleagues (2009). None of those instruments was developed specifically for children with ASD. The review highlighted a number of weaknesses in the field including the lack of involvement of families in the development of instruments, a focus on functioning rather than well-being, the use of negatively worded items which may impact upon self-esteem and the use of proxy report only; QoL is an individual's perception, and parents and their children may differ in their understanding and interpretation of items. Indeed studies have previously shown

discrepancies between child and parent ratings when measuring QoL (Eiser & Morse 2001) with proxy reporters underestimating QoL compared with self report (White-Koning *et al.* 2008), suggesting that proxy rating should be used if possible in conjunction with, rather than as a substitute for, self report.

For children and young people with ASD, specific measurement issues arise. Children with ASD may lack awareness of their own emotions and have limited capacity for self-reflection (Attwood 2007; Rieffe *et al.* 2011). Furthermore, their interests and enthusiasms may differ from those of typically developing children (Attwood 2007), which may affect how they value aspects of QoL identified in conceptual models derived from studies of typically developing young people. For example, interpersonal relationships and leisure activities feature among the subdomains of Felce and Perry's (1995) model of QoL, but these may not be considered important by children with ASD who may prefer very specific activities and time alone (Plimley 2007) and indeed leisure activities may engender stress and social anxiety in children with ASD (MacNeil *et al.* 2009). Recently, several studies of QoL within both adults and children with ASD have been published (see Table 1). The studies with adults with ASD broadly indicate that the QoL for this population is comparable to that of those with an intellectual

**Table 1.** Articles included in review after title and abstract searching

Sample	Reference	n	Age range (years)	Report self/proxy	Measure
Asperger's syndrome/HFA	Burgess & Turkstra (2010)	14	13–19	Both	Quality of communication life scale perceived support network inventory
	Jennes-Coussens <i>et al.</i> (2006)	12	18–21	Self	WHOQOL-BREF
	Limbers <i>et al.</i> (2009)	22	6–12	Proxy	PedsQL
Autism Spectrum Disorders	Billstedt <i>et al.</i> (2011)	108	17–40	Proxy	Quality of life measure 1 (QOL1) Quality of life measure 2 (QOL2) Social outcome interview
	García-Villamizar & Dattilo (2010)	37	17–39	Both	Quality of life questionnaire (QOL.Q) The stress survey schedule for persons with autism and other PDD
	Kamp-Becker <i>et al.</i> (2011)	42	6–18	Both	Inventory for the assessment of QoL in children and adolescents (ILK)
	Kuhlthau <i>et al.</i> (2010)	286	2–18	Proxy	PedsQL
	Renty & Roeyers (2006)	58	18–53	Self	Quality of life questionnaire (QOL.Q)
	Saldana <i>et al.</i> (2009)	74	18–40	Proxy	ComQOL
	Shipman <i>et al.</i> (2011)	39	12–18	Both	PedsQL
Autism/intellectual disability	Beadle-Brown <i>et al.</i> (2009)	12	27–40	Self	Lifestyle satisfaction scale
	Totsika <i>et al.</i> (2010)	72	27–41	Proxy	Quality of life questionnaire (QOL.Q)
		87	50–90	Proxy	Index of participation in domestic life Index of community activities
PDD	Mugno <i>et al.</i> (2007)	69	20–58	Self	WHOQOL-BREF
Psychiatric disorders (not specified)	Bastiaansen <i>et al.</i> (2004)	310	6–18	Both	PedsQL Child and Adolescent Functional Assessment Scale
	Clark <i>et al.</i> (2007)	53	5–18	Self	PedsQL

ComQOL, Comprehensive Quality of Life Scale; HFA, high functioning autism; ILK, inventory for the assessment of QoL in children and adolescents; PedsQL, Pediatric Quality of Life Inventory; PDD, pervasive developmental disorder; WHOQOL-BREF, World Health Organization Quality of Life – Brief.

