

# **The relationship between child anxiety and the quality of life of children, and parents of children, on the autism spectrum.**

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**Running Head:** Anxiety and quality of life

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**The relationship between child anxiety and quality of life in children, and parents of children, on the autism spectrum.**

Children on the autism spectrum experience high rates of anxiety but little is known about the impact of anxiety on child or parent quality of life (QoL). This study aimed to investigate the relationship between anxiety, autism characteristics, and QoL in children and their parents. Sixty-four parents of children on the spectrum completed questionnaires on their child's autism characteristics, anxiety symptomatology, and both child (PedsQL) and parent QoL (WHOQoL-BREF). Parents of children with elevated anxiety reported lower child and parent QoL. Regression models highlight specific anxiety subscales as predictive of PedQL school and emotional functioning but not of parent QoL. Anxiety symptomatology may be a significant factor contributing to specific aspects of QoL for children on the spectrum.

**Keywords:** autism, anxiety, health-related quality of life

The autism spectrum is a lifelong neurodevelopmental condition with a current prevalence rate of 1 in 59 individuals (CDC, 2018). Children on the autism spectrum are more vulnerable to anxiety than are typically developing children, with up to 40% of children on the autism spectrum meeting criteria for a co-morbid anxiety disorder (van Steensel, Bogels, & Perrin, 2011). Moreover, it is not uncommon for individuals on the autism spectrum to concurrently experience more than one type of anxiety (Rodgers et al., 2017). The presence of an anxiety disorder has been found to cause functional impairment over and above the characteristics of autism (Matson & Nebel-Schwalm, 2007). Despite anxiety symptoms being amongst the most common presenting concerns for children and adolescents on the spectrum (White et al., 2015), both clinicians and researchers can find it inherently difficult to assess anxiety symptoms in individuals on the spectrum due (at least in part) to the overlapping symptomatology of the two conditions that increases the challenge of delineating autism and anxiety (Rodgers et al., 2016).

There is increasing evidence that whilst some aspects of anxiety are similar between those with and without a diagnosis of autism, there are also some aspects of anxiety which can manifest differently in children on the spectrum. The presentation of anxiety can vary as a function of autism characteristics or profile, associated autism diagnostic subtype, age of the child, cognition and language abilities (Caporino et al., 2017; Lecavalier et al., 2014; Wigham, Rodgers, South, McConachie, & Freston, 2015) and/or environment (Adams, Young, Simpson, & Keen, 2018). There is also the suggestion of atypical as well as typical signs of anxiety (Kerns & Kendall, 2012) as well as an increased prevalence of difficulties with tolerating uncertainty (den Houting, Adams, Roberts, & Keen, 2018b). The potential differences in anxiety symptomatology combined with the potential for overlap with autism characteristics have led to growing concern around the validity and reliability of assessing anxiety symptomatology in individuals on the autism spectrum using instruments originally

developed to capture anxiety in typically developing children. To that end, the Anxiety Scale for Children with ASD (ASC-ASD; Rodgers et al. 2016) was adapted from the Revised Child Anxiety and Depression Scale (Chorpita, Yim, Moffitt, Umemoto, & Francis, 2000) to include items that measure anxiety around sensory experiences, difficulties with uncertainty, and specific phobias, bridging the gap in the assessment of anxiety in children on the spectrum. Adapting a measure of anxiety designed for typically developing children allowed for the recognition of the overlap of anxiety experiences between those with and without a diagnosis on the spectrum as well as measuring additional autism-specific factors not captured on measures designed for typically developing individuals.

While the high prevalence of anxiety in the autism population has been recognised, the impact of anxiety on the functioning of children on the autism spectrum is not well understood. To date, there has been a greater focus on how anxiety impacts upon the development, health, and well-being of typically developing children. Childhood anxiety has been found to implicate the development of typically developing children in a number of ways. Children experiencing anxiety are more vulnerable to cognitive and language impairments and psychopathology such as depression later in life (Beesdo, Knappe, & Pine, 2009). Further, anxiety in typically developing children has been associated with increased social competence deficits and, thus, has been associated with poorer social outcomes when compared to children without anxiety (Spence, Donovan, & Brechman-Toussaint, 1999). Sleep disturbances associated with childhood anxiety are also well documented (Caporino et al., 2017; Gregory et al., 2011; Gregory & Sadeh, 2012; Ivanenko, McLaughlin Crabtree, O'Brien & Gozal, 2006) and can heighten a child's risk of other health complications (Mahrer, Montano, & Gold, 2012). To date, research has not extensively explored the impact of anxiety in children on the autism spectrum, so it is not yet known if patterns are similar to or different from those noted in typically developing children. While the functional

impairment varies depending on the nature and severity of the specific anxiety condition (Beesdo et al., 2009), findings from typically developing children suggest that childhood anxiety can have negative repercussions for a child's quality of life.

### *Quality of life in children on the autism spectrum*

Quality of life (QoL) is a broad, multidimensional construct defined by the World Health Organisation (WHO) Group as the subjective perception of one's life and well-being, assessing both positive and negative dimensions of functioning (The WHOQOL Group, 1998). 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).

