Contributing factors to parental stress and health-related quality of life in parents of children with autism spectrum disorder

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Ethical approval was obtained by the Auckland University of Technology Ethics Committee (AUTEC) and granted in July 2021. Reference number: 21/211.

Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed  Date 11/11/2022

Abstract

Background: Autism spectrum disorder (ASD) is a life-long neurodevelopmental condition often requiring substantial support from parents. Research has identified that parents of children with ASD tend to experience increased stress and lower quality of life (QoL) compared to parents of typically developing children. However, little research has investigated child factors related to ASD and the impact of these on parental stress and QoL in New Zealand.

Aim: The present study aims to explore how the severity of child core ASD symptoms, child comorbidities, and problem behaviours might impact upon parent stress and health-related QoL (HR-QoL).

Method: Using a quantitate approach and cross-sectional design, 494 parents of children with ASD were recruited for the study between August and September 2021 by voluntary sampling. Participants completed the Autism Impact Measure (AIM), Strengths and Difficulties Questionnaire (SDQ), a comorbidities checklist, Parental Stress Scale (PSS), and Short Form-36 Questionnaire (SF-36) to assess parent-rated child factors and obtain self-rated measures of stress and QoL.

Results: Pearons's correlation analyses revealed all child factors and parent mental and physical HR-QoL were significantly associated with parent stress. The mental HR-QoL of parents declined significantly with increasing parental stress. Path analysis demonstrated that child problem behaviours significantly predicted mental HR-QoL directly, and indirectly with partial mediation via stress. Moreover, the only child factor significantly predicting parent physical HR-QoL was a positive direct effect observed from ASD symptom severity. Parental stress was a direct and significant predictor of QoL in both mental and physical health domains for parents of children with ASD.

Conclusion and implications: Findings of the present study add to the body of literature investigating the impact of child factors on parent stress and quality of life for parents caring for a child with ASD in New Zealand. It has been highlighted that child factors can impact both the mental and physical HR-QoL of these parents, with mental HR-QoL most affected. The exploration of environmental and personal factors acting to mediate child variables and parent outcomes could further develop our understanding of how best to support parents and guide development of mental health intervention.

Introduction and Literature Review

Historical Context of Autism

Derived from the Greek term *autos*, or *self* (Sharpe & Baker, 2007), the term autism was introduced by Bleuler in his work on schizophrenia in the early 1900's (McNally, 2009). On observing schizophrenic individuals, Bleuler first described autistic tendencies as a "detachment from reality" (as cited in Parnas et al., 2008, p. 131).

Following this, Kanner (1943) differentiated autism from schizophrenia identifying autism as a unique syndrome. Though at the time childhood schizophrenia and autism presented with symptomatic similarities, Kanner (1943) noted distinct differences, for example, language impairment, social isolation, and a need for sameness in autistic individuals. Further observed in autistic children was a shared fundamental characteristic presenting as an "inability to relate themselves in the ordinary way to people and situations from the beginning of life" (Kanner, 1943, p. 242).

At a similar time, Asperger wrote about autism as a personality disorder and queried the possibility of familial inheritance (Asperger, 1991). Based on Asperger's work, Wing (1981) coined the term *Asperger's Syndrome*, a mild to moderate form of autism. Today, the diagnostic and statistical manual of mental disorders (5th ed., text revised; DSM-5-TR) combines autism, Asperger's syndrome, and pervasive developmental disorder under one diagnosis: *Autism spectrum disorder* (ASD) (American Psychiatric Association [APA], 2022).

Defining Autism Spectrum Disorder

Autism spectrum disorder is defined as a lifelong neurodevelopmental disorder most often observed within the early years of life (APA, 2021). Characterised by changes in brain function and socio-emotional deficiencies, children with ASD experience unique symptomatology with varying degrees of challenges, such as verbal and non-verbal communication, relationship formation and maintenance, atypical sensory reactivity, and emotion regulation (APA, 2022). ASD is an incurable disorder with numerous models proposing varying aetiological perspectives and highlighting the presence of neurodiversity (Dawson et al., 2009; Fountain et al., 2012). Nevertheless, the cause of ASD remains poorly understood.

Table 1 outlines common symptoms which may be presented by children, adolescents, or adults with ASD. These symptoms are used as a guide only and are intended to inform significant persons, such as caregivers, teachers, and health providers to the need for appropriate referral (Ministries of Health and Education, 2016).

Table 1

Adapted from New Zealand Autism Spectrum Disorder Guideline

Social	Communication	Behaviours or Cognitions
Lack of eye contact, social smiling, and/or imitation of others.	Verbal and non-verbal communication deficient (e.g. difficulty understating others, difficulty following direction of pointing by others).	Desire for sameness and/or inability to cope with change e.g. strict routine(s), get upsent when routine(s) interrupted, completing tasks in certain order).
Disinterest in or unusual approaches towards other children.	Abnormal language development (e.g. echolalia, muteness, monotone voice).	Lack of cooperative and imaginative play.
Prefers to play alone or makes inappropriate attempts to play with others.	Tendency to spend significant time talking about specific interests.	Poor coordination or motor skills.
Lacks awareness of social norms e.g. appropriate classroom behaviour.		Sensory over-or under-sensitivity (e.g. seeks or avoids certain visual stimuli, textures, touch, smells, body movements, and sounds, unusual response to pain).
Relates inappropriately to adults (e.g. hyper or hypo interest).		Preoccupation with restricted patterns of interest and focus, repetitive motor movements, and play with toys/objects (e.g. flapping of hands, lining up of toys, hyperattention to certain objects).
Easily overwhelmed.		

Note. Adapted from *New Zealand autism spectrum disorder* guidelines (2nd ed.) by Ministries of Health and Education, 2016, Wellington: Ministry of Health https://www.health.govt.nz/system/files/documents/publications/nz-asd-guideline-aug16v2_0.pdf

Diagnosing Autism Spectrum Disorder

In New Zealand, there is no formal referral pathway for the assessment and diagnosis of persons suspected to have ASD, with an average of three years between initial consultation and final diagnosis (Eggleston et al., 2019). Assessment may be carried out by an ASD-specialised individual such as a private health care provider, publicly funded organisation, general practitioner, paediatrician, psychiatrist, or other qualified clinician (Ministries of Health and Education, 2016).

The DSM-5-TR outlines five criteria (Criteria A-E) required to be met for the diagnosis of ASD by a qualified professional. In addition, disorder severity is indicated based on the individual's need for external support, depicted by impairment of socio-communicative ability, and repetitive, restrictive behaviours (APA, 2022). Criterion A requires persistent deficits in social communication and inter-personal interaction evident across multiple settings, including verbal and non-verbal communication, socio-emotional reciprocity, and the development and maintenance of relationships. Criterion B requires the presence of at least two of the following: repetitive, or stereotyped behaviours (e.g., echolalia); repetitive behaviours such as twirling body around in the air, lining up toys or objects; inflexibility, and insistence on sameness, like showing extreme distress when routine disturbed, rigid black and white thinking patterns; hyper-focussed and restricted interests, such as being highly attached to certain objects or interests, and/or; hyper- or hypo-reactivity to or interest in sensory stimuli (e.g., adversely responding to certain sounds, movement, or light). Criterion C requires symptoms to be present from early development, and D specifies the need for symptoms to cause significant impairment in life functioning. Lastly, Criterion E requires the presentation of the aforementioned symptoms to not be better explained by any other intellectual disability or developmental delay, which may also co-occur (APA, 2022).

Prevalence

Between the year 2000 and 2018, the Centers for Disease Control and Prevention (2021) reported a 3-fold increase in ASD cases in American children from 1 in 150 to 1 in 44 8 year olds. In 2019, identification of young persons living in New Zealand through the Integrated Data Infrastructure suggested a prevalence rate of ASD in 8 year olds of 1 in 102 (Bowden et al., 2020). Global data shows greater incidence of ASD in males than females and notes vast variations in national recording strategies (Zeidan et al., 2022). Moreover, in reporting these findings for research it is important to consider the difficulty of estimating ASD prevalence (Mandell & Lecavalier, 2014).

Although the number of children diagnosed with ASD in New Zealand may be lower than other areas of the world, the stress and psychological distress experienced by parents and caregivers of children with ASD is substantial, and greater than those of typically

developing (neurotypical) children and children with other neurodevelopmental disorders (Hemati Alamdarloo & Majidi, 2022; Padden & James, 2017; Parsons et al., 2020; Shepherd et al., 2021; Siu et al., 2019).

Parenting a child with Autism Spectrum Disorder

Parenting and Quality of Life

The quality of life (QoL) of parents is impacted by low psychological wellbeing presenting as, for example, depression, anger, worry, caregiver strain, and maladaptive coping (Hemati Alamdarloo & Majidi, 2022; G. K. Lee & Shivers, 2019). Many factors contribute to one's subjective perception of the life they live, including their functioning within environmental, social, and cultural settings. The World Health Organisation (2012) defines QoL as:

> " [*sic*] individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [*sic*]. It is a broad ranging concept incorporating in a complex way the persons' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment. (p.3)

ASD greatly affects the QoL of those living with the disorder and those caring for them (Hemati Alamdarloo & Majidi, 2022; Sáez-Suanes & Álvarez-Couto, 2021; Shepherd et al., 2021). An Australian study by Parsons et al. (2020) found greater self-reported experiences of stress and lower QoL in those caring for a child with ASD compared to the general population, irrespective of the family's local population density. Moreover, parents of children with ASD tend to report increased anxiety, depression, poor general health with expectation of decline, and psychological distress (Padden & James, 2017), all of which impact life quality. Indeed, a systematic review of studies by Yirmiya & Shaked (2005) indicated parents of children with ASD are at greater risk of psychiatric disorders compared to parents of typically developing children. It also is necessary to consider the bidirectional effect that parent stress may have on parent-child attachment, parenting behaviours, and child functioning (Clauser et al., 2021; Teague et al., 2018).

