

Using self-report to explore the relationship between anxiety and quality of life in children on the autism spectrum

Short Title: Self-reports of anxiety and quality of life

Dawn Adams^{1,2,3}, Megan Clark^{1,2,3}, Deb Keen^{1,2,3}

¹ Autism Centre of Excellence, School of Education and Professional Studies, Griffith University, Brisbane, Australia

² Griffith Institute of Educational Research, Griffith University, Brisbane, Australia

³ Cooperative Research Centre for Living with Autism (Autism CRC), Australia

Correspondence regarding this article should be addressed to:

Dr Dawn Adams

Autism Centre of Excellence

School of Education and Professional Studies

Griffith University

Mount Gravatt, Brisbane

QLD 4122

Australia

Email: dawn.adams@griffith.edu.au

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Dawn Adams declares that she has no conflict of interest with respect to this publication.

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Abstract:

Anxiety is now recognised as one of the most common conditions that co-occur with autism. Whilst there has been increased research describing the typical and autism-specific anxiety symptomatology and assessing the effectiveness of potential interventions, there has been less research exploring the impact that elevated anxiety may have on an individual and their quality of life (QoL). This study aimed to explore the impact of anxiety on the QoL in children on the autism spectrum. Children and young adolescents on the spectrum were invited to participate in a self-report study measuring anxiety and health-related QoL (HRQoL). The sample consisted of 71 children, aged 6 – 13. Children who scored above the cut-off for elevated anxiety on the autism-specific measure of anxiety (ASC-ASD) had poorer total HRQoL and poorer scores on the social, emotional, physical, and school functioning QoL domains. Regression analyses indicate that children’s self-reported ratings of difficulties with uncertainty on the ASC-ASD predicted all domains of HRQoL, with higher levels of difficulty with uncertainty predicting poorer HRQoL. Elevated levels of anxious arousal were also predictive of poorer physical functioning. This study highlights the importance of exploring the impact of anxiety on individuals on the spectrum and suggests that using carefully planned interventions to reduce difficulties with uncertainty may be a potential way to work towards improving the QoL of children on the spectrum.

Lay summary:

Research has shown us that individuals on the autism spectrum are more likely to have poor “quality of life” or general well-being. Because many individuals with a diagnosis on the autism spectrum also receive a diagnosis of anxiety, this study looked at whether a child’s autism symptoms or their anxiety have a bigger impact on their quality of life. Children on the autism spectrum completed questionnaires and the results showed us that one factor, difficulty with uncertainty, had the biggest impact on the child’s quality of life.

Keywords: autism, self-report, mental health, well-being, anxiety

Introduction

Quality of life (QoL) is a construct that represents an individual's perception of his/her experience of and satisfaction with life in relation to their culture, value systems, goals, and expectations (World Health Organisation, 1997). QoL is accepted as a multidimensional concept which can include measures of emotional, physical, and social well-being; it can be either collected directly from the individual or an objective perception of QoL from proxy report, for example by a parent or guardian (de Vries & Geurts, 2015). Health-related quality of life (HRQoL) is a subjective and multidimensional construct under the QoL umbrella that focuses on the dimensions of QoL more directly related to physical or mental health and includes the domains related to physical activities, positive health behaviours, school functioning, and psychosocial well-being. It is therefore well suited to conditions that have a multidimensional impact, such as the autism spectrum (Kuhlthau et al., 2010). Systematic reviews conclude that when measures designed for the typically developing population are used, the QoL and HRQoL of children, adolescents, and adults on the autism spectrum are reported to be significantly lower than those reported in their typically developing peers (Ayres et al., 2018; van Heijst & Geurts, 2015). To date, assessments have typically relied on parent report of child QoL with comparatively fewer studies including child self-report (see review by Ikeda, Hinckson, & Krageloh, 2014). While parents are aware of their child's strengths and difficulties and are able to provide valuable information on their child's functioning (Coghill, Danckaerts, Sonuga-Barke, Sergeant, & the ADHD European Guidelines Group, 2009), QoL is a *subjective* measure and for that reason it is arguably best captured by the individual themselves (Egilson, Olafsdottir, Leosdottir, & Saemundsen, 2017; Shipman, Sheldrick, & Perrin, 2011). As such, relying on parent-only report may be a significant limitation.