disability (Totsika *et al.* 2010) and that participation in recreational activities or occupation positively influences QoL (García-Villamizar & Dattilo 2010; Billstedt *et al.* 2011). For children and adolescents with ASD, QoL scores are significantly lower than published norms (Burgess & Turkstra 2010; Kuhlthau *et al.* 2010), but higher than in other psychiatric disorders; where both children and parents have participated, children's scores are significantly higher than parent proxy scores (Kamp-Becker *et al.* 2011). A range of generic QoL measures has been utilized in these studies and, therefore, the question of reliability and validity of the use of such measures within an ASD population should be considered. Scrutinizing quantitative aspects of the Pediatric Quality of Life Inventory (PedsQL), such as internal consistency of subscales, and concurrent validity, Shipman and colleagues (2011) concluded that young people with ASD aged 12–18 are able to report on their own QoL in a valid and reliable manner. Results such as these, however, should be interpreted with caution as concurrent validity was demonstrated using mental health measures which similarly have not been validated within an ASD population, and the researchers did not explore young people's understanding of individual items. The purpose of this pilot study is to explore the validity of two generic QoL questionnaires for use with children who have a diagnosis of ASD.

## Method

### Participants

Participants were recruited through the Database of Children Living with ASDs in the North East of England – Dasl<sup>ne</sup> (McCornachie *et al.* 2009). Inclusion criteria were that the child had a formal diagnosis of ASD and was aged between 8 and 12 years. Exclusion criteria were severe learning difficulties and non-English speaking. Of the 60 families approached, 11 families (10 children and 11 parents) returned the consent forms and

questionnaires. The children were all male, with a mean age of 10.9 years (SD 1.38); parents were one father and 10 mothers/female carers. Fourteen participants consented to be interviewed (10 parents, and four children aged between 9 and 12 years).

## Measures

### Identification of candidate measures

In order to identify candidate measures for further investigation, a review was carried out to see which QoL measures (both generic and condition-specific) were commonly used with paediatric neurodevelopmental disorder samples, including those with ASD. The following databases were searched from 1990 to 2011: Embase, IngentaConnect, ISI Web of Science, Medline, PsycInfo and Scopus. Searches were based around the following keywords: ADHD, ASD, Asperger's, autism, cerebral palsy, Down's syndrome, fragile X, learning difficulty, learning disability, mental illness, pervasive developmental disorder, quality of life. Internet search engines were used to identify additional references. Title and abstract searching were used to identify papers suitable for inclusion in the review.

The four measures used most frequently in published papers were PedsQL (Varni *et al.* 1999), Child Health Questionnaire (Landgraf *et al.* 1996), Kidscreen (Ravens-Sieberer *et al.* 2005), Cerebral Palsy Quality of Life Child (Waters *et al.* 2007) (Table 2). All use Likert type scales, have self and parent reports available for children aged 8–12 years, and take a similar amount of time to complete (15–25 min). Each measure was mapped onto the Felce and Perry (1995) theoretical domains of QoL. The Child Health Questionnaire was not considered further following this process, because the physical health domain was considered to be over-represented in the questionnaire items. The Cerebral Palsy Quality of Life Child was also ruled out because of its focus on the relationship between par-

**Table 2.** Summary of candidate quality of life (QoL) measures

Measure	Framework	Age range	Self report available	Proxy available	No. of items
PedsQL	HRQoL	2–18	Yes	Yes	Toddlers: 21 items; Young children, Children, Teens: 23 items [Young adults: 23 items (PedsQL™ 4.0 Generic Core scales)]
CHQ	HRQoL	5–18	Yes	Yes	Parent Form: 50 items (PF50) and 28 items (PF28)/Youth Form: 87 items (CF87)
KIDSCREEN	HRQoL	8–18	Yes	Yes	KIDSCREEN-52: 52 items covering 10 HRQoL dimensions, KIDSCREEN-27: 27 items covering 5 HRQoL dimensions, KIDSCREEN-10 Index: 10 items general HRQoL Index
CP-QOL child	HRQoL & QoL	4–12	Yes	Yes	Parent proxy: 66 items Child self report: 53 items

CHQ, Child Health Questionnaire; CP-QOL, Cerebral Palsy – Quality of Life for Children Questionnaire; HRQoL, health-related quality of life; PedsQL, Pediatric Quality of Life Inventory.

participation and access to specialist equipment, which would not have been relevant to ASD. The remaining questionnaires were the PedsQL and the Kidscreen:

- *PedsQL – The Pediatric Quality of Life Inventory UK Version 4* (Varni *et al.* 1999): The PedsQL consists of a core QoL scale with optional additional modules for different conditions. The core QoL scale comprises four subscales: Physical Health (e.g. Item 2. It is hard for me to run), Emotional Functioning (e.g. Item 3. I feel angry or cross), Social Functioning (e.g. Item 1. I have trouble getting on with other kids) and School Functioning (e.g. Item 2. It is hard to pay attention in class). Different versions are available for age ranges between 2 and 25 years, with self report and parent proxy report available for each age range except the toddler's version, which is parent report only. All versions have 23 items apart from the toddler's version which has 21 and all ratings are given on a 5-point scale with a time frame of the past month. Upton and colleagues (2005) examined the psychometric properties of the UK version of the PedsQL and found good reliability and validity, with internal consistency of over 0.9 for the total score. US proxy report normative data and UK self report data were used (Upton *et al.* 2005; Limbers *et al.* 2009).
- *Kidscreen Questionnaire* (Ravens-Sieberer *et al.* 2005): The Kidscreen questionnaire assesses subjective health and well-being, and can be used with children and adolescents between the ages of 8 and 18 years. A parent proxy report version is also available. Versions of 52, 27 and 10 items are available. The 27-item version was chosen for this study as it was comparable in length to the PedsQL and had a time frame of the past week. Ratings are given on a 5-point scale in the five core subscales: Physical Well-being (e.g. Item 2. Have you felt fit and well?), Psychological Well-being (e.g. Item 6. Have you felt lonely?), Social Support and Peers (e.g. Item 4. Have you been able to rely on your friends?), School Environment (e.g. Item 1. Have you been happy at school?) and Autonomy & Parents [e.g. Item 3. Have your parent(s) had enough time for you?]. This questionnaire has good reliability and validity, with good internal consistency of all domains reaching 0.8 or above (The KIDSCREEN Group Europe 2006). There is also a moderate to high level of convergent validity across dimensions of PedsQL and Kidscreen-27 (Ravens-Seiberer *et al.* 2007). UK normative data were used (The KIDSCREEN Group Europe 2006).

#### *The interview*

The interview was developed by the research team and followed the structure of the subscales within the standardized measures.

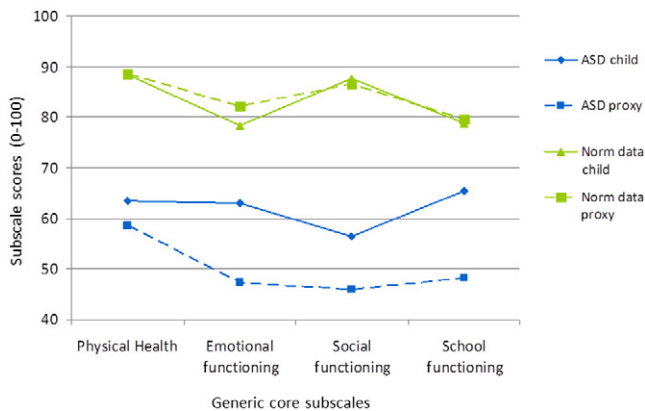
Participants were asked to describe what they were thinking about when they answered individual questions (Physical Health, Emotional Functioning, Social Functioning, School Functioning and Autonomy & Parents). Two members of the research team (HMcC & LT) also generated additional questions which included items such as 'what things really make a difference to your (your child's) QoL?' (positive/negative) or 'what do you really enjoy doing?' Further prompts were included relating to access and frequency of the activity. A 'special interest' topic was included in the interview because during completion of the standardized measures within the social functioning domain, parents frequently noted that having access to their special interest had a big impact on their child's QoL.