Parenting a child with ASD brings many challenges. A review of qualitative studies on the impact of family experiences involving children with ASD, illuminates common parental experiences of denial, grief, and disappointment in diagnosis, as well as increased emotional strain, and the need to adapt daily life to meet the needs of their child with ASD (Corcoran et al., 2015). The complex nature of QoL means it cannot be defined to just one area of life, with each domain influenced by different contributing factors. Using the short form-36 (SF-36) to measure QoL, Liu et al. (2021) highlighted both maternal and paternal parents of children with ASD in China rated significantly lower on mental and physical QoL domains than parents of age-matched typically developing children.

It is well-documented that factors such as adequate support and coping are protective of QoL. Nwafor et al. (2022) showed that moderate to high levels of perceived stress had a significantly lower impact on family QoL as family support increased. Additionally, when caring for a child with ASD in New Zealand, research has demonstrated the use of coping strategies such as cognitive reframing and planning are most often used by parents, along with social supports such as government funded services, social media, and that which is received by one's spouse (Shepherd et al., 2020; Shepherd, Landon, Taylor, et al., 2018). Interestingly, it is not only ones own stress that can affect QoL. A study by Vahedparast et al. (2022) observed direct and indirect relationships between parenting stress and quality of life domains in parents of children with ASD. Though statistically non-significant, Vahedparast et al. (2022) found paternal parenting stress had a small indirect influence on maternal mental QoL. Moreover, one's own parenting stress directly affected the same persons' mental and physical QoL; in addition to an indirect association observed between stress and physical QoL mediated by mental QoL.

Parenting Stress

Parenting is inherently challenging, even when dealing with normative family events typically experienced by all parents (McCubbin et al., 1980), and even more so when a child may have additional needs. For example, the decreased capacity for individuals with intellectual disability to adjust personal behaviours such as stereotypy, has been shown to account for 34% of the variance in maternal child-related stress (Weiss et al., 2003).

It has not been ignored that mothers tend to report significantly greater parenting stress than fathers (Di Renzo et al., 2022; Johnson et al., 2011; Rodriguez et al., 2019), with much research focusing on mothers as the primary caregiver of adults and children with disability, beyond the greater tendency for mothers to respond to research surveys (Boyd et al., 2019; Clauser et al., 2021; Davys et al., 2017; Landon et al., 2018)**.** Indeed, mothers tend to report greater parenting responsibility (Padden & James, 2017)**,** nevertheless, it cannot be denied that caring for a child with ASD also contributes to parental stress in males. However, research has demonstrated non-significant differences in self-reported stress levels between mothers and fathers of children with ASD (Derguy et al., 2016; Padden & James, 2017).

An American study by Rodriguez et al. (2019) observing parenting stress and child ASD symptoms and problem behaviours in 188 families caring for a child with ASD, found maternal and paternal stress had a significant effect on child internalising behaviour 12 and 24 months later, whereas the reverse was not found. Additionally, when comparing the role of core ASD symptoms and comorbid conditions influencing parental stress in New Zealand,

Shepherd et al. (2021) found parenting stress associated with child core ASD symptoms was highly correlated with psychiatric distress in parents.

It is evident that greater stress is experienced by parents raising a child with ASD. Numerous child and parent factors influence the level of stress reported by parents, such as parental coping, and core ASD symptoms and behaviours experienced by the child.

Core Autism Symptoms and Parental Outcomes

ASD core symptoms involve social, emotional, and communication behaviours. Individuals diagnosed with ASD display abnormalities in behaviours such as imaginative play, inability to reciprocate peer interaction and understand relationships; restricted interests, and abnormal sensory reactivity, like hypersensitivity to noise or light or seeking certain stimuli; and stereotypy, such as flapping hands, or spinning in circles (APA, 2013).

Core symptoms such as those outlined in Table 1 have been shown to impact the QoL of individuals living with ASD and their parents. Oakley et al. (2021) showed that young adults with ASD score, on average, significantly lower than neurotypical adults on physical and mental health, social relationships, and environmental QoL domains. Conversely, when analysing self-report scores at the individual level, many adults with ASD did not in fact subjectively report low QoL, with 34.9 - 66% (depending on life domain) scoring within 1 standard deviation of comparison adults (Oakley et al., 2021). Research on families in New Zealand found parental stress increased with their child's severity of core ASD symptoms, for example, social or communicative deficits (Shepherd, Landon, Taylor, et al., 2018). Moreover, parental stress relating to core ASD symptoms had a greater impact on psychological distress compared to co-occurring behavioural or physical conditions, with parental stress mediating this relationship (Shepherd et al., 2021).

Further research has observed the relationship between atypical sensory processing and maladaptive behaviours in Australian children with ASD (Griffin et al., 2022). Griffin et al. (2022) reported statistically significant associations between all sensory behaviours measured (sensory seeking, avoiding, sensitivity, and registration) and behaviours of irritability, lethargy, inappropriate speech, and stereotypy. Furthermore, hyperactive or non-compliant behaviours strongly correlated with sensory sensitivity, seeking, or avoiding. Indeed, these maladaptive behaviours accounted for over 57% of the variance in caregiver strain measured in this study (Griffin et al., 2022). This demonstrates potential for core ASD symptoms, beyond the sensory domain, to influence child problem behaviours and parent QoL.

Problem Behaviours and Parental Outcomes

In addition to core ASD symptoms, individuals with ASD often experience psychopathological problems in the form of internalising and externalising emotional and

behavioural problems or difficulties. Internalising difficulties are those which are privately experienced by the individual and include emotional reactivity, anxiety, depression, and withdrawal, while externalising behaviours are defined as behaviours projected outward and visible to others. These might be displayed as impulsivity, hyperactivity, aggression, other conduct issues, and self-injury (Goodman, 1997; Lin et al., 2021; Matson & Nebel-Schwalm, 2007; Mello et al., 2022).

Parents of children with ASD tend to report higher levels of internalising and externalising child problem behaviours and parenting stress than parents of typically developing children (Siu et al., 2019). Interestingly, Rodriguez et al. (2019), who studied the directional relationship between parental stress, ASD symptoms, and problem behaviours, noted that over time paternal but not maternal stress increased in response to their child's externalising problem behaviour. Similarly, while observing parenting stress relating to child problem behaviours, Lin et al. (2021) found over 25% of parents reported clinically significant stress arising from child behavioural attributes. In this sample, up to 49% of young children under 3 years of age showed clinical levels of internalising behaviours, with an additional 14 – 21% indicating borderline clinical levels. With respect to externalising symptoms, 21 – 28% of children in the same study were at clinically significant levels with a further 19% borderline clinical levels. Interestingly, there were no significant relationships between severity of child ASD and either level of child problem behaviour or parenting stress in this sample. Of further importance, cross-lagged modelling found child problem behaviours and parenting stress both remained stable over a 1.5 year period (Lin et al., 2021).

In contrast, research using the perceived stress scale and strengths and difficulties questionnaire has supported findings of positive correlations between parent stress and child problem behaviours, including conduct issues (Lovell et al., 2015; Lovell & Wetherell, 2016). Thus, research presents some ambivalence with regards to the association between internalising and externalising child problem behaviours and stress experienced by parents of children with ASD.

Comorbid Conditions and Parental Outcomes

Comorbidities presenting in children with ASD is another critical factor when considering carer stress and QoL. Defined as an individual experiencing two or more disorders (Matson & Nebel-Schwalm, 2007), comorbidities are observed in approximately 70% of children with ASD in New Zealand (Bowden et al., 2020), higher than the general population (Dizitzer et al., 2020). Common comorbidities occurring alongside ASD include intellectual disability (ID), attention deficit hyperactivity disorder (ADHD), sleep difficulties, conduct disorders, obsessive compulsive disorder, anxiety and mood disorders, eating

disorders, and gastrointestinal issues (GI) (Bowden et al., 2020; Leader et al., 2022; Matson & Nebel-Schwalm, 2007). In addition, 48% of children with ASD may have other mental health conditions (Silkey et al., 2022), with some research presenting historical incidence of up to 73% of individuals with ASD having at least one psychiatric comorbidity (Abdallah et al., 2011).

Among comorbid disorders, ADHD is the most predominantly reported condition co-occuring with ASD (up to 70%) after ID (Abdallah et al., 2011; Dizitzer et al., 2020; Mayes et al., 2021; Mohammadi et al., 2019). Research suggests ADHD prevalence in children with ASD can range from 4.1%, as clinical diagnostic reporting suggested in one Israeli study (Dizitzer et al., 2020), and up to 79%, as reported by mothers of children with comorbid ASD (Mayes et al., 2021).

Anxiety disorders present another commonly occurring comorbidity. Reported anxiety prevalence in children with ASD differs greatly with up to 42% occurrence, depending on measurement criteria, information source, and symptom specification (Mayes et al., 2021; Mohammadi et al., 2019). In children with ASD ages 5 and under, and 6 and under, 23% and 28% were reported to have parent-rated clinical levels of anxiety, respectively; with predominant symptoms of nervousness, fearfulness, and dependence on others (Llanes et al., 2020).