In their review of QoL studies in children and adolescents with autism, Ikeda et al. (2014) explored agreement between proxy and child self-report measures of QoL and concluded that discrepancies are both present and large between informant types. However, these discrepancies may be reflective of differing perspectives on the same experience, as when parents are asked to complete a proxy measure of QoL and to respond in the way they think their child would respond (rather than responding as they would like to respond as a parent), agreement between child and parent reporting increased. There is often stronger agreement between accounts of "observable domains" such as physical functioning and less agreement when considering the "non observable" domains including emotional and social functioning (Eiser & Morse, 2001). This

provides further evidence of differences between parent and child accounts which may reflect differences in the understanding and interpretation of the QoL constructs. In light of this incongruence between parent and child reports, QoL researchers have stressed the importance of self-report data to capture a child's unique perspective of their own well-being (Clark, Magill-Evans, & Koning, 2014; Kamp-Becker, Schroder, Remschmidt, & Bachmann, 2010; Rapley, 2003; <removed for blind review>).

With the consistent finding of poorer QoL (on available measures) for individuals on the spectrum than for typically developing individuals, studies have now begun to explore the factors that influence QoL for those on the autism spectrum. A systematic review by Chiang and Wineman (2014) revealed differing factors associated with QoL for adults and children. For adults, greater behavioural difficulties and less engagement in leisure activities were associated with poorer QoL. For children, the number of factors associated with poorer QoL was larger (which may reflect the higher volume of research for children than for adults), including higher child age, more autism symptoms/characteristics, and the presence of/more severe behavioural difficulties or co-occurring conditions.

One of the most prevalent conditions to co-occur with autism spectrum conditions is anxiety. Anxiety disorders affect approximately 40 – 60% of individuals on the autism spectrum (van Steensel, Bogels, & Perrin, 2011; White, Oswald, Ollendick, & Scahill, 2009). However, this may be an underestimate given the high degree of overlap in anxiety symptomatology and autism characteristics that can lead to diagnostic overshadowing (Kerns et al., 2014) and the presentation of behavioural, rather than emotional symptoms (Adams, Young, Simpson, & Keen, 2018). A comorbid diagnosis of autism and anxiety is likely to have a serious impact on a child's QoL overall, but research to date investigating the impact of autism, and of anxiety and autism, on QoL has been limited.

There has been considerable research exploring the impact of mental health, and in particular anxiety, on the HRQoL of neurotypical individuals, with more research exploring the relationship in adults than in children. A review of the HRQoL of adults with anxiety disorders concluded that "*QoL assessment has been instrumental in exposing the extent and seriousness of anxiety disorders*" and that note an extensive reduction in the QoL of individuals with anxiety when compared to those with no diagnoses (Mendlowicz & Stein, 2000). One of the few studies to explore the relationship between anxiety and QoL in children identified relationships between anxiety and specific subscales of the PedsQL (Bastiaansen, Koot, Ferdinand &

Verhulst, 2004). Ramsawh and Chavira (2016) built upon this by exploring the impact of anxiety symptomatology on PedsQL scores using regression analyses for parent and child report. Using child self-report, the Multidimensional Anxiety Scale for Children (MASC) physical symptoms domain (which measures tense/restless and somatic/autonomic symptoms) significantly predicted total PedsQL scores, with the total model explaining 58% of the variance. The analysis using parent-report also identified the MASC physical symptoms subscale as a significant predictor, but also identified a second predictor; the MASC social anxiety subscale. The parent-report model explained 50% of the variance in the PedsQL total score. Ramsawh and Chavira also noted that HRQoL decreased significantly with a greater number of anxiety diagnoses as well as a greater number or severity of anxiety symptoms, highlighting that both diagnosis and severity of symptomatology “matters” in exploring the impact of anxiety on QoL.

Two recent studies have explored the association between mental health and QoL in adults on the autism spectrum. Mason et al. (2019) report that adults on the spectrum (aged 55 and above) with anxiety and/or depression reported lower subjective QoL. Analysing parent-report for 241 adults on the spectrum (aged 18-27 years), Smith, Ollendick and White (2019) identify anxiety as a stronger predictor of QoL than autism characteristics. Three studies have measured both QoL and anxiety in children on the autism spectrum. van Steensel, Bogels, and Dirksen (2012) explored the impact of anxiety and the impact of autism characteristics on the QoL of children with (n = 115) and without (n = 122) a diagnosis on the autism spectrum. Using parent report, they conducted two separate analyses the first exploring the impact of autism characteristics on QoL and the second, the impact of anxiety on QoL, identifying significant parameter estimates for both autism and anxiety. Although autism characteristics are a well-established predictor for QoL, van Steensel et al. did not explore the impact of anxiety and autism characteristics in the same analysis. This therefore limits the extent to which the findings can be used to understand the impact of anxiety on QoL, over and above that associated with autism characteristics. Shipman et al. (2011) asked 39 adolescents with a confirmed autism diagnosis to self-report on their HRQoL (using the Pediatric Quality of Life Inventory [PedsQL]; Varni, Seid, & Kurtin, 2001) and their anxiety (using the 5-item version of the Screen for Child Anxiety Related Emotional Disorders [SCARED]; Birmaher et al., 1999). Shipman et al. note negative correlations between the PedsQL subscale scores and the 5-item SCARED score, with stronger correlations for the emotional and physical functioning subscale scores than for the social or school functioning subscale

scores. However, these correlations do not statistically control for the impact of other factors known to be predictive of QoL in individuals on the spectrum, such as autism characteristics.