#### **Procedure**

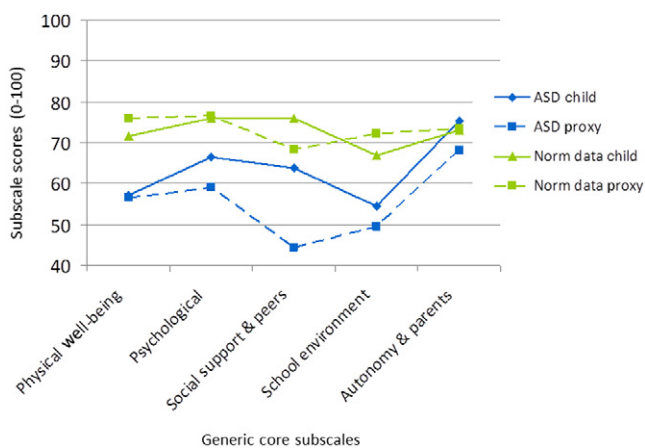
A favourable ethical opinion was obtained from Sunderland Research Ethics Committee. The Kidscreen and PedsQL were then posted to the participants along with information sheets for both the child and parents. Both were also invited to participate in an interview consisting of additional reflections on the items in each questionnaire. Children were interviewed at home face to face by a trained researcher (LT); parents were interviewed either face to face or by telephone. All children were interviewed in the presence of their parents. The child interviews took generally between 20–30 min. The adult interviews approximately 30 min. Detailed notes were taken during interviews.

#### **Results**

The results from both measures were plotted against normative data provided with the measures. Given the small sample size no formal statistical analyses were undertaken and so any conclusions drawn are tentative. Visual inspection of the data suggests that the young people with ASD in our sample experience a lower QoL compared with a normative sample (Figs 1 & 2). In addition differences between proxy (parent) report and self report QoL subscale scores can be seen for both measures. Proxy reports suggest a lower QoL than self report, with apparently larger differences in scores between child and proxy reports for the children with ASD than apply for normative data. Our sample of young people with ASD report a lower QoL than normative data across all core subscales except the Kidscreen subscale, 'Autonomy & Parents'. This suggests that our sample of children with ASD aged 8–12 years have similar perceptions of



**Figure 1.** PedsQL™ 4.0. Comparison of Autism Spectrum Disorder (ASD) sample and norm data mean scores.



**Figure 2.** Kidscreen 27. Comparison of Autism Spectrum Disorder (ASD) sample and norm data mean scores.

their relationship with their parents and the resources available to them as typically developing children.

Framework analysis was used to analyse the interview data about the two measures (Spencer *et al.* 2003). From the written notes, a framework of themes was established by identifying similar concepts and placing them together under a unifying super-ordinate theme, and continuously rereading notes until no new themes were identified. Initial framework analysis was undertaken by one researcher (LT) and following initial analysis of each interview discussion took place between two of the research team (LT & HMCC) to reach consensus agreement on key themes.

Six key themes emerged: Misinterpretation of Items, Ability to Generalize, Emotional Vocabulary, Social Functioning, Anxiety and the Likert Scale (Fig. 3). Quotations are given below as broadly representative of each key theme.

## Key theme 1: Misinterpretation of Items

### Physical Health

Participant interviews revealed that psychological, social and sensory factors had informed participants' responses to the physical health domain rather than the young person's physical health as intended in the core scales. This, therefore, questions construct validity within the physical health scale. The findings also highlight that the level of restriction on activity remains high for young people with ASD although the underlying reasons for this restriction may not reflect physical health difficulties per se. For example, Participant 3 highlighted that many items within the Physical Health scales of both measures were not applicable because their child does not like to go outside because of social phobia.

### PedsQL

Q1. It is hard for me to walk down the road a little bit.

He finds walking down the road difficult due to psychological reasons rather than physical (Pp 7 parent)

Q3. It is hard for me to do sports or running games.

He misses out on things as he is very easily upset or offended, not because he can't do it (Pp 4 parent)

Q5. It is hard for me to have a bath or shower by myself.