Around 11% of children with ASD complain of frequent stomach ache and/or nausea (Mayes et al., 2021), with some research showing comorbid GI disorder diagnoses of 5.4% (Dizitzer et al., 2020). Additionally, children with ASD are significantly more likely to present with sleep issues than typically developing children. Mothers report over 39% of children with ASD experience difficulty falling asleep to the extent of it being often or very often a problem, compared to 10% of typically developing children, with 29% and 10%, respectively, experiencing frequent night-time waking (Mayes et al., 2021). Moreover, when adjusting for burden of care, and child and parent age, Liu et al. (2021) found that parents whose children with ASD had greater sleep issues reported lower physical health scores, while parents of typically developing children scored lower on mental health. Taken together, these findings indicate that comorbidities can cause substantial stress and impair life quality for those with ASD and their parents (Adams et al., 2020; Leader et al., 2021; Liu et al., 2021; Oakley et al., 2021; Zablotsky et al., 2013).

Present Study

The present study aims to expand existing literature exploring the relationship between parental stress and health-related quality of life (HR-QoL) for parents caring for a child with ASD in New Zealand. There are numerous studies globally presenting the benefits of understanding parenting stress, including the need for effective support services and

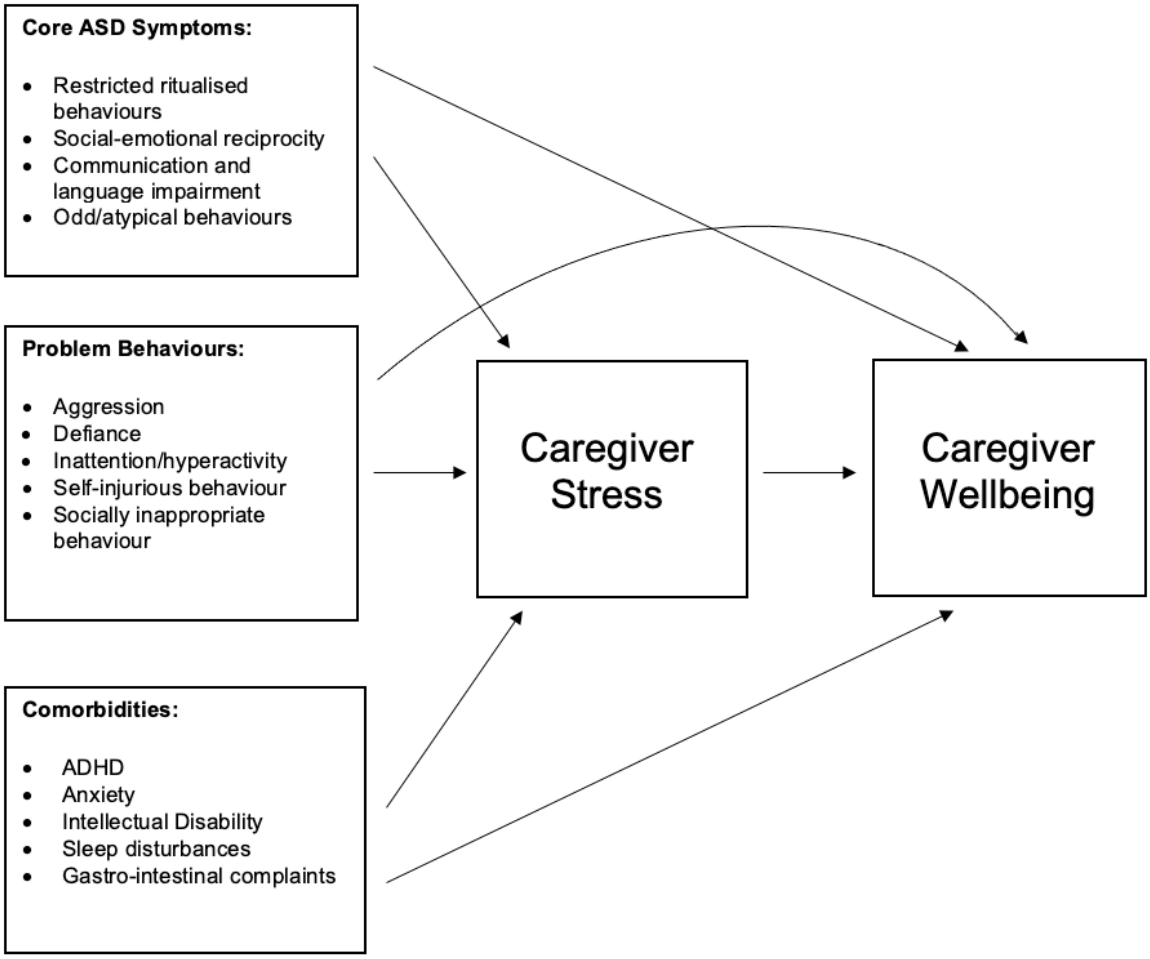
interventions for parents of children with ASD coping with higher levels of stress, psychological distress, anxiety, and depression (Padden & James, 2017; Shepherd et al., 2021; Shepherd, Landon, & Goedeke, 2018). Shepherd et al., (2021) have explored the relationship between child core ASD symptoms, parenting stress, and mental health using the General Health Questionnaire-28 (GHQ-28) and other parent-rated measures in a New Zealand population. Evidence was found to support a relationship between parenting stress, as impacted by the child's core ASD symptoms, and parent mental health. Indeed, stress had a greater effect on the mental health of parents in comparison to child functioning resulting from the impact of core ASD symptomology, suggesting the presence of indirect effects (Shepherd et al., 2021).

However, to date little is known about the interaction between child core ASD symptom severity, comorbidities, child problem behaviours, parenting stress, and parent HR-QoL for caregivers in New Zealand. Therefore, the aim of the present study is to explore the direct and indirect effects of child-related measures on both parental stress and HR-QoL (see Figure 1).

Considering the existing research surrounding parenting stress and QoL in caregivers of children with ASD, the present study hypothesises that child factors have both a direct effect on parental QoL, and an indirect effect on QoL, with parent stress as an intervening variable (Hypothesis 1). In addition, parenting stress directly predicts parent QoL where increases in stress reduces mental and physical HR-QoL (Hypothesis 2).

Figure 1

Conceptual Model for Observing Relationships Between Child and Parent Variables


Core ASD Symptoms:
Restricted ritualised behaviours
Social-emotional reciprocity
Communication and language impairment
Odd/atypical behaviours
Problem Behaviours:
Aggression
Defiance
Inattention/hyperactivity
Self-injurious behaviour
Socially inappropriate behaviour
Comorbidities:
ADHD
Anxiety
Intellectual Disability
Sleep disturbances
Gastro-intestinal complaints
Caregiver Stress
Caregiver Wellbeing

Methods

All procedures performed in this study were in accordance with standards set out by the Auckland University of Technology Ethics Committee (AUTEC: 21/218) and were ethically approved by AUTEC before the research project commenced. Data were collected using Qualtrics, a software program designed for research data collection. Participants were able to access the online questionnaire by clicking the Qualtrics survey link from any computing device. A participant information sheet was provided outlining the purpose, benefits, and implications of the current study, in addition to explaining privacy, confidentiality and informed consent, and researcher contact information, before commencing the survey (refer to Appendix A).

Participants

Four hundred and ninety-four parents of persons with ASD voluntarily participated in the current study. To be eligible to participate in this study, participants must be parenting an individual with ASD, be over the age of 18 years, and reside within New Zealand at the time of responding. Participants were 437 females (88.5%) and 57 males (11.5%), ranging from age 25 to over 70 years with a mean age of 45 years (*SD* = 9.42), with one participant not disclosing their age. Consisting mostly of married (63.0%), European (80.4%), and educated individuals attaining qualifications from a Polytechnic institution or University (84.8%), the participants were caring for individuals with ASD whose ages ranged from 2 to 51 years with a mean age of 13 years (*SD* = 7.52). Age data were missing for six of these persons, as displayed in Table 2. The gender of individuals with ASD consisted of 373 (75.5%) males and 115 (23.3%) females with undisclosed gender for six individuals.

On average, signs and symptoms of ASD in these children were noticed by parents around age 2–2.5 years, with some as early as 1 year and up to 11 years old. Diagnosis of ASD occurred at 4.5–5 years of age, with the majority being diagnosed by a Paediatrician (58.1%), or Psychologist/Psychiatrist (33.2%). The frequency of child age at which core ASD symptoms were recognised by parents and the age at which formal diagnosis occurred is depicted in Figure 2.

In relation to comorbid conditions, Table 3. demonstrates that for children with ASD in the present study, of those whose parents responded yes to anxiety symptoms, just over one-half (52.2%) had formal diagnoses. Similarly, formal diagnoses were given to 43.7%, 61.3%, and 69.2% of those whose parents indicated child comorbid symptoms of gastrointestinal (GI) issues, sleep issues, and ADHD, respectively.

Table 2

Descriptive Information of Participant Characteristics (Parent)

Category	*n*	%
Gender		
Female	437	88.5
Male	57	11.5
Missing	0	0
Ethnicity		
European	397	80.4
Māori	48	9.7
Pasifika	12	2.4
Asian	35	7.1
Other	2	0.4
Missing	0	0
Education level		
Primary school	5	1.0
Secondary school	69	14.0
Polytechnic	163	33.0
University	256	51.8
Missing	1	0.2
Relationship status		
Married	311	63.0
Single/solo parent	103	20.9
Living together in a relationship, but not married	71	14.4
In a relationship, but living independently	7	1.4
Missing	2	0.4
Other children in parents's care		
None	1	0.2
One	172	34.8
Two	178	36.0
Three	86	17.4
Four	37	7.5
Five	11	2.2
Missing	9	1.8

Note: ADHD: Attention deficit hyperactivity disorder. *Missing* denotes participant did not provide a response.