The only study, to our knowledge, which has statistically explored levels of anxiety on QoL in children on the spectrum whilst controlling for characteristics known to predict QoL relied upon parent-report is (<removed for blind review>). Regression analyses identified a child's anxiety symptoms as a stronger predictor of HRQoL than their autism characteristics (as measured by the Social Communication Questionnaire [SCQ]; Rutter, Bailey, & Lord, 2003). Elevated anxiety symptoms were related to poorer total HRQoL score and were associated with poorer functioning in the physical, emotional, and school functioning subdomains of the PedsQL. However, this study was based upon parent report which (as discussed earlier) may differ from self-report and based on the premise that there may be differences in parent and child perceptions of QoL, there is a need to explore the relationship between anxiety and QoL in individuals on the autism spectrum from the child's own account. Therefore, while three studies have explored anxiety and QoL in children on the autism spectrum, there are significant limitations with each study; only one (<removed for blind review>) controlled for autism characteristics (consistently reported to be predictive of QoL in individuals on the spectrum), but this relied on parent report. Although Sheldrick et al. (2011) used self-report, they did not control for factors known to be predictive of QoL in individuals on the spectrum and van Steensel et al. (2012) used parent report and did not explore factors known to be predictive of QoL in individuals and anxiety in the same analysis. There is therefore a need for a study which uses self-report to explore the impact of anxiety on QoL, whilst controlling for autism characteristics, in children on the spectrum.

In summary, despite the high prevalence of anxiety in autism, little is known about the impact of autism and anxiety on how children and adolescents on the autism spectrum perceive, interpret, and report on their own functioning. This will be the first study to investigate the impact of anxiety symptoms and autism characteristics on the QoL of children on the autism spectrum via self-report using the PedsQL. The total score and the four subdomains of the PedsQL scale (physical, social, emotional, and school functioning) will be examined. We hypothesised that, consistent with the reviewed studies, children's anxiety symptomatology would predict the self-reported QoL of school-aged children on the autism spectrum. Additionally, we hypothesised that children who reported higher anxiety symptoms would experience poorer QoL when compared to children reporting lower anxiety symptomatology.

Methods

This study used data collected as part of the <removed for blind review>. Ethical approval for this study was obtained from all participating universities and relevant health authorities.

Recruitment Procedures

The full recruitment procedure for the larger <removed for blind review> cross-sequential study is described in <removed for blind review>. In brief, parents of children on the autism spectrum aged 4 – 5 or 9 – 10 years living in <removed for blind review, 2017> were invited through clinics and advertisements on social media to take part in a 6-year study with annual data collection through an online survey. The sample was therefore self-selecting and for reasons of confidentiality and practicality, the research team was not provided with any information on families who may have been provided with recruitment information but who did not choose to enroll into the study. Upon entry into the study, all participants were requested to provide copies of their diagnostic reports as well as to complete a measure of autism characteristics (SCQ; Rutter et al., 2003).

In the third year of the longitudinal study, all 272 parents who were participating were sent invitations for their child to complete an optional online survey about their own feelings and experiences. If both parent and child gave consent, parents were emailed a link to the online self-report questionnaire, which could be completed across a number of sittings if required. Parents and children were informed that parents could be present when their child was completing the survey, but parents were asked to neither assist with the answers nor include their own perspectives.

Participants

In total, 83 children began the questionnaire. Nine children had a score on the SCQ below 15 but all had community diagnostic reports to confirm a diagnosis on the autism spectrum so were retained in the study. Twelve participants were excluded as they had completed less than 90% of the questions that are focused upon in the study. There were no significant differences in responders and non-responders in gender ($\chi^2(1) = .22, p = .64$), parent education ($U = 6542, p = .20$), or family income ($U = 6601, p = .38$). However, there was a significant difference in age at enrolment into the study ($t(270) = -3.20, p = .002$), with those participating in the self-report being significantly older than those who did not participate.