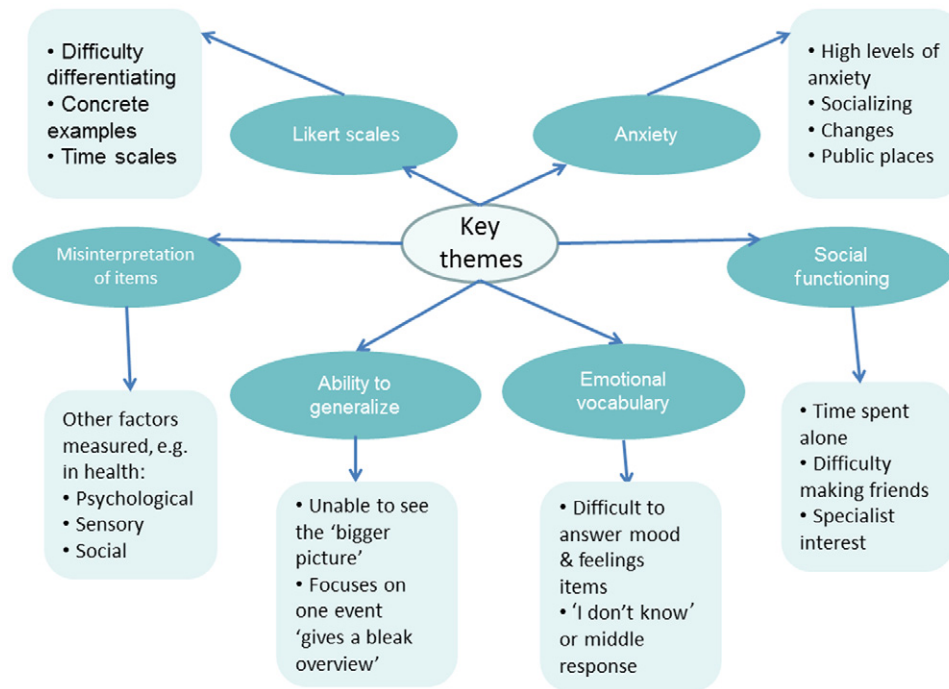
He has sensory difficulties with water (Pp 7 parent)

I can't open my eyes when I'm in the shower so my Mum helps me (Pp 9 child)

That's far too personal! You can't ask that (Pp 5 child)

### Emotional Functioning

A proportion of the language used within the QoL measures was misinterpreted by children with ASD producing scores resulting from embarrassment or physical illness, rather than from low mood or depression. The emotions selected within the questionnaires may have also contributed to inaccurate measurement of mood and feelings. For example, a parent observed that feeling frustrated may be a more relevant emotion than the ones provided such as feeling angry. This was supported by a child participant who suggested an additional question could be incorporated enquiring about emotional distress. Further dis-



**Figure 3.** Key themes from semi-structured interviews.

cussion clarified that the participant was referring to feeling agitated or frustrated with other people. Use of clear, simple language when phrasing items was suggested by parents in an effort to increase the young people's understanding.

You could ask do you ever have any emotional distress (Pp 5 child)

### Kidscreen

Q5. Have you felt so bad that you didn't want to do anything?  
Yes because I get embarrassed (Pp5 child)

Yeah when I had a cold I didn't want to do sports (Pp7 child)

### Key theme 2: Ability to Generalize

Parents frequently reported that their children found it difficult to generalize their answers or 'see the bigger picture', often answering the items with reference to one particular incident. This was observed during the interview with Participant 5 (child) who suggested he would rescale his answer from 'almost always' to 'sometimes' after encouragement from the interviewer to think about his experiences 'overall within the last

month' as the questionnaire requests, rather than focussing on one particular negative experience when a friend had lied to him.

He is unable to generalise his answers. He focuses on negative experiences and tends to look bleakly and see things as the end of the world (Pp8 parent)

### Key theme 3: Emotional Vocabulary

Parents generally reported that their child's lack of emotional vocabulary impacted on their ability to respond to items about their mood and feelings. In contrast Participant 6 (parent) commented on how their child had been able to answer the items because they had good emotional literacy after attending a 'social and emotional' group at school. In addition the 5-point scale was suggested to be potentially unhelpful and likely to elicit the mid-range responses [i.e. sometimes (PedsQL) or moderately (Kidscreen)] because of fluctuations in mood and emotions.

#### Mood and feelings

He doesn't have the expressive language to discuss how he feels. He frequently answered 'I don't know' and needed me to unpick the question for him (Pp1 parent)

He doesn't have the emotional vocabulary to scale feelings from happy to sad; he will therefore answer 'happy' to everything (Pp10 parent)

### *Kidscreen*

Q1. Has your life been enjoyable?