Table 3

Descriptive Information of the Children with ASD Cared for by Participants

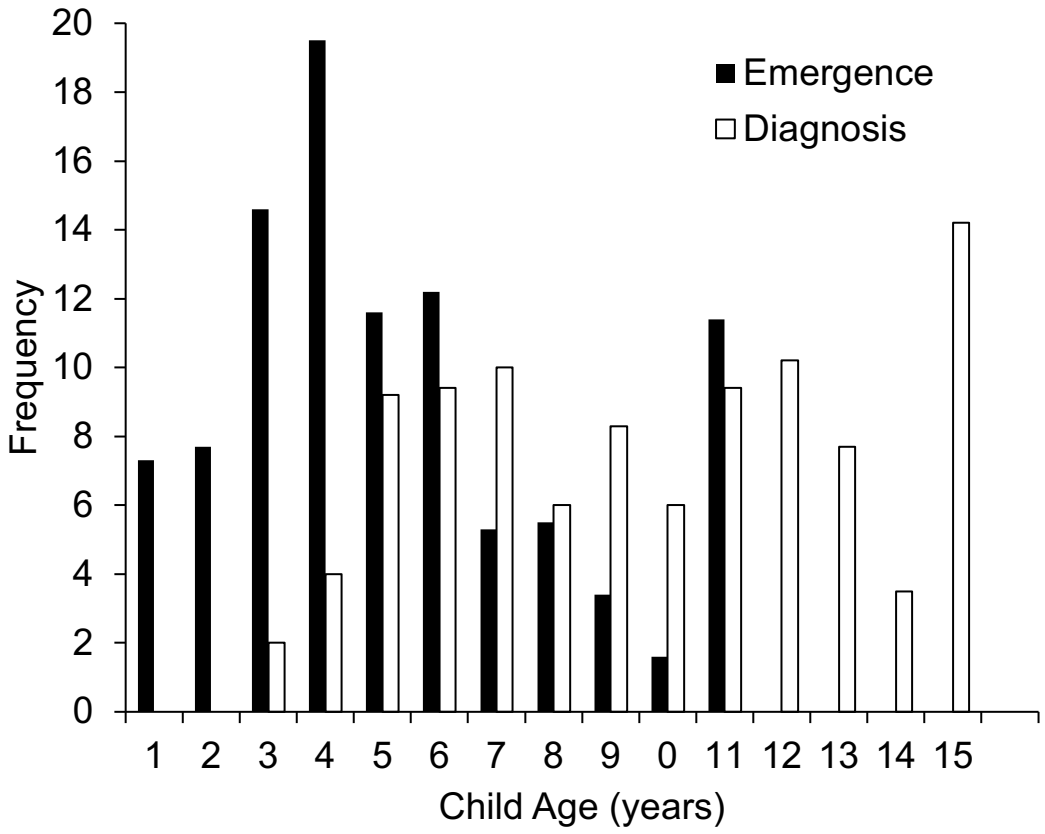
Category	*n*	%	Missing data %
Gender			
Female	115	23.3	–
Male	373	75.5	–
Missing	6	1.2	–
Formal ASD diagnosis provided by			
General Practitioner	19	3.8	–
Paediatrician	287	58.1	–
Psychologist or Psychiatrists	164	33.2	–
Never received formal diagnosis	10	2.0	–
Missing	14	2.8	–

Category	*n*	%	Missing data %
Comorbidity symptom presentation			
Anxiety	420	85.0	5.7
ADHD	173	35.0	5.9
Intellectual disability	164	33.2	5.9
Sleep issues	307	62.1	6.1
Gastrointestinal issues	185	37.4	6.1
Comorbidity professionally diagnosed			
Anxiety	217	52.2	15.8
ADHD	119	69.2	65.2
Intellectual Disability	122	75.8	67.4
Sleep issues	185	61.3	38.9
Gastrointestinal issues	80	43.7	63.0

Note: ADHD: Attention deficit hyperactivity disorder. *Missing* denotes that participant did not provide a response.

Figure 2

Parent-reported Child Age at Onset of ASD Behaviour and Age at Formal Diagnosis



Note: This figure demonstrates frequency of parents reporting when they first noticed their child's ASD symptoms (black bars) and the age of the child at the time of formal diagnosis (white bars).

Instruments

Autism Impact Measure (AIM)

The autism impact measure (AIM) was used to assess the child's ASD symptom severity (e.g. how much the symptom affects the child's functioning), as reported by the parent. Developed by Kanne et al. (2014), the AIM is a reliable and valid psychometric tool designed to quantify the impact and frequency of core ASD symptoms as a measure of treatment outcome in children with ASD.

A total of 25 parent-rated items were presented assessing the impact domain of the AIM. The AIM contains four subdomains exploring how much the child's core ASD symptoms interfere with the child's functioning over the previous two weeks. Each item is rated by selecting a number on a Likert-type scale ranging from 1 (not at all) to 5 (severely), where higher subdomain and total scores represent greater dysfunction. The first subscale asks questions related to the child's restricted and ritualised behaviours such as avoidance of certain sounds, textures or smells, or lining up of objects. The second subscale looks at possible communication and language impairments like problems with speech. The third subscale covers odd and atypical behaviours, for example, repetitive hand flapping or inappropriately responding to others. The fourth and final subscale observes the child's capacity for social and emotional reciprocity, such as, eye contact and facial expression. All ratings across the four subscales can be summated to produce a total score, with higher scores indicating greater symptom severity.

Research examining the psychometric properties of the AIM support the tool, showing excellent structural validity (Grimm et al., 2021; Mazurek et al., 2020). Moreover, good convergent validity was observed with the Social Communication Questionnaire-Lifetime (SCQ) and Repetitive Behaviours Scale-Revised (RBS-R), with AIM total scores positively correlating with total scores of the SCQ and RBS-R. In addition, the AIM has shown high internal consistency for total and impact domain scores (α = .96 and .95 respectively; Houghton et al., 2019). Numerous studies have successfully used the AIM to examine the impact of ASD symptoms on the life functioning of children living in New Zealand (Landon et al., 2018; Shepherd et al., 2018a, 2018b, 2020, 2021).

Strengths and Difficulties Questionnaire (SDQ)

To gain measures of child problem behaviours due to ASD, the strengths and difficulties questionnaire (SDQ) was used (Goodman, 1997). The SDQ contains 25 items divided into five scales exploring observer-rated strengths and challenges demonstrated by an individual child. These scales categorise emotional and behavioural strengths and difficulties into classifications of *hyperactivity,* where a child might display behaviours such as restlessness, become easily distracted, or conversely, demonstrate a strong attention

span, or the ability for decision-making before acting; *emotional symptoms* scale encompasses behaviours like worry, tearfulness, and loss of confidence; *conduct problems* include obedience, dishonesty, and temper tantrums; *peer problems* such as whether the child is liked by other children and has friends, or are bullied and play alone; and *prosocial*, covering behaviours like care and consideration for others, and sharing. A total difficulties score between 0–40 is generated by summing scores from the hyperactivity, emotional, conduct, and peer subscale categories, with a 0 score indicating best outcome. The prosocial subscale on the other hand considers child strengths and is not incorporated within the total difficulties score (Goodman, 1997). The prosocial subscale will therefore not be considered for analysis in the present study.

For the present study, parents were asked to record their response regarding a specific behaviour using one of three possible answers: “not true”, “somewhat true”, or “certainly true” based on the child’s everyday behaviour over the past six months.
The psychometric properties of the SDQ have been well-studied. Originating in England, reliability and validity scores have also been explored among children residing in South America, Europe, China, and New Zealand (Goodman, 1997, 2001; Kersten et al., 2018; Muris et al., 2003; Sargisson & Stanley, 2016; Silva et al., 2015; Thompson et al., 2021; Yao et al., 2009). These studies have found generally acceptable internal consistency for parent - rated scores in British, Chinese, and Dutch children and adolescents, with poorer results for the peer and conduct subscales (Goodman, 2001; Muris et al., 2003; Silva et al., 2015; Thompson et al., 2021; Yao et al., 2009). Test-retest reliability of the SDQ has shown to be satisfactory over a 2-month follow-up period (Muris et al., 2003; Yao et al., 2009) though diminishing as the interval increases (Goodman, 2001; Kersten et al., 2018).

Comorbid Conditions

Information regarding child comorbid conditions was obtained from parents responding to yes-no questions asking about the presence and diagnosis of anxiety, attention deficit hyperactivity disorder (ADHD), intellectual disability, gastrointestinal symptoms, and sleep difficulties. If a parent responded “yes” then two questions were asked pertaining to the effect of the comorbid condition on the child’s everyday life functioning and how much the comorbid condition affected parental stress levels. These two questions were rated on a 5-point Likert-type scale from “very mildly”/“not at all” to “very severely”/”extremely”.

Parental Stress Scale (PSS)

To gain measures of stress experienced by parents raising a child with ASD, the parental stress scale (PSS) was employed. The PSS, developed by Berry & Jones (1995), is a brief 18-item self-report tool covering some of the core benefits and challenges of

parenting. Positive parenting experiences are reverse-scored and include those involving emotional fulfilment, life satisfaction and personal growth. While negative experiences are themed around the personal and financial strain of parenthood (Berry & Jones, 1995). Each question response was recorded using a 5-point Likert-type scale ranging from “strongly disagree” to “strongly agree”.