Children and youth with a diagnosis on the autism spectrum are frequently reported to have poorer QoL and specifically, poorer HRQoL when compared with their typically developing peers (Kuhlthau et al., 2010; Lee, Harrington, Louie, & Newschaffer, 2008; Limbers, Heffer, & Varni, 2009; Sikora, Vora, Coury, & Rosenberg, 2012; van Heijst & Geurts, 2015) and this continues across the lifespan (van Heijst & Geurts, 2015). They are also reported to have overall poorer HRQoL than children with psychiatric disorders (Bastiaansen, Koot, Bongers, Varni, & Verhulst, 2004). HRQoL is an important measure of outcome for individuals on the autism spectrum as it provides a comprehensive view of functioning across multidimensions including physical, social, emotional, and environmental functioning. Bastiaansen et al. (2004) highlighted the importance of considering HRQoL at this domain level as differences are reported across the HRQoL domains across disorders. For example, based on parent reporting, children and youth on the autism spectrum score

within the normative range on the domains of autonomy and parent relations (Biggs & Carter, 2016; Egilson, Olafsdottir, Leosdottir, & Saemundsen, 2017) and school environment (Biggs & Carter, 2016). By contrast, scores on the social functioning (Egilson et al., 2017), emotional functioning (Bastiaansen et al., 2004), and psychological health subdomains (Tung et al., 2014) are often reportedly lower. Exploration of specific domains, and the predictors of these specific domains, therefore allows for a more accurate description of HRQoL within children on the autism spectrum, which is critical should targeted interventions be developed.

### *Predictors of HRQoL in autism*

In an attempt to better understand HRQoL in autism and ways of providing support for children on the autism spectrum, research has moved towards identifying the factors that are predictive of HRQoL outcomes. Chiang and Wineman (2014) reviewed 16 studies of HRQoL within autism to identify the factors associated with increased HRQoL. While the influence of autism characteristics and adaptive behaviour on HRQoL outcomes has yielded mixed results in the literature, more behaviour problems, greater social impairment, and poorer social communication skills were identified as common predictors of HRQoL in both adults and children. Intellectual ability has also been associated with HRQoL outcomes of children and youth on the autism spectrum, where co-occurring intellectual disability (ID) is often related to poorer HRQoL outcomes than for children on the autism spectrum without ID (Arias et al., 2018; Chiang & Wineman, 2014; Totsika, Felce, Kerr, & Hastings, 2010). These results identify that factors other than, or in addition to, characteristics of autism predict HRQoL.

While anxiety has been associated with increased psychological and physical health concerns (Bittner et al., 2007), social difficulties (Gregory & Sadeh, 2012; Kingery, Erdley, Marshall, Whitaker, & Reuter, 2010), and sleep disturbances (Caporino et al., 2017; Gregory

et al., 2011), and poorer HRQoL, in typically developing children (Gilbertson, Morgan, Rapee, Lyneham, & Bayer, 2017), we cannot assume that anxiety will impact children on the autism spectrum in the same way. Similarly, we cannot assume that a child on the autism spectrum will have poorer HRQoL due to their diagnosis alone, without properly understanding other potential factors contributing to their HRQoL. According to Tavernor, Barron, Rodgers, and McConachie (2013), anxiety may be a key factor which impacts upon the HRQoL of children on the autism spectrum, highlighting the need for studies which explore this relationship in detail. Steensel, Bogels, and Dirksen (2012) explored the impact of anxiety and the impact of autism characteristics on QoL in two separate analyses, with the results highlighting a stronger parameter estimate of autism characteristics than anxiety symptoms, but as both autism and anxiety were not entered into a single analysis, the relative contribution of each factor in the presence of the other factor cannot be deduced. This substantiates the importance of further exploring how psychiatric conditions such as anxiety can impact the HRQoL of children on the autism spectrum.

Compared with other paediatric conditions, there has been less focus on the HRQoL of children on the autism spectrum (Tavernor et al., 2013). While the research on HRQoL in children and adolescents on the autism spectrum is continuing to emerge, there is limited knowledge about the factors associated with HRQoL in children on the autism spectrum and additional research is needed to firmly establish the relative contribution of anxiety symptomatology and autism characteristics on the HRQoL. Understanding the impact of anxiety on the physical, social, emotional, and psychological functioning domains of children on the autism spectrum can help to inform appropriate provisions during childhood to minimize maladjustment and to improve well-being during adolescence and adulthood.

*Quality of life in parents of children on the autism spectrum*



Although research in typically developing children has established associations between child emotional and behavioural problems, including anxiety, and elements of parental well-being (e.g. Crnic et al., 2005; Ford et al., 2004), there has been limited research exploring this relationship within children on the autism spectrum. A recent systematic review into QoL in parents of children on the autism spectrum showed that all studies reported lower QoL in parents of children with autism than in parents of typically developing children in at least one domain (Vasilopoulou & Nisbet, 2016). Four of their identified studies explored the impact of emotional problems on parental QoL, with only two studies reporting a significant correlation between either child emotional symptoms (Totsika, Hastings, Emerson, Berridge & Lancaster, 2011) or child emotional QoL (Bourke-Taylor, Pallant, Law & Howie, 2012) and parental QoL. No studies explored the impact of specific diagnoses, such as anxiety, and parental QoL. There were also mixed results within the studies included in the review in relation to child autism characteristics or severity and parental QoL. Such mixed results led Vasilopoulou & Nisbet (2016) to conclude that further exploration of parental QoL (with a broad instrument such as the WHOQoL-Bref) and its predictors is required.

### *Aims*

The current study aimed to investigate the individual contribution of specific aspects of anxiety symptomatology and autism characteristics in the prediction of child HRQoL in a sample of school-aged children on the autism spectrum. The current study extends existing work in the field of child QoL which have only considered the total score on HRQoL measures by exploring both the total score of the Pediatric Quality of Life (PedsQL) scale and the four subdomains (physical, social, emotional, and school functioning) to assess for subscale differences. The study will also be the first to use the autism-specific measure of

anxiety (ASC-ASD) as a predictor of HRQoL, exploring the impact of overall anxiety as well as the relative contribution of the specific subscales.

In addition to this, given the established relationships between child anxiety and parental QoL in typically developing children and the highlighted need for further work exploring correlates and predictors of parental QoL in parents of children with autism (Vasilopoulou & Nisbet, 2016), this study will explore the impact of child anxiety on parental QoL at both the total score and subscale level. The study will also be the first to use the autism-specific measure of anxiety (ASC-ASD) as a predictor of parental QoL, exploring the impact of overall anxiety as well as the relative contribution of the specific subscales.