Following exclusions, the sample consisted of 71 children with a diagnosis on the autism spectrum. Due to the dual-cohort design of the larger longitudinal study, the 23 children from the younger cohort were aged between 6 years 7 months and 8 years 8 months and the 48 from the older cohort were aged between 11 years 1 month and 13 years 8 months. Overall, the mean age for the total sample is 10 years 8 months ($SD = 28$ months). The sample was 81.7% male, which is in line with the recent gender ratio estimates (Loomes, Hull, & Mandy, 2017). The majority of children lived in households where the parents had a tertiary education (74.6%) and were employed either full- or part-time (64.1%); 59.2% had reported an income at or above the national median income for <country removed for blind review>.

Measures

Demographic characteristics. Information about the child (age, gender, age at diagnosis) and parent and family demographics (education, employment) is collected annually as part of the longitudinal study. Relevant information was taken from the Time 3 longitudinal study demographic questionnaire.

Autism characteristics. The Social Communication Questionnaire (Rutter et al., 2003) is a behavioural checklist that requires parents to indicate the presence of certain social, communicative, or stereotyped behaviours by answering yes or no to 40 items. The SCQ has been extensively researched, with a recent meta-analysis (Chesnut, Wei, Barnard-Brak, & Richman, 2017) concluding that it is an acceptable screening measure for autism spectrum disorder (area under the curve .89). A higher score represents a higher number of behaviours which may be considered indicative of autism. In the current study, internal consistency was good based on Cronbach's alpha; $\alpha = .84$.

Child anxiety. The Anxiety Scale for Children with Autism Spectrum Disorder – Child Form (ASC-ASD-C; Rodgers et al., 2016) aims to assess both the typical and autism-specific symptoms of anxiety experienced by children on the autism spectrum. It consists of 24 items which are grouped into four subscales: Performance Anxiety (five items, maximum score 15); Anxious Arousal (six items, maximum score 18); Separation Anxiety (five items, maximum score 15), and Uncertainty (eight items, maximum score 24). Severity was rated on a 4-point scale ranging from 0 (*never*) to 3 (*always*). Although the scale was originally developed for children aged 8 or above, the parent version has been used in younger samples of children on

the autism spectrum to describe anxiety symptomatology (e.g., Keen, Adams, Simpson, den Houting, & Roberts, 2017).

The scale has good validity, reliability, and internal consistency and is highly correlated with the Screen for Child Anxiety Related Emotional Disorders (SCARED) (Birmaher et al., 1999), a robust measure of anxiety in the general population. In the current study, internal consistency was identified as acceptable to excellent for all subscales based on Cronbach's alpha: Anxious Arousal $\alpha=.85$, Separation Anxiety $\alpha=.79$, Performance Anxiety $\alpha=.86$, and Uncertainty $\alpha=.89$. Two indicative cut-off points for the ASC-ASD-C total scale have been put forward by the authors: scores ≥ 20 suggest "significant anxious symptomatology", and scores > 24 are considered to be a "more specific indication of significant anxiety". PRMSE values indicate that the ASC-ASD is statistically valid at subscale level, with subscales adding clinical utility above using the total score alone (Adams, Simpson & Keen, 2018). Den Houting, Adams, Roberts, & Keen (2018a) report good concurrent validity between the Spence Child Anxiety Scale – Child Report (SCAS-C) and the ASC-ASD-C as well as good concurrent validity between the ASC-ASD-C cut-offs and parent-reported formal diagnosis of an anxiety disorder. Within this study, the higher cut-off score of 24 was used to indicate elevated anxiety symptomatology.

Quality of Life. The PedsQL 4.0 (Varni, Seid, & Rode, 2001) is a measure of HRQoL and consists of 23 items. Children completing this measure were asked to rate how often they have had problems with a specific task or experience (rather than rate the presence or absence of a certain behaviour). Four subscales can be derived: physical functioning (e.g., energy, activity, strength), emotional functioning (e.g., feeling angry, sleep, worry), social functioning (e.g., friendships, getting teased) and school/work functioning (e.g., attendance, completing schoolwork).