Overall, the PSS has good internal reliability and test-retest reliability over a six-week period with a Cronbach’s alpha coefficient of .83 and .81 respectively, and no significant differences observed between maternal and paternal scores (Berry & Jones, 1995). Scores between parents completing the PSS and the perceived stress scale, a well-documented, valid, and reliable measure of stress (Lee, 2012; Park & Colvin, 2019), were positively and significantly correlated for clinical and non-clinical child samples (Berry & Jones, 1995). Moreover, the PSS shows sensitivity in stress ratings for parents of children with clinically relevant behavioural issues compared to those without (Berry & Jones, 1995).

Short-Form 36 Questionnaire (SF-36)

To assess the quality of life of parents caring for a child with ASD the short-form 36 (SF-36) questionnaire was used. The SF-36 offers a broad measure of certain aspects of health by assessing physical, social, mental, and emotional domains. The SF-36 is a 36-item self-administered survey divided into eight subscales covering physical functioning, role limitations due to physical concerns, role limitations due to emotional concerns, social functioning, bodily pain, mental health, vitality, and general health perceptions (Ware & Sherbourne, 1992). These subscales create two distinct dimensions: the physical component summary (PCS), and the mental component summary (MCS) (Lins & Carvalho, 2016; Scott et al., 1999).

Exploration of the psychometric properties of the SF-36 show satisfactory reliability and validity (Butterworth & Crosier, 2004; McHorney et al., 1993), and use of the SF-36 in a large New Zealand population group demonstrated acceptable internal consistency with moderate to high item discriminant validity (Scott et al., 1999).

For the present study, participants were instructed to respond to each item using either a yes-no, three-point or five-point Likert-type scale. Responses for Items 1, 2, 17, 18, 22, 24, 27, 28, 31, 34, and 36 were reverse-coded for analysis as high scores for these items indicate less favourable health outcomes for the respondent. Once transformed, high scores for the PCS and MCS domains indicate greater states of HR-QoL for the corresponding construct.

Procedure

Invitations for this online survey were sent out to parents of children with ASD via email with the assistance of national non-government organisations, Autism New Zealand

and the Child's Autism Foundation. A Qualtrics link to this survey was presented in an advertisement within the organisations newsletters. The survey was further advertised in the Autism Parenting group on Facebook. Data were collected during the period 17th August 2021 to 11th September 2021 while New Zealand was undergoing numerous national lockdown and household isolation periods due to COVID-19 infection.

To ensure privacy and confidentiality, participation in this survey was anonymous and voluntary with confirmation of participation occurring once the individual clicked 'submit' at the end of the survey. All privacy, confidentiality, study, and survey information was thoroughly explained to participants in the participant information sheet supplied before entry to the survey (Appendix A). Participants were informed of being able to withdraw at any time during the survey, however, due to anonymity, once participants clicked the final submit button, removal of their response was no longer possible.

Statistical Analysis

Data were downloaded from Qualtrics into a Microsoft Excel spreadsheet where it was conditioned and prepared for input to IBM Statistical Package for the Social Sciences (SPSS, v. 28). Surveys aborted part way through were classified incomplete and removed from Excel. Once in SPSS, data were further conditioned and information for further analysis uploaded to AMOS (v. 27). Frequency analysis was conduction on participant and child demographic responses to provide characteristics of the sample, and to document the frequency of ASD symptoms and diagnostic milestones. Scale reliability for each measure used (AIM, SDQ, PSS, and SF-36) was assessed using descriptive statistics providing mean scores, standard deviations, corrected item total-correlations, and Cronbach's alpha (α_c) values for each scale. Lastly, α_c if item deleted was calculated and reported to assess whether certain items decreased overall reliability of the scale. Items were removed from the scale where α_c if item deleted value was greater than the α_c value for the overall scale.

To assess associations between child and parent factors from the AIM, SDQ, SF-36 subscale scores and PSS total scores, Pearson's correlational analyses were performed in SPSS. Subsequently, AMOS (v. 27) was used to perform path analysis and assess direct, indirect, and total effects between child and parent factors: core ASD symptoms, comorbidities, total behavioural difficulties, parental stress, and HR-QoL. Standardised variables were estimated and bootstrapping undertaken to observe significance. Path models were derived from Figure 1.

Results

Descriptive Analysis and Reliability Statistics

Descriptive statistics comprising of means (*M*) and standard deviations (*SD*) for all scale items and composite (i.e. total score) variables were generated using SPSS (v. 28). In addition, to assess the item and scale reliability corrected item-total correlations and Cronbach's alpha was calculated.

Autism Impact Measure

Appendix B shows mean scores and standard deviations for each item in the four subscales of the AIM. Higher mean scores indicate a greater perceived impact of that behaviour on the functioning of the individual with ASD. Results show Cronbach's alpha does not increase if items are deleted from a subscale and all items within each subscale show sufficient inter-item correlation (i.e., >.03). This suggests the scale is unidimensional, with all items measuring the same construct. Overall, Appendix B demonstrates good psychometric properties for the use of the AIM.

Table 4 displays mean scores and standard deviations for the four subscales of the AIM, where a higher mean score indicates the behavioural domain impacts more severely on the child's life functioning, as rated by their parents. Parents perceive the child's life functioning to be most impacted by restricted/ritualised behaviours, followed by odd/atypical behaviours, social/emotional reciprocity, and communication/language impairment. All subscales have a Cronbach's alpha above 0.7 indicating good internal consistency and appropriate use of the AIM subscales for research purposes.

Strengths and Difficulties Questionnaire (SDQ)

Appendix C presents the means, standard deviations, corrected item-total correlations, and Cronbach's alpha for each subscale of the SDQ. The prosocial subscale was excluded from reliability analyses due to it not being part of the total difficulties scale. Overall subscale results show that according to parents, children with ASD experience the most difficulty with hyperactive behaviour, followed by peer problems, emotional problems, and conduct issues, as presented in Table 5. Cronbach's alpha coefficients for the different subscales were generally satisfactory. Overall, internal consistency for the SDQ was acceptable for research purposes.

Parental Stress Scale (PSS)

The means, standard deviations, corrected item-total correlations, and Cronbach's alpha values for each item in the PSS are displayed in Appendix D. Higher mean scores indicate parents reported experiencing a greater level of stress caring for a child with ASD. Cronbach's alpha value greater than 0.7 suggests good internal consistency, indicating the

scale is appropriate for use in research. Twenty-nine participants (5.9%) were excluded from the reliability analysis of the PSS due to missing data.

Moreover, Cronbach's alpha for the scale did not substantially increase when item PSS_2 "would do anything for child", or PSS_4 "doing enough for child" were removed, and therefore, despite low corrected item-total correlations, these items remained within the scale. The summated PSS scale items showed excellent internal consistency (Appendix D).

Short-form 36 Questionnaire (SF-36)

Internal consistency of the physical component summary (PCS) and mental component summary (MCS) of the SF-36 were calculated as shown in Appendix E and F, respectively. Additionally means, standard deviations, and corrected item-total correlations for each item were assessed, with higher mean scores indicating greater HR-QoL. For the PCS domain, sixty (12.1%) participants were excluded from the reliability analysis due to missing data. Scale means, standard deviations, and Cronbach's alpha values for the overall PCS subscale are displayed in Appendix E. All items within the subscale were suitably correlated suggesting a unidimensional scale and deletion of items did not result in increased Cronbach's alpha value. A Cronbach's alpha over 0.7 indicates acceptable internal consistency and, therefore, the internal consistency overall for the PCS domain was excellent (α_c = .912).

Appendix F shows item reliability scores for the MCS domain of the SF-36. Sixty (12.1%) participants were excluded from the analysis due to missing data. Overall the Cronbach's alpha for the MCS domain was high (α_c = .907), suggesting excellent internal consistency.

Correlations in Child Factors, Parenting Stress, and Caregiver Quality of Life

To observe associations between parent stress, parent HR-QoL, and child factors, Pearson's correlation analyses (two-tailed) was applied with results displayed in Table 6 and Appendix G.

Table 6 shows correlations of total scores between the AIM, SDQ internalising and externalising behavioural domains, SF-36 PCS and MCS domains, total comorbidities, and the PSS. The left of the major diagonal displays zero-order Pearson's correlation coefficients, and to the right of the major diagonal the partial correlation values are displayed. Parent age and gender are controlled for in the partial correlations.

Parenting stress scores were positively and significantly correlated with total scores of the AIM, SDQ total difficulties, SF-36 PCS domain, and total comorbidities of the child. Additionally, parent mental health, measured by the SF-36 MCS domain, showed a significant and negative correlation with parenting stress even after controlling for parent age and gender. On the other hand, the SF-36 PCS domain displayed a very small significant

and positive correlation with parenting stress on both zero-order and partial correlations. Child internalising and externalising problem behaviours had significant negative associations with parent mental health. There were no significant associations between child problem behaviours and parent physical HR-QoL. As Table 6 demonstrates, once controlling for parent age and gender, the small negative correlation observed between the AIM and SF-36 PCS and MCS domains was no longer significant.

When observing associations between child variables (see Table 6 and Appendix G) ASD symptom severity, number of comorbidities, and problem behaviours are all positively and significantly correlated. No significant associations were found between conduct problems and language difficulties, or between the impact of social challenges scale and difficulties in the emotional, peer, or conduct domains.