The scale for responses does not represent a child who is very up and down and experiences emotional extremes. When he is low he would say that he has a 'terrible life' but other days he would say he was happy (Pp4 parent)

Moderately/Average response seems likely to be given as no one is happy or sad all the time (Pp5 parent)

### **Key theme 4: Social Functioning**

One parent spoke of how completing the questionnaires was a useful experience as it had provided an opportunity to think about QoL and what might improve their child's QoL. Strong views were held by both parents and the young people themselves regarding the social functioning subscales of both measures. While many felt that it is important that the measures record the impact of friendship upon QoL, others raised the issue that some young people with ASD may prefer time alone and, therefore, their answers may be incorrectly 'pulling down' their QoL scores.

### *PedsQL & Kidscreen*

I answered the questions producing negative scores but upon reflection I think my child actually prefers being alone (Pp3 parent)

Loneliness is alright as long as it is balanced out with time with people (Pp9 child)

Friends are a very important factor to my child and their QoL – previously bullied but he has a good set of friends now (Pp6 parent)

Participants discussed how for many young people with ASD time spent alone provides an opportunity to engage in their special interest. Parents suggested that, should their child's special interest be limited or removed, then this would definitely have a negative impact upon their QoL. One parent also discussed the 'feelings of guilt' they had experienced, prior to participating in the study, following a series of unsuccessful attempts to engage their child in social activities.

You could ask me questions about video games or trains and if I like playing on my own or playing in a group? (Pp5 child)

Possibility of measuring specific hobbies which have a positive impact on their QoL (Pp1 parent)

I thought my child was lonely but after completing the questionnaires I've realised he is happy playing on his computer alone. It was useful to gain both perspectives (Pp3 parent)

### **Key theme 5: Anxiety**

The effect of a child's anxiety upon their own QoL, and in turn the family's overall QoL, was raised as an important construct when measuring QoL within an ASD population. The impact of high levels of anxiety upon daily living was raised by all parents as absent from the generic measures chosen for validation. Socializing, coping with change and going to public places were most frequently cited as causing increased levels of anxiety.

### *PedsQL*

Q1. I feel afraid or scared.

I'm scared of going to new places (Pp 7 child)

Factors which my child would probably rate as decreasing his QoL are being made to socialise or go to public places, e.g. shops (Pp3 parent)

You could include questions looking at the impact of anxiety on QoL, as anxiety has a big effect on his life. Fear of being on his own restricts his life; he needs to constantly be in close proximity with me (Pp4 parent)

Question about coping with changes in routine at home or school? This will impact his QoL (Pp5 parent)

### **Key theme 6: the Likert Scale as a metric**

The descriptors for each point on the Likert scale were commented upon by parents, who reported that their children had experienced difficulty, for example, with the term 'seldom'. It was also commented on that the young people often thought rigidly about time scales, and/or struggled to think retrospectively.

It would have been better to have given concrete options, e.g. Sometimes = 3 times a week. He was unable to differentiate between seldom, quite often and very often (Pp8 parent)

He was fixated on the timescales on questionnaire (last week or month) and may have given different answers during term time (Pp3 parent)

I worked out what the word 'seldom' meant due to its position between 'never' and 'quite often' (Pp9 child)

## Discussion

Initial quantitative results using two generic QoL measures concur with recent findings (Kuhlthau *et al.* 2010; Kamp-Becker *et al.* 2011; Shipman *et al.* 2011) that young people with ASD report a lower QoL compared with their peers. Previous studies have shown parents to report QoL scores for their children with ASD which are significantly lower than both normative data (Kuhlthau *et al.* 2010) and self report scores (Saldana *et al.* 2009), a pattern replicated within the current study. Further exploratory work involving interviews focussing on the experience of completing the measures with four child and 10 parent participants has produced valuable qualitative data which suggest that the use of generic QoL measures needs to be undertaken with caution in a child ASD population. Six key themes emerged following framework analysis of the interview data: Misinterpretation of Items, Ability to Generalize, Emotional Vocabulary, Social Functioning, Anxiety and the Likert Scale.

The three key areas in which people with ASD experience difficulty, referred to as the triad of impairments (Wing 1997), are social communication, social interaction and social imagination. The triad of impairments were observed in the participants' approaches to completing the generic QoL measures and in their parents' reflections upon the process. Language and communication difficulties including literal interpretation of items resulted in core scales measuring inappropriate factors, e.g. psychological factors within the physical health scale. Communication difficulties were also highlighted by parents as impacting on participants' ability to complete mood and feelings scales because of a lack of emotional vocabulary. Difficulty with flexibility of thought or imagination was exhibited by participants who frequently provided answers based on a single event and struggled to generalize their answers or see 'the bigger picture'. The use of Likert scales and time frames (last week or month) were reported to cause added difficulty for participants who found it difficult to think retrospectively or interpret some of the language used within the Likert scale.