Based on the previous literature, the following hypotheses were made:

### *Hypotheses*

1. Autism characteristics have previously been shown to be predictive of a child's HRQoL over and above a child's age and ability (de Vries & Geurts, 2015). Therefore, it was hypothesised that a child's autism characteristics (as measured by the Social Communication Questionnaire [SCQ]) would significantly predict child HRQoL (measured using the PedsQL) as reported by their parents.
2. It has also been established that co-occurring mental health diagnoses including anxiety were predictive of poorer child HRQoL (Kose et al., 2013; Sikora et al., 2012). Therefore, it was expected that anxiety symptomatology (measured by the ASC-ASD) would predict the HRQoL of school-aged children on the autism spectrum.
3. Given the previous work by van Steensel et al. (2012), it was hypothesised that autism characteristics would be a stronger predictor of HRQoL than would anxiety symptoms.

Given the mixed and conflicting findings in the systematic review by Vasilopoulou & Nisbet (2016) in relation to predictors of parental QoL, no hypotheses were made about the impact of anxiety and autism characteristics on parental QoL.

## **Methods**

Ethical clearance for this study was granted through the <removed for blind review> University Human Research Ethics Committee, approval number xxx/xxx.

### *Recruitment procedures*

Parents of children on the autism spectrum were recruited through social media posts and parent information sessions held at the University. Parents could complete the questionnaire online or using pen and paper. In total, 91 parents completed and returned the questionnaire. Twelve were excluded as they had a total score on the Social Communication Questionnaire (SCQ) (Rutter, Bailey, Lord & Berument, 2003) below the cut-off of 15 or their SCQ questionnaire was incomplete. A further 15 were excluded as the child was below the age of 5 or the child's age was not provided.

### *Participants*

After exclusions, the sample consisted of data on 64 children on the autism spectrum. The sample was predominantly male (71.9%) with a mean age of 10 years 1 month (*SD* 3 years 1 month), ranging from 5-16 years. Based upon parent-report, children had a range of levels of self-help and adaptive skills. All children were reported to be continent all of the time or with only occasional incidents for both wetting and soiling during the day. Almost all (92.2%) were fully continent for soiling during the night with the remaining five children (7.8%) reported to have occasional night-time soiling incidents. Nine (14.1%) children were reported to have frequent wetting incidents at night, seven (10.9%) occasional night-time

wetting incidents; the remaining 75% (n=48) of the sample were reported to be continent (wetting) at night. When asked about their child's washing and dressing skills, 67.2% of parents said that their child is able to wash and dress independently, 28.1% were able to wash with help and 29.7% were able to dress with help. Three children (aged 5.3 years, 6.25 years and 11.5 years) were unable to wash themselves even with help and two children (aged 5.3 years and 11.5 years) were unable to dress themselves with help. A small group had moderate to significant hearing difficulties (n = 6, 9.9%) vision difficulties (n = 5, 8.2%) or delayed speech (n = 5, 7.9%). Twenty-four (37.5%) children had a parent-reported diagnosis of anxiety (which is concordant with estimates from meta-analyses, e.g., van Steensel et al., 2011), of whom six were reported to be prescribed selective serotonin reuptake inhibitors (SSRIs). Twenty-one (32.8%) children were reported to have a diagnosis of an attention deficit disorder, of whom nine were prescribed Methylphenidate.

Parent informants were mostly mothers (96.9%) and no respondents reported living separately from the child. Six (9.4%) parents reported having a diagnosis of an autism spectrum disorder and 17 (26.6%) reported having a diagnosis of a mental health difficulty. The majority of the respondents reported having at least a tertiary education (89.1%) and having a family income in excess of AUD \$80,000 (67.2%). For reference, the 2016 Australian Census reported the median Australian annual family income to be AUD \$90,168.

### *Measures*

**Demographic characteristics.** These were collected using a parent questionnaire focusing upon child (age, gender, age at diagnosis, self-help skills, hearing, speech or language skills), parent (education, employment), and household (income) variables.

**Autism characteristics.** The SCQ (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) if used within the correct age range. A higher score represents a higher number of behaviours which may be considered indicative of autism.

**Child anxiety.** The Anxiety Scale for Children - Autism Spectrum Disorder Parent Form (ASC-ASD-P) (Rodgers et al., 2017) consists of 24 items which divide 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, it has been used in younger samples of children on the autism spectrum to describe anxiety symptomatology (Keen, Adams, Simpson, den Houting, & Roberts, 2017). The scale has good validity, reliability, and internal consistency and is highly correlated (suggesting good concurrent validity) with the Screen for Child Anxiety Related Emotional Disorders (SCARED) (Birmaher et al., 1999) and the Spence Child Anxiety Scale (SCAS; den Houting, Adams, Roberts & Keen, 2018a), two robust measures of anxiety in the general population. den Houting et al. (2018a) and Keen et al. (2017) also report good discriminant validity against measures of autism characteristics. Adams, Simpson, and Keen (2018) explored PRMSE values for each subscale, concluding that this measure is statistically valid at subscale level and that subscales add clinical utility above using the total score alone. In the current study, internal consistency was identified as acceptable to excellent for all subscales based on Cronbach's alpha: Anxious Arousal  $\alpha=.86$ , Separation Anxiety  $\alpha=.84$ , Performance Anxiety  $\alpha=.87$ , and Uncertainty  $\alpha=.86$ .