Two versions of the PedsQL were utilised in the current study: a young child report for children aged 5 – 7 and a child report for children aged 8 – 12. Severity was rated on a 3-point scale for the young child report, consisting of 100 (*never*), 50 (*sometimes*), or 0 (*almost always*), and the child version rated on a 5-point scale of 100 (*never*), 75 (*almost never*), 50 (*sometimes*), 25 (*often*) and 0 (*almost always*). A higher score reflects a higher QoL. The numbers (100, 50, 0) and words associated with the numbers (*never*, *sometimes*, *almost always*) in the young child are identical in the child report, but the child report also has the option of responding with *almost never* (score of 75) and *often* (score of 25). Limbers et al. (2008) state that these

instrument differences were deliberately designed to make the self-report measure more understandable for 5 – 7-year-olds based on extensive and iterative focus groups and cognitive interviewing protocols, whilst also allowing for comparable scoring. Exploring data from 8,591 self-report PedsQL across children aged 5 – 16, Limbers et al. explored measurement invariance of the range of forms of the *PedsQL*. The 5-factor structure of the *PedsQL* holds across children across all age ranges, and that scores from the 3-point Likert ratings did not differ significantly from the scores from the 5-point ratings. They therefore concluded that that children had a similar interpretation of the items on the PDSQL regardless of age. Therefore, within this study, the PedsQL scores from the younger and older cohort are combined to explore HRQoL across the cohort of 71 children. In the current study, internal consistency for the young child report was identified as acceptable for all subscales based on Cronbach's alpha: Physical $\alpha=.76$, Emotional $\alpha=.75$, Social $\alpha=.78$, and School $\alpha=.71$.

Data Analysis

Data were screened to ensure they met assumptions of normality using skew and kurtosis. As all skew and kurtosis statistics were below 1, parametric analyses were conducted. As the current study was a novel exploration of the impact of anxiety and autism characteristics on child HRQoL using self-reports, and is aimed at highlighting areas for in-depth investigation in future research, increased risk of Type 1 errors was considered less of a concern than Type 2 errors. Although the design required multiple analyses which potentially raised the possibility of increased Familywise error, Bonferroni correction was considered too conservative (Perneger, 1998). Thus, the decision was made a priori to retain a p-value of .05 across analyses.

First, child HRQoL was compared between those who were above and below the cut-off indicative of anxiety on the ASC-ASD-C using a ANOVA (for the total score) and MANOVA (to explore subscale scores). Effect sizes were calculated using partial eta-squared (ηp^2), where .01 is considered a small effect size, .06 a medium effect size, and .14 a large effect size. Second, to study whether specific subscales of the ASC-ASD-C were predictive of different aspects of HRQoL, forced entry linear regression analyses were conducted with HRQoL subscales as the dependent variables and ASC-ASD-C subscale scores as predictor variables. Prior to examining prediction models, bivariate correlations were conducted which revealed no collinearity of predictors ($r > .80$), thus all were retained (see Table 1). Although the nine children who had an SCQ score below cut-off all had community diagnostic reports to verify diagnosis, analyses were undertaken both with

and without these children within the sample. As there were no notable differences in the results, the results from the full sample are reported below.

<Insert Table 1 about here>

Results

Child HRQoL in those with and without elevated anxiety symptomatology

Forty-one children (57.7%) reported an ASC-ASD-C above the cut-off, suggesting elevated anxiety; 15 of these were from the younger cohort and 26 were from the older cohort. Children who reported elevated anxiety symptomatology self-reported significantly lower overall HRQoL scores ($\bar{x} = 51.6$, $sd = 12.3$) than those who did not reported elevated anxiety ($\bar{x} = 71.4$, $sd = 10.6$) ($F(1, 68) = 49.0$, $p < .001$, $\eta p^2 = .42$). A MANOVA identified significant differences in the the HRQoL subscale scores in those with and without elevated anxiety symptomatology ($F(4, 65) = 11.9$, $p < .001$, $\eta p^2 = .42$). As summarised in Table 2, children who reported elevated anxiety also had significantly lower scores in the physical, emotional, school, and social functioning subscales. All comparisons had a large effect size.

<Insert Table 2 about here>

Influence of child anxiety symptomatology on child HRQoL

In order to explore whether specific subscales on the measure of anxiety predict self-reported total HRQoL score and/or specific aspects of their HRQoL, a series of linear regressions were undertaken. As autism symptomatology has previously been shown to be predictive of child HRQoL over and above child ability on the basis of parent report (e.g., de Vries & Guerts, 2015), the child's total SCQ score was entered alongside the ASC-ASD-C subscale scores using the forced entry/enter method. Child age was also added as a predictor as the sample was combining those from the younger and older cohorts of the longitudinal study and therefore contained children across a range of ages (see participant description). The results are presented in Table 3 (n.b., higher scores on the HRQoL scale indicate a better HRQoL, whilst higher scores on the ASC-

ASD-C represent more anxiety symptomatology and higher scores on the SCQ represent more autism characteristics).