Table 4

Descriptives, Means (M), Standard Deviations (SD), and Cronbach's Alpha (α_c) for the Summated Scales of the AIM

Subscale	*n*	Missing Sample Data (%)	Scale Items	*M*	*SD*	α_c
Restricted/Ritualised Behaviour	493	.20	8	27.4	6.0	.805
Communication/Language	494	.00	5	14.6	5.5	.856
Odd/Atypical Behaviour	490	.80	5	18.2	5.5	.798
Social-Emotional Reciprocity	491	.60	7	15.7	4.5	.849
AIM Total	487	1.4	25	75.9	15.5	.887

Table 5

Descriptives, Means (M), Standard Deviations (SD), and Cronbach's Alpha (α_c) for the Summated Scales of the SDQ

Subscale		*n*	Missing Sample Data (%)	Scale Items	*M*	*SD*	α_c
Internalising	Externalising						
Emotional symptoms		477	3.4	4	4.1	2.3	.700
	Hyperactivity	476	3.6	5	6.5	2.6	.767
	Peer problems	476	3.6	4	5.0	1.8	.447
	Conduct issues	478	3.2	5	2.9	2.1	.690
SDQ Total		468	5.3	18	17.9	5.8	.770

Table 6

Correlations Between Caregiver-Rated Stress, QoL, and Child Factors

Scale	1	2	3	4	5	6
1 AIM Total	–	**.32*****	**-.12***	-.08	**.23*****	**.11***
2 SDQ Total Difficulties	**.39*****	–	.02	**-.39*****	**.48*****	**.51*****
3 SF36 PCS	**-.10***	.03	–	**-.27*****	-.04	**.11***
4 SF36 MCS	**-.12***	**-.40*****	**-.28*****	_	**-.20*****	**-.57*****
5 Total Comorbidities (child)	**.25*****	**.47*****	-.05	**-.20*****	–	**.26*****
6 Parenting Stress	**.12****	**.50*****	**.11***	**-.55*****	**.25*****	–

Note: This table demonstrates Pearson correlation coefficients between scale total scores and child total comorbidities as rated by the parent. To the left of the major diagonal are zero-order correlations. To the right of the major diagonal are correlations controlling for parent age and gender. All correlations have two-tailed significance.
* $p \leq .05$ (two-tailed). ** $p \leq .01$ (two-tailed). *** $p \leq .001$ (two-tailed)

Assessing associations between subscale total scores and parenting stress, parenting stress scores were significantly correlated with all subscale scores except for the AIM language and AIM social domains (see Appendix G). As SF-36 physical, physical role functioning, emotional role functioning, bodily pain, general health, and especially vitality and mental health scores increased, parenting stress scores significantly decreased. Moreover, parenting stress and child conduct displayed a substantial positive correlation with statistical significance. Appendix G illustrates that for parent HR-QoL, as measured by the SF-36 PCS and MCS subscales, both physical health and the ability to carry out life roles due to physical health were significantly negatively correlated with the AIM restricted/ritualised and odd/atypical behaviours subscales, as well as the SDQ peer and conduct subscales. The SF-36 vitality subscale was significantly correlated with all AIM, SDQ, and SF-36 variables except for the AIM language and social subscales, with the greatest positive correlation observed with the SF-36 mental health subscale. The Pearson's coefficients indicated sufficient variance exists across the measures to proceed with path analysis.

Exploring Relationships Between Child Factors, Parental Stress and Quality of Life

Path analysis was performed using AMOS (v. 27) to test hypotheses exploring the directional relationship between child factors; problem behaviours (total difficulties), core

ASD symptoms, and comorbidities; parent stress, and parent QoL domains (refer to Figure 3 and 4). Path loadings (i.e. standardised regression weight, β) and total effects for each predictor were calculate. Chi-square goodness of fit indices were .764 for MCS and .680 for PCS domains, where a values of 1 represents perfect fit. All endogenous child factors bidirectionally predicted the other, with small to moderate effect, and this covariance was accounted for as part of the path modelling.

Mental Component Summary of SF-36

Hypothesis 1. Consistent with Hypothesis 1, as child problem behaviours and ASD symptom severity increased, the mental health domain of parent QoL decreased (see Figure 3). The direct effect of child problem behaviours on parents mental QoL scores was significant. Conversely, a negligible increase in parent mental health was directly observed as the number of child comorbidities increased.

Indirectly, Table 7 demonstrates the effect of child factors on parent mental health-related QoL, as partially mediated by stress. While child problem behaviours increased, a moderate and significant decrease in parent mental health was observed. Child ASD symptom severity and number of comorbidities had small positive indirect effects on the parent mental health domain of QoL.

Hypothesis 2. Figure 3 and Table 7 demonstrate that as parenting stress increased, mental health scores of parent QoL decreased with statistical significance.

Physical Component Summary of SF-36

Hypothesis 1. The physical heath domain of parent QoL decreased as child comorbidities and ASD symptom severity increased. A small but significant direct effect was observed between ASD symptom severity and physical QoL, as demonstrated in Table 7. Surprisingly, child problem behaviours predicted a direct but insignificant relationship with parent physical HR-QoL in the opposite direction, with physical QoL marginally increasing as the severity of child problem behaviours increased (see Figure 4). As the number of child comorbidities increased, parents' physical HR-QoL decreased, with stress partially mediating the small effect observed in this relationship. Again, child problem behaviours opposed those seen for ASD symptom severity and comorbidities, with parents' physical QoL indirectly decreasing as child problem behaviours decreased. Table 7 demonstrates ASD symptom severity as the only significant total effect predictor of parent QoL for the physical component summary.

Hypothesis 2. Though Table 7 and Figure 4 illustrate a significant direct relationship between parenting stress and QoL where parent physical HR-QoL increased with increasing parent stress, the relationship did not follow the predicted direction. Thus, supporting the null hypothesis.

Table 7

Path Analyses of Effects on MCS and PCS domains Mediated by Parent Stress

Variable	Direct Effect (β)		Indirect Effect (β)		Total Effect (β)	
	MCS	PCS	MCS	PCS	MCS	PCS
SDQ	-.19**	.04	-.25**	-.01	-.44**	.05
AIM	-.01	-.12*	.04	.02	.03	.03*
Comorbidities	.02	-.08	-.01	.01	.01	-.07
Parent Stress	-.48**	.13*	–	–	–	–

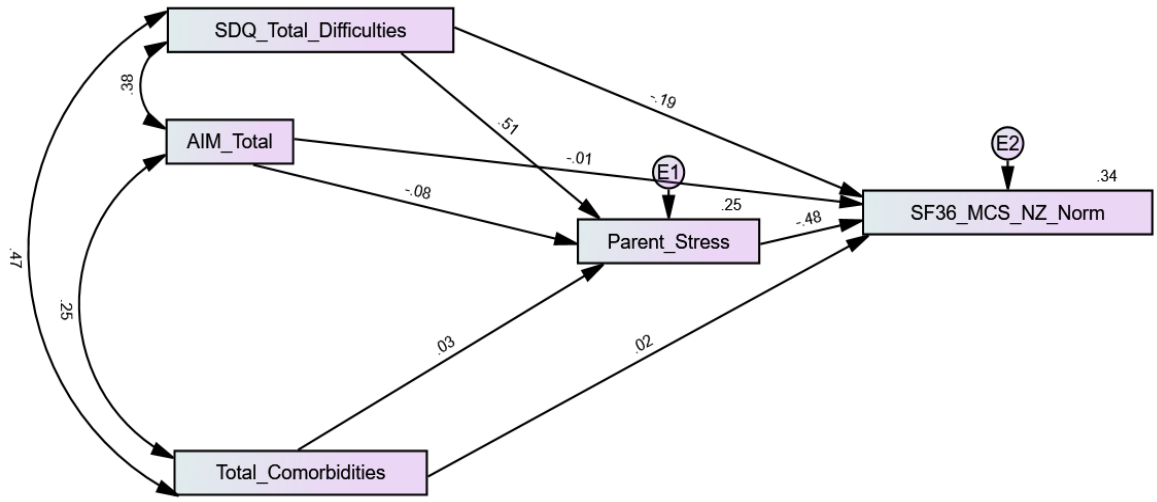
Note: This table demonstrates effect sizes using standardised regression weights to observe directional relationships between child and parent variables where parental stress mediates the relationship between child problem behaviours (Strengths and Difficulties Questionnaire, SDQ, *n* = 466), ASD symptoms severity (Autism Impact Measure, AIM, *n* = 487) and total comorbidities (*n* = 494) on MCS and PCS SF-36 (*n* = 434) scores. MCS, Mental Component Summary; PCS, Physical Component Summary of Short-Form 36 Questionnaire.

β = Standardised regression weight, beta coefficient

* $p \leq .05$ (two-tailed). ** $p \leq .001$ (two-tailed).