Two indicative cut-off points for the ASC-ASD-P total scale have been put forward by the authors: scores  $\geq 20$  suggest "significant anxious symptomatology", and scores  $> 24$

are considered to be a “more specific indication of significant anxiety” (Rodgers et al., n.d.). These cut-off scores have been explored in relation to an established measure of anxiety (Spence Child Anxiety Scale) and parent-reported clinical anxiety diagnosis status with 100% of children with a clinical anxiety diagnosis achieving a score of 20 or higher on the ASC-ASD-P and 71% of children with a clinical anxiety diagnosis achieving a score of 24 or higher (den Houting et al., 2018a). Within this study, the cut-off score of 24 will be used to indicate elevated anxiety symptomatology. The significant majority (83.3%) of children within this sample who had a clinical diagnosis of anxiety achieved a score of 24 or more.

**Child-health-related quality of life (C-HRQoL).** The Pediatric Quality of Life Inventory 4.0 (PedsQL; Varni, Seid & Kurtin, 2001) is one of the most widely studied and cited assessments of c-HRQoL. Informants respond to 23 items which cover the core health dimensions identified by the WHO. The informant is not asked to rate the presence or absence of a certain behaviour, but asked to rate how often their child has had problems with a specific task or experience. 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 functioning (e.g., attendance, completing schoolwork). The Psychosocial Health domain score consists of items within the emotional, social, and school functioning subscales. A higher score indicates a higher level of health-related quality of life. As the number of items differs across subscales, the mean score per question will be presented when describing subscale data. The PedsQL has been widely used in children on the autism spectrum (Kuhlthau et al., 2010; Thomas, Sciberras, Lycett, Papadopolous, & Rinehart, 2018) and has been identified as having adequate reliability within this population (Stokes, Kornienko, Scheeren, Koot, & Begeer, 2017). In the current study, internal consistency was identified as acceptable to excellent for all

subscales based on Cronbach's alpha: Physical  $\alpha=.85$ , Emotional  $\alpha=.74$ , Social  $\alpha=.76$  and School  $\alpha=.76$ .

**Parent Quality of Life (P-QoL).** The World Health Organization Quality of Life Assessment-BREF (WHOQOL-BREF) is an abbreviated form of the WHOQOL-100 and measures individuals' physical, psychological, social, and environmental health. It has been used to assess parental QoL in a number of studies of parents of children with autism (e.g. Dardas & Ahmad, 2014; Tung, Huang, Tseng, Yen & Tsai, 2014). The 26 items of the scale range from 1 to 5 with higher scores denoting higher QoL. As the number of items differs for each subscale, the mean score per question will be presented when describing subscale data. Both the subscale and the total QoL scores were used in the analyses. In the current study, internal consistency was identified as acceptable to excellent for all subscales based on Cronbach's alpha: Physical  $\alpha=.81$ , Emotional  $\alpha=.87$ , Social  $\alpha=.70$  and Environmental  $\alpha=.84$ .

#### *Data analysis*

Data were screened to ensure they met assumptions of normality. First, c-HRQoL and p-QoL were compared between those who were above and below the cut-off indicative of anxiety on the ASC-ASD-P using one-way ANOVAs. Second, to study whether specific subscales of the ASC-ASD-P were predictors for different aspects of c-HRQoL and p-QoL, linear regression analyses were conducted with c-HRQoL and p-QoL subscales as the dependent variables and ASC-ASD-P subscale scores as predictor variables. Alpha was set to .05 for all analyses due to the exploratory nature of the study. Effect sizes were calculated using partial eta squared, where 0.01 is considered a small effect size, 0.09 a medium effect size and .25 a large effect size. Prior to examining prediction models, bivariate and point-serial correlation analyses were conducted. These revealed no collinearity of predictors ( $r > .80$ ), thus all were retained (see Table 1).

**Table 1.***Pearson Correlations between Predictor Variables*

	2	3	4	5
1. SCQ total score	-.09	-.08	--.06	.06
2. ASC-ASD-P Performance	-	.66**	.63**	.63**
3. ASC-ASD-P Anxious Arousal		-	.68**	.69**
4. ASC-ASD-P Separation			-	.62**
5. ASC-ASD-P Uncertainty				-

\*  $p < .01$ ; \*\*  $p < .001$ .**Results***Profile of results on the ASC-ASD*

Across the sample, ratings were given between 0 and 3 for each item on the ASC-ASD-P. The three items with the highest mean score (representing elevated anxiety) across the sample were “*My child always needs to be prepared before things happen*” (mean = 2.02, SD = .95), “*My child worries if they don't know what will happen next e.g. if plans change*” (mean = 1.72, SD = .97), and “*My child is afraid of entering a room full of people*” (mean = 1.48, SD = .94), all of which are from the Uncertainty subscale. The three items with the lowest mean score across the sample were all from the Anxious Arousal subscale: “*My child suddenly becomes dizzy or faint when there is no reason for this*” (mean = 0.28, SD = .65), “*My child suddenly starts to tremble or shake when there is no reason for this*” (mean = 0.34, SD = .70), and “*My child suddenly feels so anxious he/she feels as if he/she can't breathe when there is no reason for this*” (mean = 0.47, SD = .78).

The average total ASC-ASD-P was 25.9 (SD = 14.6) which equates to a mean score per question of 1.1 (SD = 0.65). Total ASC-ASD-P scores ranged from 3-70; 34 (53%) of



parent ratings placed their child in the range for “elevated anxiety”. The subscale averages (mean score per question) were 1.2 (SD = 0.8) for Performance Anxiety, 0.65 (SD = 0.62) for Anxious Arousal, 1.0 (SD = 0.89) for Separation Anxiety and 1.33 (SD = 0.70) for Uncertainty.

#### *Profile of results on the measure of c-HRQoL: PedsQL*

Across the sample, ratings were given between 0 and 100 for each item on the PedsQL. The items with the highest mean scores (representing higher c-HRQoL and/or less difficulties in undertaking that activity) across the sample were predominantly from the Physical Functioning subscale; *Walking more than a block* (mean = 77.7, SD = 30.6), *Running* (mean = 69.5, SD = 34.4), *Lifting something heavy* (mean = 69.1, SD = 31.4). One item from the School Functioning subscale was the joint third highest rated item: *Missing school to go to the doctor or hospital* (mean = 69.1, SD = 26.6). The three items with the lowest mean average scores across the sample were *Forgetting things* (mean = 33.2, SD = 26.4), *Keeping up with school activities/schoolwork* (mean = 37.1, SD = 28.5) (both from the School Functioning domain) and *Feeling angry* (mean = 37.9, SD = 23.1).