All models, with the exception of social functioning, were significant, predicting 28 – 58% of the variance. The consistent predictor of HRQoL (total score and subscale scores) was the Uncertainty scale of the ASC-ASD-C. Standardised beta coefficients indicate that those with higher levels of anxiety around uncertainty have poorer HRQoL. Anxious arousal was also a significant predictor (in conjunction with uncertainty) for physical functioning only; standardised beta coefficients indicate that those with higher levels of anxiety around uncertainty and those with higher anxious arousal symptoms have poorer physical functioning HRQoL scores.

<Insert Table 3 about here>

Discussion

This is the first study to use self-report to investigate the relationship between children's autism characteristics, anxiety symptomatology, and HRQoL in children on the autism spectrum. Despite the growing evidence that individuals on the autism spectrum are more vulnerable to anxiety conditions (van Steensel et al., 2011; White et al., 2009) and that they may experience anxiety differently from neurotypical populations (Lecavalier et al., 2014; White et al., 2015), there has been little research to understand the impact that anxiety has on the HRQoL of children on the autism spectrum. This study provides evidence that when controlling for autism characteristics, anxiety significantly impacts upon the HRQoL of children on the autism spectrum and highlights the need for further research in this area.

As hypothesised, the current study found that children with elevated anxiety symptoms self-reported poorer HRQoL overall (PedsQL total score) when compared to children with lower anxiety symptoms. Those children who reported higher anxiety symptoms also reported poorer physical, emotional, social, and school functioning. These results are consistent with the correlational results of Shipman et al. (2011) and the comparisons of parent-report measures of anxiety and HRQoL in <removed for blind review>.

In the <removed for blind review> study, forced entry linear regression analyses indicated that autism characteristics were predictive of the physical functioning HRQoL domain whilst specific aspects of anxiety

symptomatology (using the parent version of the ASC-ASD) explained two domains of HRQoL (the emotional and school domains) whilst controlling for autism characteristics. None of the factors entered were unique significant predictors to the total HRQoL score. In contrast, within this self-report study, when controlling for autism characteristics, there was one subscale of the ASC-ASD, the Uncertainty subscale, which significantly predicted the total HRQoL score alongside all of the domain scores. This warrants further discussion. In developing the ASC-ASD, Rodgers et al. (2016) based some of the Uncertainty items on the Intolerance of Uncertainty scale (Freeston, Rheaume, Letarte, Dugas, & Ladoucer, 1994) and some were derived from the Revised Children's Anxiety and Depression Scale (RCADS; Chorpita, Yim, Moffitt, Umemoto, & Francis, 2000) upon which the ASC-ASD is based (see Rodgers et al., 2016, for a full description). This means that within the Uncertainty subscale, a number of items are specifically related to intolerance of uncertainty (IU), a cognitive construct related to anxiety (Boulter, Freeston, South, & Rodgers, 2014; Wigham, Rodgers, South, McConachie, & Freeston, 2015). It is possible then that IU is impacting upon an individual's QoL and therefore their functioning and well-being. Parents describe the significant impact that IU has on their child and consequently the measures they put in to place to attempt to reduce IU in their child's lives (Hodgson, Freeston, Honey, & Rodgers, 2017). However, whilst avoidance of uncertain situations may help to reduce anxiety and foster calm in the short term, life is notoriously unpredictable so Rodgers et al. (2017) have developed a treatment for IU. One method of exploring the impact of IU on QoL would be to incorporate QoL measures into the assessment measures given pre and post the IU intervention with reports from both parent and children. South and Rodgers (2017) propose a model to explain the link between characteristics associated with autism (atypical sensory function, alexithymia, rigidity of thought) through IU to restricted and repetitive thoughts and behaviours and anxiety which may form the basis of future work exploring HRQoL and the process by which IU impacts HRQoL in children on the spectrum.

The differences between the specific aspects of anxiety which predicted areas of QoL in this study (using child self-report) and <removed for blind review> using parent report highlight the importance of gathering information from multiple sources. As noted in Adams et al. (2018) and <removed for blind review>, each informant is a potentially important source of information and perhaps on this occasion, highlights possible differences between the internal experience (self-report indicating Uncertainty as having the largest influence on HRQoL) and external perception (parent-report suggesting differing aspects of

anxiety and autism characteristics impacting upon HRQoL) of anxiety. There may also be differences in the sample characteristics, for example, the parent report method of <removed for blind review> had a large age range and may have allowed for reporting on broader range of child ability. In order to extend the knowledge around anxiety, there is a need for further work which sees the value in combining, rather than comparing informant reports.