Figure 3

Path Analysis of Child Factors on Parent Stress and Mental Health Related QoL

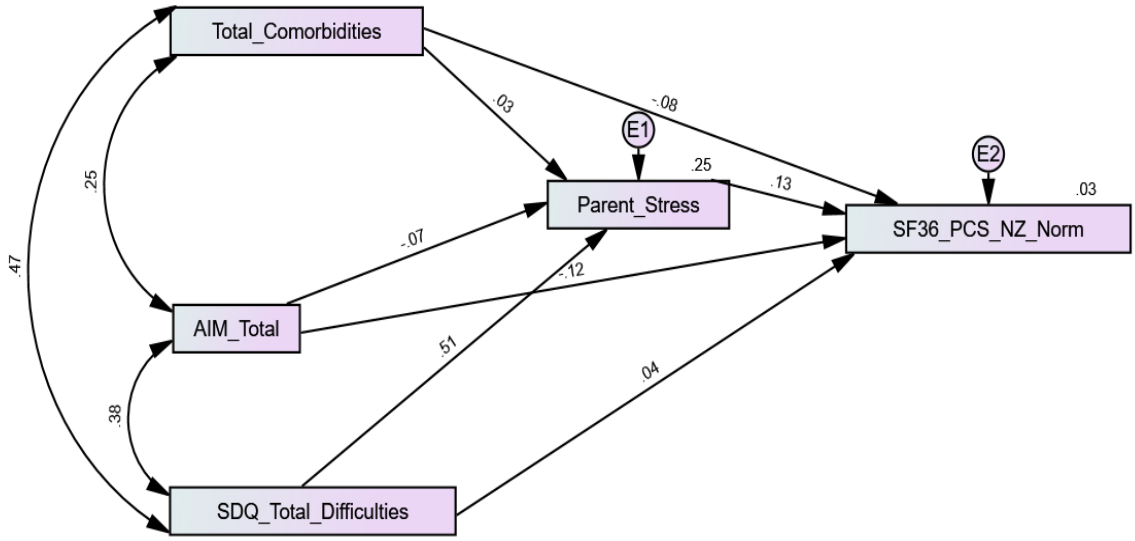


Note: Path model of exogenous child factors: SDQ_Total_Difficulties, Strengths and Difficulties Questionnaire; AIM_Total, Autism Impact Measure total scores, and Total_comorbidities scores on endogenous parent variables: Parent_Stress, Parental Stress

Scale; and SF36_MCS_NZ_Norm, Mental Component Summary of the Short-Form 36 Questionnaire.

Figure 4

Path Analysis of Child Factors on Parent Stress and Physical Health Related QoL



Note: Path model of exogenous child factors: SDQ_Total_Difficulties, Strengths and Difficulties Questionnaire; AIM_Total, Autism Impact Measure total scores, and Total_comorbidities scores on endogenous parent variables: Parent_Stress, Parental Stress Scale; and SF36_PCS_NZ_Norm, Physical Component Summary of the Short-Form 36 Questionnaire.

Discussion

The present study aimed to investigate parental stress and HR-QoL by exploring child ASD symptom severity, problem behaviours, and comorbidities and how these child factors interact with, and influence, parent outcomes.

Child ASD Symptoms and Problem Behaviours

The parent-rated AIM indicated that restricted/ritualised behaviours have the greatest impact on child functioning, followed by odd/atypical behaviour, social emotional reciprocity, and lastly communication/language impairments. The observation that restricted/ritualised behaviours affect child functioning the greatest is consistent with previous research findings using the AIM (Kanne et al., 2014; Landon et al., 2018; Mazurek et al., 2020; Shepherd et al., 2020, 2021; Shepherd, Landon, Taylor, et al., 2018). New Zealand research by Shepherd et al. (2018, 2021) supports the present finding that child functioning is least impacted by communication/language impairments. However, results for the remaining symptoms differed from previous studies with odd/atypical behaviour (Kanne et al., 2014) and social emotional reciprocity (Mazurek et al., 2020; Shepherd et al., 2020) reported as having the lowest impact on life functioning for children with ASD.

The SDQ identified hyperactive behaviour as the greatest challenging behaviour experienced by children with ASD in the current sample. Following on from hyperactivity in ranked order were peer, emotional, and conduct issues. These results mirrored those reported by Grasso et al. (2022) who also found SDQ mean scores highest in the hyperactivity domain and lowest for conduct issue in children with ASD. Indeed ASD hyperactivity scores were similar to children with ADHD in comparison to other developmental and neurodiversity disorders. When comparing the results of Grasso et al. (2022) to the present findings, Grasso et al. (2022) presented similar mean scores in all internalising and externalising behavioural domains for children with ASD. Using the SDQ to investigate behavioural difficulties in twins with and without ASD, Colvert et al. (2022) found children with ASD exhibited higher levels of problem behaviours, as indexed by SDQ mean scores, than age-matched typically developing children over a 3 and 9 year follow up period.

Correlational Analyses

Associations Between Child Factors and Parent Outcomes

Comparing PSS mean scores of the present study to that found by developers of the PSS measuring stress in parents of typically developing children, current mean scores were substantially greater than those for parents of children with clinically relevant levels of behavioural problems and non-clinical samples (Berry & Jones, 1995). On the contrary, research has also suggested far greater stress levels (M = 76.4, SD = 5.8; Ede et al., 2020)

for parents of children with ASD than that found in the present sample (*M* = 51.6, *SD* = 12.6). However, cultural factors may be a key contributor on self-reported stress ratings observed between the aforementioned and present study (Ede et al., 2020; Williams et al., 2019).

Current findings indicate parenting stress was positively and significantly correlated with all child variables with weak to moderate associations. However, when controlling for parent age and gender, the relationship between parent stress and child ASD symptom severity was no longer significant. Similar results were also found for parent QoL, controlling for parent age and gender removed significance for the weak inverse relationship observed between child ASD symptom severity and parent mental and physical QoL.

Although previous research supports the relationships between parenting stress and mother-rated child ASD symptom severity, child comorbidities, and problem behaviours (Adams et al., 2020; Mello et al., 2022), agreement in the literature as to the significance of interaction between child comorbidities and parenting stress is inconclusive (Sim et al., 2018). Moreover, parent age has been associated with better mental health (Scott et al., 1999) and lower levels of maternal stress (Falk et al., 2014).

Relationship Between Parental Stress and HR-QoL

Participants in the present study reported similar levels of physical health related QoL, and substantially lower mental HR-QoL compared to a normative New Zealand population sample using the SF-36 (Scott et al., 1999). These results are similar to those by Parsons et al. (2020) who reported parents caring for children with ASD in Western Australia scored significantly lower on the World Health Organisation's Quality of Life-BREF (World Health Organization, 2012) social, environmental, physical, and psychological QoL domains compared to a general population sample.

Child Factors as Predictors of Parent Stress and QoL

Parent Mental HR-QoL

Comorbidities. Hypothesis 1: Child comorbidities were not found to significantly predict parent mental HR-QoL for the present sample. Mixed findings have been presented by the literature, possibly due to differences in comorbidity specification such as whether observing individual comorbid conditions or combining comorbidities into a single total score. Positive and significant correlations have been shown for comorbid anxiety in children with ASD and parent psychological QoL (Adams et al., 2020). Additionally, mothers were significantly more likely to be treated for depression when their child with ASD presented with one or more comorbid psychiatric conditions compared to none (Zablotsky et al., 2013). However, regression modelling has shown no significant associations between child sleep and parent mental HR-QoL (Liu et al., 2021). The current study did not individually quantify

comorbidities, instead only used the score for total number of child comorbidities, and this can be considered a weakness of the study. Although research found links between some individual child comorbidities and parental QoL (Adams et al., 2020; Liu et al., 2021), these relationships have not been supported by the current findings.

Severity of Core ASD Symptoms. Hypothesis 1: Like the number of child comorbidities, ASD symptom severity did not significantly predict mental HR-QoL in parents. Child ASD symptom severity has been linked to parenting stress in previous research (McStay, Dissanayake, et al., 2014; Shepherd et al., 2021). However, the present study found no significant indirect association on parent QoL when using stress as a mediator.

Problem Behaviours. Hypothesis 1: When observing the effect of child factors on caregiver mental HR-QoL, child problem behaviours were the only significant direct and indirect predictor, thus exhibiting partial mediation via parent stress. Child externalising behaviours have shown to be unique predictors of both maternal and paternal parenting stress for parents of children with ASD (McStay, Trembath, et al., 2014). In addition to this, higher levels of maternal stress was reported by those with a sense of lower family coherence and with less ability to see stressors as a challenge (McStay, Trembath, et al., 2014). A systematic review by Enea & Rusu (2020) also noted a directional and bidirectional nature in the relationship between child problem behaviours and parenting stress. The current findings support the hypothesis that child factors influence parental stress.

Parental Stress. Hypothesis 2: the direct effect of stress on mental QoL was accepted, where increasing stress negatively impacted mental HR-QoL. These results support previous findings that have observed a direct inverse relationship between stress experienced by the parent and their own mental QoL (Enea & Rusu, 2020; Vahedparast et al., 2022).

Parent Physical HR-QoL

Comorbidities. Hypothesis 1: There were no significant effects found for the number of child comorbidities in predicting parent physical HR-QoL in the current sample. This finding opposes previous research, with recent studies noting significant negative associations with anxiety (Adams et al., 2020) and sleep (Liu et al., 2021) on parent PCS HR-QoL using the SF-36. Possible explanations for inconsistencies between the present study and previous research has already been outlined, specifically the manner in which comorbidities were represented in the analysis.

Severity of Core ASD Symptoms. Hypothesis 1: The only statistically significant child impact was severity of core ASD symptoms. Physical HR-QoL of parents for the present sample was significantly reduced as a direct influence of increasing child ASD symptom severity. The same has been noted by Bohadana et al. (2019) in Australian

parents of children with ASD. Moreover, ASD symptom severity has been shown to be a significant predictor of parenting distress once child age, intelligence quotient, and adaptive behaviour are accounted for (Mello et al., 2022); with stress consistently showing inverse associations with QoL (Bohadana et al., 2019; Ng et al., 2021; Willet et al., 2018). In addition, parents of children with ASD report significantly lower physical QoL than the general population (Parsons et al., 2020). Landon et al. (2018) observed a significant negative correlation between parent satisfaction with life ratings and child ASD symptom severity. These findings support the notion that parent QoL is affected by the severity of child ASD symptoms. However, research tends to focus less on the physical aspects of QoL, instead reporting on general QoL or mental health factors.