The average total PedsQL score (mean score per question) was 50.8 (SD = 15.6), with scores ranging from 22-95. The subscale averages (mean score per question) were 62.0 (SD = 23.2) for Physical Functioning, 48.45 (SD = 20.0) for Social Functioning, 47.7 (SD = 19.9) for School Functioning and 45.1 (SD = 21.0) for Emotional Functioning.

#### *Profile of results on the measure of p-QoL: WHOQOL-BREF*

Across the sample, ratings were given between 1 and 5 for each item on the WHOQOL-BREF with the exception of the questions which ask about having the information available needed in day-to-day life (item 13), how able they are to get around (item 15) and how satisfied respondents are with their access to health care services (question 24), all of which

had a minimum score of 2 and maximum of 5. Two of the three items with the highest mean scores (representing higher p-QoL and/or less difficulties in undertaking that activity) were from the Physical domain: *How well are you able to get around?* (mean = 4.6, SD = 0.71), *How much do you need any medical treatment to function in your daily life?* (mean = 4.1, SD = 1.0) and one was from the Environment domain: *How satisfied are you with your transport?* (mean = 4.4, SD = 0.72). Two of the three items with the lowest mean scores were from the Social domain; *To what extent do you have the opportunity for leisure activities?* (mean = 2.5, SD = 1.2), *How satisfied are you with the support you get from your friends?* (mean = 3.0, SD = 1.0) and one was from the Physical domain; *How satisfied are you with your sleep?* (mean = 3.0, SD = 1.1).

The average total WHO-QOL BREF score (mean score per question) was 3.6 (SD = 0.6), with scores ranging from 47-118. The domain averages (mean score per question), from highest to lowest were Environment (mean = 4.2, SD = 0.8), Physical (mean = 3.7, SD = 0.7), Psychological (mean = 3.3, SD = 0.8) and Social (mean = 3.2, SD = 0.8).

#### *C-HRQoL in those with and without elevated anxiety symptomatology*

As summarised in Table 2, parents of children experiencing elevated anxiety symptomatology reported lower overall c-HRQoL scores for their children as well as significantly lower scores in the c-HRQoL physical, emotional, and school functioning subscales. All significant comparisons had a medium to large effect size with the exception of school functioning, which had a small to medium effect size.

#### *P-QoL in those with and without elevated anxiety symptomatology*

As summarised in Table 2, parents of children experiencing elevated anxiety symptomatology reported lower overall p-QoL scores (with a medium effect size) as well as

significantly lower scores in the physical and psychological domains (with medium effect sizes) subscales.

*C-HRQoL and P-QoL dependent upon child and parent demographic variables*

Exploratory comparisons of c-HRQoL and p-QoL split by child gender, child age (median split) and parent mental health are documented in the supplementary material. There were no significant differences in c-HRQoL and p-QoL based upon child gender or age. There were no significant differences in c-HRQoL based upon parent mental health diagnosis. Parents who reported a diagnosis of a mental health condition also reported lower physical, psychological, environmental and total p-QoL.

**Table 2.**

*PedsQL and WHOQoL-BREF Scores (Mean Score Per Question) split by Children Scoring Above and Below the ASC-ASD-P Cut-off for Elevated Anxiety*

		Below ASC-ASD-P cut-off	Above ASC-ASD-P cut-off	Statistic	<i>p</i>	Partial eta squared
		Mean (sd) <i>N</i> = 30	Mean (sd) <i>N</i> = 34			
PEDSQL	Physical Functioning	70.4 (20.8)	54.6 (23.1)	F(1,62) = 8.23	.006**	.12
	Emotional Functioning	57.8 (19.0)	33.8 (15.6)	F(1,62) = 30.73	<.001***	.33
	School Functioning	53.3 (21.8)	42.6 (16.8)	F(1,62) = 4.89	.03*	.07
	Social Functioning	52.7 (22.7)	44.6 (16.7)	F(1,62) = 2.68	.11	.04
	Total C-HRQoL score	58.6 (15.3)	43.9 (12.4)	F(1,62) = 17.56	<.001***	.22
	Psychosocial Health	54.6 (16.7)	40.3 (12.4)	F(1,62) = 15.3	<.001***	.20
WHOQOL-BREF	Physical	3.97 (0.53)	3.50 (0.74)	F(1,61) = 7.93	.007**	.12
	Psychological	3.56 (0.71)	3.09 (0.80)	F(1,61) = 6.08	.02*	.09
	Social	3.26 (0.83)	3.17 (0.86)	F(1,61) = 0.20	.66	<.01
	Environmental	4.37 (0.74)	3.98 (0.79)	F(1,61) = 3.87	.05	.06

Total	3.90 (0.57)	3.50 (0.66)	F(1,61) = 6.41	.01*	.10
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\* $p < .05$ ; \*\* $p < .01$  \*\*\* $p < .001$ .