The Anxious Arousal subscale of the ASC-ASD, together with the Uncertainty subscale, was associated with reduced physical functioning including poor energy, reduced concentration, and physical aches and pains. Education of parents and teachers to raise awareness of these physical manifestations of anxiety could help in the detection of anxiety at home and school and ensure children have access to appropriate supports and interventions. A recent systematic review identified a lack of anxiety research for school-aged children on the autism spectrum (<removed for blind review>), which is problematic given children spend extensive time in the school environment. School functioning was identified in this study as an area impacted by elevated Uncertainty subscales scores (although, interestingly, not the Performance Anxiety subscale). This reiterates the need for further research to assist teachers with both the identification and implementation of strategies to support anxiety in their students on the autism spectrum (<removed for blind review>).

The lack of correlation between the SCQ and the ASC-ASD scores is in-line with previous explorations of the ASC-ASD parent report (e.g den Houting et al., 2018b; Keen et al., 2019) as well as other studies reporting on the ASC-ASD self-report (den Houting et al., 2018a). den Houting et al. (2018a) suggest that the consistent lack of correlation between the SCQ and ASC-ASD lends support to the notion that the ASC-ASD specifically measures anxiety rather than autism characteristics. However, as other measures of anxiety (e.g Spence Child Anxiety Scale; SCAS parent and child versions; den Houting et al., 2018a) also do not correlate with the SCQ, further research is needed to explore the relationship between measures of anxiety and other measures of autism characteristics such as the Autism Diagnostic Observation Schedule, 2nd edition (ADOS-2; Lord et al., 2012) and/or the Autism Diagnostic Interview, Revised (ADI-R; Rutter, Le Couteur, & Lord, 2003). Although previous studies have found autism characteristics to be predictive of HRQoL, within this study, when controlling for autism characteristics, anxiety symptoms (specifically Uncertainty) were the strongest predictor of HRQoL, providing further support for the conclusion that anxiety causes more

disruption to the individual than their autism characteristics (Matson & Nebel-Schwalm, 2007). Further work is needed to explore how and why this may be, combining qualitative and quantitative self-report and informant report data across a range of ages.

The use of self-report data was a strength of this study as, to date, research has largely considered anxiety and QoL from the parents' perspective with little known about how children on the autism spectrum themselves identify and report on their own experiences, strengths, and weaknesses. The use of the autism-specific measure of anxiety was also a strength, given the importance in considering diagnosis when assessing emotions (Flynn et al., 2017; Oliver et al., 2010). However, the QoL measure was one designed for typically developing children. When asked to review measures of QoL, parents of children on the spectrum identified ways in which some of their child's autism characteristics, including language and communication difficulties, preferences for recalling specific examples rather than providing global likert-scale answers to questions that about "in the last week/month" and difficulties with emotional vocabulary, can impact upon the interpretation of the questions and/or the answers provided (Tavernor, Barron, Rodgers & McConachie, 2012). There are increasing suggestions that measures of QoL designed for typically developing individuals may need addendums or modifications to measure all aspects of QoL that are important to individuals on the spectrum. McConachie et al. (2018) have developed the Autism Specific QoL items (ASQoL) with input from consultees (including individuals on the spectrum and autism researchers). The ASQoL is used as a supplement to a widely used adult self-report measure of QoL in order to "*elucidate some of the challenging issues they [adults on the spectrum] may be experiencing in their lives*" such as sensory overload and barriers to accessing healthcare. Future research should begin to develop such autism-specific measures for children and aim to use autism-specific measures of QoL (where available) to further extend our knowledge in this area. Such measures would also be important in beginning to extend this work and explore the impact of other factors associated with anxiety, such as those suggested in the model by South and Rodgers (2017), on HRQoL.

Limitations and future directions

The current study utilized online questionnaires without any direct child assessment to confirm autism diagnosis or determine child ability. Whilst this allowed for a relatively large sample size (for a child self-

report study) across a broad geographical region, it also has inherent limitations in that there is no independent validation of autism diagnosis nor any measure of IQ. Future research should consider supplementing self-report with assessments of child ability including adaptive functioning and cognition, as these have been associated with QoL outcomes in other studies (Arias et al., 2018; Chiang & Wineman, 2014; Totsika, Felce, Kerr, & Hastings, 2010) to extend the models and remove the reliance on the SCQ which is not a diagnostic tool but an autism characteristics screener. The current study did not have access to a control group to compare the self-reported QoL of children on the autism spectrum to their peers who do not have a diagnosis on the spectrum, which is a significant limitation which should be addressed in future studies. However, numerous systematic reviews have documented the consistent pattern of QoL being poorer in individuals on the spectrum, which is the reason why this study specifically looked at factors which may then contribute to poorer QoL in this population. Due to the nature of the recruitment from an existing longitudinal study with two age cohorts, there is a bimodal distribution of ages and due to sample size restrictions, analysis could not be undertaken for each age cohort separately. Although child age was controlled for in the analysis, future studies should be carefully designed to allow for a more equal distribution of child age across the sample.