Some of the social interaction difficulties experienced by young people with ASD were captured in the participants' responses to the social functioning scales. Interestingly both participants and their parents stated that many young people with ASD may indeed prefer their own company and, therefore,

measuring friendships as a construct within QoL for a person with an ASD may have a different significance. The impact of frequently occurring additional difficulties for this population, for example, anxiety was also highlighted as a key factor which impacts on QoL and should be incorporated into any measures of QoL for ASD in the future.

The findings of this pilot study highlight the need to carefully consider both the content and the face validity of existing generic measures (PedsQL & Kidscreen) when administered to an ASD sample or in the development of new ASD-specific measures. Parents reported that they did not feel the measures were accurately capturing the QoL of young people with an ASD diagnosis. The measures were described as focussing on constructs which may not be valued by their child in terms of their QoL. They report that access to special interests or experiencing high levels of anxiety may have a greater impact on QoL than some of the constructs highlighted in the generic measures, suggesting that adaptation could be made to enhance sensitivity and specificity for this population.

The generalizability of the current findings needs to be considered. The sample in the current study included young people between the ages of 8–12 years. Shipman and colleagues (2011) concluded in their recent study that young people with ASD aged 12–18 are able to report on their own QoL in a valid and reliable manner using the PedsQL. All children were asked to consent if they were willing to be interviewed when they completed the self report measures by post; however, only four of the young people consented to be interviewed. Discussion with parents indicated that all the children who did not want to take part reported high anxiety at the idea of talking to a stranger. Consideration should be given in future studies to the development of methods to increase participation in such studies by young people with ASD, so that their voices can be heard. The limitations of this study have already been outlined; nevertheless, it is possible that an older group of young people with ASD can self report on a generic QoL measure. Future research could focus on the validity of self report QoL measures in an older adolescent ASD sample as young people with ASD may develop greater emotional intelligence and reflective skills eventually, though at a later stage than typically developing children (Attwood 2007).

This exploratory study identifies potential threats to validity which arise when generic measures are used with an ASD population to measure QoL and the data highlight avenues for future potential work with larger samples. Indeed our findings suggest that a new condition-specific measure, grounded in ASD children's own perspectives of their lives, is needed. Such a measure would have significant utility in terms of routine clinical care and management of children with ASD. Limitations of the study

include the low response rate of 18% which precluded formal statistical analysis. In addition our sample consisted of all male self report participants and predominantly female carer proxy report participants. Consideration also needs to be given to the potential impact of response bias in terms of the characteristics of those who opt to participate in this type of study and whether they are representative of the wider population. Future replication of this study could utilize a different method of sampling to ensure both male and female self report participants are recruited, and perhaps use interviewers already known to the young people. Further, the use of audio taping might have captured further nuances of data, but may result in children talking less freely.

The key findings discussed provide a foundation for future research into the validity of using self report generic QoL measures within an ASD population. Consideration of both the chronological and developmental age of participants will be required, and alternative modes of administration should be explored (McDonagh & Bateman 2011). For example, the use of computer software to administer the PedsQL which would allow questions to be presented one at a time and read aloud via a recorded voice (Varni *et al.* 2008) may increase accessibility. The use of summary items requesting participants to scale their overall QoL, or scale each individual domain, would enable the scores generated by the generic QoL measures to be compared with the young person's overall perception of their QoL. It is recognized that active involvement of young people with ASD and their families is integral to the development of a theoretical framework for QoL within ASD, and any future development of a condition-specific measure.

### Key messages

- To date there has been a lack of focus on quality of life (QoL) as an outcome measure for children and young people with Autism Spectrum Disorder (ASD).
- Young people with ASD, and their parents, report lower child QoL compared with a normative sample.
- Psychological well-being and access to special interests should be included in any assessment of QoL of children with ASD.
- Young people and their families should be actively involved in the development of a theoretical framework for QoL within ASD, and in any future development of an ASD-specific measure.

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