### *Influence of child anxiety symptomatology on c-HRQoL*

In order to explore whether specific aspects of a child's anxiety symptomatology predict overall and/or specific aspects of c-HRQoL, a series of linear regressions were undertaken. As autism characteristics have previously been shown to be predictive of c-HRQoL over and above child age and ability (de Vries & Geurts, 2015), the child's total SCQ score was entered alongside the ASC-ASD-P subscale scores. The results are presented in Table 3 (n.b., higher scores on the c-HRQoL scale indicate a better quality of life, whilst higher scores on the ASC-ASD-P 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 18-46% of the variance. None of the ASC-ASD-P subscales or the SCQ total score were significant predictors of the overall c-HRQoL score; however, the following significant predictors were found: (1) total SCQ score ( $R^2 = .26, p < .01$ ) predicted physical functioning, with children with less autism characteristics having fewer difficulties with physical functioning; (2) ASC-ASD-P anxious arousal predicted the school functioning score ( $R^2 = .16, p < .05$ ), indicating that children with lower levels of anxious arousal have fewer difficulties with school functioning; and (3) ASC-ASD-P anxious arousal and separation anxiety scores predicted levels of emotional functioning ( $R^2 = .46, p < .001$ ) (see Table 3). Standardised beta coefficients indicate that those with lower levels of separation anxiety and anxious arousal have fewer difficulties with emotional functioning. Hypotheses 1-3 can therefore all be rejected in relation to the total c-HRQoL score but each partially accepted for specific c-HRQoL domain scores.

**Table 3.**

*Results of Linear Regressions Exploring Anxiety (ASC-ASD-P) Subscales and Autism Characteristics (SCQ) Predicting c-HRQoL Subscales (PedsQL)*

		Child Quality of Life (PedsQL)					
		Total HRQoL	Psychosocial Functioning	Physical Functioning	Emotional Functioning	School Functioning	Social Functioning
Total R <sup>2</sup>		.30	.26	.24	.46	.18	.08
F(58,5)		4.96**	4.0**	3.68**	9.84***	2.46*	.97
		β	β	β	β	β	β
ASC-ASD-P	Performance	.00	-.03	.04	-.18	.09	.02
	Anxious Arousal	-.23	-.28	-.09	-.40**	-.46*	.21
	Separation Anxiety	-.25	-.19	-.25	-.29*	.05	-.21
	Uncertainty	-.13	-.06	-.18	.13	-.04	-.25
SCQ		-.09	.46	-.25*	-.01	.08	.06

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

### *Influence of child anxiety symptomatology on p-QoL*

In order to explore whether specific aspects of a child's anxiety symptomatology predict overall and/or specific aspects of p-QoL over and above autism characteristics, a series of linear regressions were undertaken. As shown in Table 4, none of the models were significant, only predicting 3-16% of the variance.



**Table 4.***Results of Linear Regressions Exploring Anxiety (ASC-ASD-P) Subscales and Autism Characteristics (SCQ) Predicting P-QoL (WHOQoL)*

		Parent Quality of Life (WHOQoL)				
		Total QoL	Physical Health	Psychological	Social Relationships	Environment
Total R <sup>2</sup>		.14	.14	.13	.03	.16
F(56,5)		1.86	1.77	1.72	.39	2.12
		β	β	β	β	β
ASC-ASD-P	Performance	-.17	-.28	-.17	-.11	-.01
	Anxious Arousal	.36	.22	.35	.24	.37
	Separation Anxiety	-.30	-.11	-.34	-.12	-.36*
	Uncertainty	-.18	-.14	-.11	-.02	-.27
SCQ		-.07	-.17	.03	.08	-.09

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

## Discussion

This is the first study to comprehensively explore whether anxiety and autism characteristics predict HRQoL of children on the autism spectrum and QoL in parents of children on the autism spectrum. The findings indicate that children on the spectrum with elevated anxiety experience significantly poorer overall c-HRQoL and have significantly poorer scores on the physical, emotional, and school functioning domains. In addition, their parents also experience overall poorer QoL, specifically in the physical health and psychological domains.

Through exploring the predictors of c-HRQoL in school-aged children on the spectrum, this study extends the previous literature by demonstrating that scores on specific subscales of the autism-specific anxiety measure, but not autism characteristics, predicted the emotional, social, and school functioning subscales of c-HRQoL. However, autism characteristics were the only significant predictor of the Physical Functioning subscale. Importantly, it was exploring the data firstly using total scores and then also with subscale/domain scores (on both the anxiety and c-HRQoL measure) that allowed for these relationships to be identified. While it has been established that children on the autism spectrum experience poorer QoL relative to typically developing children (van Heijst & Geurts, 2015) and children with other co-occurring psychiatric and health conditions (Kose et al., 2013; Sikora et al., 2012), the range of factors that contribute to the c-HRQoL of children on the autism spectrum have been poorly understood. This study therefore builds upon the new and emerging literature proposing that psychiatric conditions such as anxiety have a negative impact on the c-HRQoL of children on the autism spectrum (de Vries & Geurts, 2015; van Heijst & Geurts, 2015; van Steensel et al., 2012). In contrast to the findings relating to C-HRQoL, anxiety symptomatology did not predict p-QoL.

### *Elevated anxiety and c-HRQoL and p-QoL*

There is a growing body of literature which suggests as well as experiencing “typical” anxiety, children on the spectrum may also experience anxiety differently from typically developing children (Kerns & Kendall, 2012; White et al., 2015) and that measures designed for typically developing children may not capture the full range of anxiety symptoms experienced by children on the spectrum. This study was the first to explore c-HRQoL in children on the autism spectrum using an autism-specific measure of anxiety, the ASC-ASD-P, looking at both clinical cut-off scores and relative contributions of each subscale score. Using the elevated anxiety cut-off proposed by Rodgers et al. (n.d.), results revealed that children who experienced elevated levels of anxiety experienced poorer c-HRQoL overall (PedsQL total score) and psychosocial health as well as achieving lower scores in the physical, emotional, and school functioning domains, with all results having a medium to large effect size with the exception of school functioning, which had a small to medium effect size. This highlights that anxiety does not just impact children’s emotional functioning, but that elevated anxiety symptomatology has a wide-ranging impact on children on the autism spectrum, which includes their physical and school functioning. This aligns with reports from individuals on the spectrum, their parents, and teachers (Saggers et al., 2016) which place anxiety in the top three factors affecting school participation and the top two factors influencing classroom support needs. The impact of elevated levels of anxiety also extends beyond the child, with parents of children with elevated anxiety reporting poorer total p-QoL and poorer physical health and psychological subscale scores of the WHO-QoL BREF.