Due to the methodology (an online survey requiring typing of open-ended answers), it was deemed appropriate to allow parents to have the option to be with their children when the child completed the survey. Even though both parents and children were informed that the researchers were interested in the child's thoughts and answers and that the adult was not to influence the responses, there is no way to be certain about the extent to which the caregiver being present may have influence responses. However, this is a limitation that is present for any online self-report study for children (with or without autism). Finally, as the data on anxiety and quality of life come from a single source, the results must be interpreted with consideration to shared or common methods variance. Future studies could address this issue by counter-balancing questionnaires and/or using other sources (such as parent report) as additional key variables.

Conclusions

To the authors' knowledge, this is the first study to explore whether anxiety and autism characteristics predicted the self-reported QoL of children on the autism spectrum. Based on the self-report of children on the autism spectrum report, this study has highlighted that it is the predominantly elevated difficulties with

Uncertainty (associated with IU) that is associated with poorer QoL in children on the spectrum. Given the emergence of new interventions showing promising results to reduce IU, this may be an avenue for improving QoL in children on the autism spectrum.

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Table 1.

Pearson Correlations Between Predictor Variables

	2	3	4	5	6	7	8	9	10	11
1. SCQ total score	.23	-.06	.25*	.06	.29*	-.24*	.05	-.09	-.07	-.13
2. Child age (months)	-	.23	-.02	-.16	-.08	-.06	-.09	-.21	.06	-.09
3. ASC-ASD-C Performance		-	.53**	.49**	.52**	-.16	-.51**	-.42**	-.46**	-.52**
4. ASC-ASD-C Anxious Arousal			-	.51**	.74**	-.02	-.46**	-.37*	-.51**	-.64**
5. ASC-ASD-C Separation				-	.67**	-.16	-.47**	-.29*	-.35*	-.44**
6. ASC-ASD-C Uncertainty					-	-.08	-.55**	-.44**	-.59**	-.72**
7. PedsQL Physical Functioning						-	.33*	.35*	.36*	.77**
8. PedsQL Emotional Functioning							-	.38**	.54**	.74**
9. PedsQL School Functioning								-	.32*	.75**
10. PedsQL Social Functioning									-	.66**
11. PedsQL Total HRQoL score										-

* $p < .05$; ** $p < .001$.

Table 2.

PedsQL Mean Score per Question for Subscale Scores Split by Children Scoring Above and Below the ASC-ASD-C Cut-Off for Elevated Anxiety

PedsQL subscale	Below ASC-ASD-C		Above ASC-ASD-C		MANOVA Post-hoc Statistic		Effect Size Parial eta squared
	cut-off		cut-off		df (1,68)		
	Mean (sd)		Mean (sd)		F	p	
	N = 30		N = 41				
	M	SD	M	SD			
Physical Functioning	79.9	13.3	61.4	20.5	22.1	<.001***	.25
Emotional Functioning	62.3	20.6	43.8	17.5	17.0	<.001***	.20
Social Functioning	68.1	15.2	51.1	19.3	23.7	<.001***	.26
School Functioning	67.9	18.7	44.5	20.6	15.6	<.001***	.19

* $p < .05$; ** $p < .01$ *** $p < .001$.

Table 3.

Results of Linear Regressions Exploring Anxiety (ASC-ASD-C) Subscales, Autism Characteristics (SCQ), and Child Age Predicting HRQoL Subscales (PedsQL)

	Child HRQoL (PedsQL)				
	Total HRQoL	Physical Functioning	Emotional Functioning	Social Functioning	School Functioning
Total R ²	.58	.37	.42	.41	.28
<i>F</i>	14.6***	6.2***	7.6***	7.3***	4.0**
<i>df</i>	63, 6	64, 6	64, 6	63, 6	63, 6
	β	β	β	β	β
ASC-ASD-C Performance	-.07	.26	-.15	-.24	-.16
ASC-ASD-C Anxious Arousal	-.20	-.37*	-.06	-.09	-.03
ASC-ASD-C Separation Anxiety	.11	.17	-.13	.18	.04
ASC-ASD-C Uncertainty	-.65***	-.52**	-.41*	-.54**	-.40*
SCQ	.12	.07	.21	.06	.07
Child age (months)	-.14	-.16	-.16	.09	-.21

* $p < .05$; ** $p < .01$ *** $p < .001$.