### *Predictors of c-HRQoL and p-QoL*

When controlling for autism characteristics as measured by the SCQ, ASC-ASD-P subscale scores were not found to significantly predict the any p-QoL scores nor the total c-HRQoL or the Psychosocial Functioning score. However, when exploring specific domains of c-HRQoL through the subscale scores, it was found that 46% of the variance in emotional functioning scores could be explained by the ASC-ASD-P domains and SCQ score, with both anxious arousal and separation anxiety as significant predictors. One ASC-ASD-P subscale (anxious arousal) was a significant predictor of school functioning in the model which explained 18% of the variance. Children who were reported to experience higher anxious arousal symptoms experienced higher difficulties in the domain of emotional and school functioning. This may be somewhat explained by level of child ability, which was not measured in this study, although anxious arousal scores were not associated with child adaptive behaviour scores in previous research (den Houting et al., 2018b). It may be that heightened anxious arousal impacts upon a child's concentration, or may in itself be an aversive experience. Separation anxiety, identified as another leading anxiety subtype experienced by children on the autism spectrum (Simonoff et al., 2008), predicted the emotional functional subscale of c-HRQoL in the current study. Separation anxiety is problematic for children and the effects may extend beyond the time of separation. For example, the anticipatory worry associated with separating may contribute to sleep disturbances throughout the night which may then impact upon emotional and school functioning.

Interestingly, two subscales of the ASC-ASD-P did not predict any aspects of c-HRQoL. Firstly, performance anxiety had a  $\beta$  of  $<.1$  for the total ASC-ASD-P score and three of the four subscales, including school functioning. Secondly, despite intolerance of uncertainty being identified as a significant factor in both anxiety and behavioural aspects of autism (Wigham et al., 2015), within this study, the Uncertainty subscale did not predict the

c-HRQoL. A lack of relationship between difficulties with, or intolerance of, uncertainty and QoL has been reported in other populations, including individuals with epilepsy (Barahmand & Haji, 2014) and women with breast cancer (Pahlevan Sharif, Ahadzadeh, & Perdamen, 2017). Barahmand and Haji (2014), whose mediation models showed that irritability completely mediated the effects of both intolerance of uncertainty and worry on QoL, suggest that it may be the consequence of the intolerance of uncertainty (i.e., that it causes irritability and frustration) that reduces the c-HRQoL, rather than the difficulties with uncertainty per se. Further work is needed to explore and explain these results within the autism population as such mediation models have important implications for intervention focus (e.g., focus upon the mediator). These findings reiterate the importance of exploring specific aspects of a construct by going beyond the total scores; if only total scale scores were considered here, important information concerning the impact of specific subdomains of anxiety on specific subdomains of c-HRQoL would have been missed.

To date, some of the “core” features associated with autism (social communication difficulties), as well as behavioural problems, have been found to predict the c-HRQoL of children on the autism spectrum (Chiang & Wineman, 2014). This has led to the suggestion that children on the autism spectrum experience poorer c-HRQoL that is attributed to the “severity” of their autism characteristics. Within this study, autism characteristics (as measured by the SCQ) predicted one (Physical functioning) domain of the PedsQL. However, when controlling for children’s autism characteristics, anxiety symptoms were the strongest predictor of emotional and school functioning aspects of c-HRQoL, making a greater contribution over and above their autism characteristics. These are consistent with the work of Matson and Nebel-Schwalm (2007) who suggested that anxiety causes more disruption to the individual than their autism characteristics. Similarly, Renty and Roeyers (2006) also found that the QoL of adults on the autism spectrum was not related to their symptoms or the

severity of their disability. These are important findings that may help to inform interventions and how outcomes are measured. It is worth noting that much of the early intervention literature measures cognitive and language outcomes, and considers a reduction in autism characteristics to be the “optimal outcome” (Fein et al., 2013; Starr, Propovic, & McCall, 2016; Towle, Vacanti-Shova, Shristi, & Higgins D'alessandro, 2014). However, in light of the current findings that convey the impact of anxiety on the c-HRQoL of children at school age, perhaps there should be a greater emphasis on identifying and targeting causes and triggers of children’s anxiety as part of early childhood interventions to enhance c-HRQoL and potentially minimise later disruption at school age. Critically, the results from this study highlight the importance of developing and increasing access to effective treatments to help reduce anxiety in children on the autism spectrum as these in turn should enhance the child’s QoL. Such targeted intervention would need to identify and (where possible) reduce the causes and/or triggers of the anxiety, including environmental factors, in order to reduce anxiety symptomatology experienced. The non-significant models exploring child anxiety symptomatology on p-QoL suggests that there may be a complex relationship which may be influenced by parent, family and social factors. It is likely that there may be mediating or moderating effects of coping strategies (Adams, Rose, Jackson, Karakstani & Oliver, 2018; Benson, 2014) parenting behaviours (Osborne, McHugh, Saunders & Reed, 2008), child age or ability (Adams et al., 2018) and systemic elements such as family income and demographics (Dardas & Ahmad, 2014). There is a need for further studies, ideally using a large cohort and a longitudinal design, to explore and model a range of child, parent and family factors and their impact upon the relationship between child emotional and behavioural presentation and p-QoL (see meta-analysis by Yorke et al., 2018)

### *Clinical implications*

The current findings have important implications for children's school adjustment. When controlling for autism characteristics, children's anxious arousal continued to have a significant impact on their school functioning over and above their autism characteristics. Children experiencing heightened anxious arousal at school may have more difficulty attending to and completing their schoolwork, which has the potential to impact their learning and subsequent development. Teachers need to be aware of the potential impact of a child's diagnosis when understanding their emotional experience and/or behavioural presentation (Oliver et al., 2013; Oliver, Woodcock, & Adams, 2010). Teachers would benefit from tailored information to aid them in identifying the range of anxiety symptomatology in their students on the autism spectrum and therefore enable them to utilise strategies to support anxiety in the classroom (<removed for blind review>) This could include a student's anxiety "signature"; an individualised profile of emotions, behaviours, expressions, verbalisations, or actions that indicate elevated anxiety for that child in that particular setting. Computerised systems which convey pupil-specific information about students on the autism spectrum to teachers through the lesson register, especially those which convey information created in dialogue with the student on the spectrum such as the FAME<sup>TM</sup> approach described in Leatherland (2018), may open up the opportunities for sharing such information. A recent systematic review conducted by <removed for blind review> revealed a lack of current school-based anxiety and autism research, with the only available studies tending to report mean scores on measures rather than the actual profile of symptoms, limiting the extent to which current work is able to inform teachers of the key anxiety symptomatology and highlighting the need for further work in this area.

Heightened separation anxiety was found to impact on children's emotional functioning in the current study. This may impact upon social interactions with peers, an area that can be problematic for children on the autism spectrum who experience inherent social

communication and peer interaction difficulties (Kasari, Locke, Gulsrud, & Rotheram-Fuller, 2011; Macintosh & Dissanayake, 2006). The results suggest that separation anxiety may benefit from being monitored in children on the autism spectrum from an early age in order to enhance c-HRQoL. Appropriate supports should be implemented as necessary to reduce any anxiety incurred by children when separating from their parents. Addressing early separation anxiety may prepare children for the separation incurred during the school transition, which may minimise the associated disruption and reduce the maladjustment at school.

#### *Limitations and future research directions*

The current study relied on parent report and, given that parents opted in to the study, may have a recruitment bias of parents interested in this area. Because the study collected all information via questionnaires, there was neither independent confirmation of autism diagnosis nor valid measure of child ability. The reliance upon parent report for c-HRQoL may be a limitation given the well-documented incongruence between child-self and proxy-parent report (Clark, Magill-Evans, & Koning, 2014; Ikeda, Hinckson, & Krageloh, 2014). To that end, research has confirmed that children on the autism spectrum are able to provide valid subjective reports on their own well-being and functioning (Shipman, Sheldrick, & Perrin, 2010). As such, a companion study gathering self-report data would complement the current findings, to inform how children on the autism spectrum perceive and report on their own anxiety and autism characteristics and how they consider that these factors impact on their c-HRQoL.

The implementation of the ASC-ASD-P assessment was a strength of this study as it allows consideration of autism-specific anxiety symptoms. However, the ASC-ASD-P would benefit from further evaluation in terms of both the areas covered as well as the validity and reliability against formal diagnostic interviews. A limitation was that the c-HRQoL measure



was one designed for the typically developing population. Rodogno, Krause-Jensen, and Ashcroft (2016) discuss the shortcomings in current assessment and understanding of QoL for individuals on the autism spectrum which is founded on the philosophy of well-being in those without a diagnosis on the spectrum. The authors raise an important point such that we cannot and should not assume that well-being in individuals on the spectrum is the same as that for individuals not on the spectrum. Rodogno et al. (2016) argue the need for current assessments to be modified to be 'autism sensitive' to more accurately capture what it is that gives value to the lives of individuals on the autism spectrum. To that end, the recent development of a self-report c-HRQoL scale designed specifically for adults on the autism spectrum that has added questions relating to barriers to accessing services, friendships, sources of support, and sensory issues is welcome (McConachie et al., 2018), but this is yet to be conducted for children or young people. It is also important to be aware of the limitations of measurement via questionnaire without the opportunity to request clarification. For example, the SCQ would define repetitive behaviours as a characteristic of autism, whereas it may be that the repetitive behaviour is actually being used as a coping mechanism to reduce anxiety. As a coping strategy, repetitive behaviours may actually be adding to an individual's quality of life by reducing their anxiety, but when assumed as an autism characteristic, it is statistically associated with reducing quality of life. Additional examples of where further information would have been useful include improving the understanding around sample characteristics, for example, asking whether formal hearing assessments had been undertaken for the 9.9% who reported moderate to significant hearing difficulties or whether co-occurring diagnoses such as developmental coordination disorder may have been the cause of the child's difficulties with washing or dressing. Further work with careful measurement of such factors is required to further explore these issues.

Finally, whilst the models and some of the predictors were significant, they do not account for all of the variance in c-HRQoL, meaning that further work with more predictors (and therefore a larger sample) is needed. A larger sample would allow for more factors, including more demographic factors, to be entered into the regression analysis. Future work should include a broader scope and measure environmental factors, including the sensory environment, and whether this interacts with the relationship between anxiety and quality of life in individuals on the autism spectrum.

## **Conclusions**

To date, anxiety has been recognised as a significant mental health concern for children on the autism spectrum who are more vulnerable to experiencing anxiety at clinically significant levels when compared to typically developing peers (van Steensel et al., 2011; White et al., 2015). This is the first study to establish the contribution of anxiety on the c-HRQoL of school-aged children on the autism spectrum. Children experiencing elevated anxiety symptoms had significantly poorer total c-HRQoL, and specifically, significantly poorer domains of emotional, school, and physical functioning. The current findings provide new insights in the c-HRQoL literature, as until now it has been widely suspected that it was the autism-related symptomatology that was limiting children's c-HRQoL. Instead, the current findings contribute a novel finding to the literature by identifying specific aspects of children's anxiety symptomatology as significant factors contributing to poorer functioning across a range of c-HRQoL domains.

## **Ethical Approval**

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

### **Informed Consent**

Informed consent was obtained from all individual participants included in the study.

### **Compliance with Ethical Standards:**

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