Problem Behaviours. A moderate but non-significant positive total effect was seen between child problem behaviours and parent physical HR-QoL. Multiple regression analysis by Vernhet et al. (2022) has found oppositional and affective problem behaviours were positively and significantly associated with the parent's perception of how much impact their child's ASD had on their QoL. However, their study did not separately differentiate physical QoL, only discussing a general QoL score (Vernhet et al., 2022).

Parental Stress. Hypothesis 2: Contrary to the expected result, increases in parenting stress had a small but significant direct effect on improving physical QoL. Though the current finding opposes the prominent view supported by literature, one study has observed a similar result. For fathers, but not mothers of children with ASD residing in Iran, the direct impact of parenting stress on physical QoL showed positive, but non-significant influence (Vahedparast et al., 2022). Indeed, path analyses in the current study did not strongly account for the physical HR-QoL domain, suggesting child factors and parenting stress are not strong predictors of parents' physical HR-QoL.

Taken together, results of the present study suggest parents of children with ASD in New Zealand experience heightened levels of parental stress, associated with child problem behaviours, and core ASD symptoms. Furthermore, this stress had a direct effect on the parents' mental HR-QoL. Indeed, physical HR-QoL was shown to be impacted by child core ASD symptom severity with child problem behaviours predicting deficits in parent mental HR-QoL. The current results add to the body of knowledge aimed at understanding experiences of stress and QoL in parents caring for a child with ASD in New Zealand (Eggleston et al., 2019; Landon et al., 2018; Shepherd et al., 2020, 2021; Shepherd, Landon, & Goedeke, 2018; Shepherd, Landon, Taylor, et al., 2018). Higher stress levels have been associated with younger parent age, high emotional expression towards the child, poor quality child-parent and parent-grandparent interaction, early ASD diagnosis, and lack of schooling for children (Derguy et al., 2016).

Additional parent factors such as self-compassion, resilience, coping styles, and ASD specific parenting self-efficacy have also shown to impact parenting stress and QoL (Bohadana et al., 2019; Enea & Rusu, 2020; Ng et al., 2021; Shepherd, Landon, Taylor, et al., 2018). High levels of parental stress in caregivers of children with ASD is particularly concerning given the association between stress and negative outcomes for parents and their children (Jones et al., 2021; Padden & James, 2017; Riany et al., 2022; Rodriguez et al., 2019). Moreso, with previous research illustrating greater risk of depression and anxiety in parents caring for children with psychiatric disorder including ASD (Mahatme et al., 2020), it is important to understand the nature and function of stressors on these parents.

Though the impact of environmental or personal factors were not measured within the present study, the need for adequate support and intervention strategies for the management of general and ASD-care related stress in primary caregivers of individuals with ASD has been illuminated. Ensuring psychoeducation and intervention systems are mobilised to support caregivers in the ASD community, identify need, and assist individuals in accessing psychological supports may improve subjective stress and QoL for parents, consequently impacting the wider family unit.

Limitations

While agreement of the current findings with previous research was mixed, findings should be considered in the context of the following limitations. The present sample consisted mostly of Caucasian females, holding disproportionate representation for male and gender diverse persons, Māori, and other ethnicities contributing to the diverse population of Aotearoa New Zealand (New Zealand Government, n.d.). Therefore, care must be taken when considering the applicability of the current findings.

Secondly, the present study is cross-sectional and although relationships between variables can be inferred from correlational and path analyses, they are not cause and effect. Furthermore, data collected were self-reports resulting in subjective rather than objective measures. Additionally, child behaviour was reported by parents, and, with the tendency for parents to over-praise child behaviour, it is likely that parent reports differ from clinical ratings (Henderlong & Lepper, 2002). Moreover, personal factors such as coping strategies have been found to impact the relationship between child ASD symptoms and parenting stress (Shepherd et al., 2018). Parents of children with developmental disability between the ages of 5 and 18 years have reported employing more coping strategies than parents with younger or adult children (Nelson Goff et al., 2016). With over 71% of children in the present sample within 5-18 years of age, it seems possible that parent coping could negate the significance between child core ASD symptoms and parent stress. To develop a

greater understanding, future research could investigate the effect of parent and child age on parent coping and stress related to ASD care.

Finally, data were collected during the global Corona virus (COVID-19) pandemic where Aotearoa New Zealand was experiencing enforced national lockdowns and household quarantine periods. The implications of nation-wide lockdowns disrupted for example routines, and access to external support, and increased job loss and financial strain, only further increasing caregiver stress (Li et al., 2022) over the past 2 years. Therefore, the potential for the COVID-19 pandemic to impact upon parent stress and QoL scores of the present sample should be acknowledged.

Conclusion and Implications

To conclude, findings from this cross-sectional exploratory study highlighted some of the implications that raising a child with ASD can have on parental stress and HR-QoL. A key finding drawn from this study is that parent-reported child factors can negatively impact QoL, with the most substantial effect on mental HR-QoL. Moreover, the current study agrees with previous research, showing parents caring for children with ASD experience reduced mental HR-QoL compared to typical populations. It should not be ignored, however, that child factors do not act alone to impair parental QoL. When addressing parents HR-QoL, additional variables such as environmental and personal factors beyond the exploration of the present study must be considered, for example, financial stress. Future research should investigate the role of resilience and self-compassion in the relationship between child ASD-associated factors and parental stress in New Zealand, in addition to the role of resilience and self-compassion in maternal and paternal self-reported levels of stress. Gaining a wider understanding of parental needs and intrinsic coping mechanisms used by parents caring for children with ASD could assist policy makers in allocating public health funding, and aid health professionals in designing effective intervention.

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Appendix A

Participant Information Sheet

Intro

Hello, Kia ora, Kia orana, Fakaalofalahiatu, Talofa lava, Gudetruolgeta, Talohani, Malo e lelei, Talofa, Ni sabulavinaka, Bonjour, Guten Tag, Nǐhǎo.

Parenting a child on the spectrum: What are you experiencing and how are you doing?

If you are the parent of a person on the spectrum then we invite you to participate in this research investigating your parenting experience.

This survey is designed to be easy to complete and should take no more than 20 minutes of your time.

By completing the questionnaire, you are expressing your consent to participate in this study.

Thank you for participating..

Daniel Shepherd
Auckland University of Technology

PIS

This research has received ethical consent from the Auckland University of Technology's Ethics Committee (AUTEC).

This survey takes between 15 - 20 minutes to complete, and is in four parts:

1) A bit about you
2) A bit about your child

3) What are you experiencing as part of your ASD parenting odyssey?
4) How are you coping with caring for an ASD child?

Participant Information Sheet

Date Information Sheet Produced: 27/05/2021

Project Title: Contributing factors to parenting stress in parents of children diagnosed with autism spectrum disorder in New Zealand

An Invitation: Dear participant, This study is the dissertation component of an Honours Degree in Psychology at Auckland University of Technology. We would like to invite you to be involved in our research exploring the factors that may predict parenting stress in parents who are caring for a child with Autism Spectrum Disorder. Participation in this research is completely voluntary and anonymous. You are under no obligation to complete the questionnaire and will be able to withdraw at any stage without question.

What is the purpose of this research? Our research aims to document your experiences for someone you care for who has an Autistic Spectrum Disorder and better understand stress factors that may be experienced. Specifically, it aims to explore factors which may predict stress when caring for a child with ASD.

How was I chosen for this invitation? Autism New Zealand have given their support to the study and agreed to advertise invitations to its members. As an individual receiving support from ANZ, or benefitting from their advocacy, you are invited to partake in the study.

What will happen in this research? You will be invited to fill out an online questionnaire about your experiences caring for a person with an Autism Spectrum Disorder. The answers from this questionnaire will be used to investigate factors that may impact the well-being of parents caring for children with ASD. Specifically, in predicting stress factors when caring for a child with ASD.

What are the benefits? By undertaking this study, we hope to inform and improve future policies and interventions aimed at understanding, assisting and supporting caregivers of persons with Autism Spectrum Disorder. The findings of this study will be shared with Autism New Zealand

and will be made available on their website.

How will my privacy be protected? Your responses are confidential, and your privacy and anonymity are protected as it is not possible to identify you through your responses. The data will be combined with all other participants' data and then presented as averages, percentages and proportions. Your anonymity is therefore completely assured at all times throughout the project.

What are the costs of participating in this research? The only cost in participating in this research is 15-25 minutes of your time to fill out the questionnaire. However, sensitive topics may be encountered in some parts of the questionnaire. There is a possibility that some questions may result in negative feelings that have not been previously addressed.

How do I agree to participate in this research? By completing the questionnaire below, you are expressing your consent to participate in this study. You are under no obligation to do so as your participation in this study is completely voluntary. You are also free to withdraw at any stage during the completion of the survey. Please feel free to keep this page for your own record.

Will I receive feedback on the results of this research? Findings of the current study will be available online. Feel free to visit http://www.autismnz.org.nz to obtain a copy of the report after the completion of this research. Additionally, you can email the project supervisor (see below) to enquire as to the study's progress.

What do I do if I have concerns about this research? You can report any of your concerns regarding the nature of this project to the Project Supervisor Dr Daniel Shepherd (daniel.shepherd@aut.ac.nz)

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, ethics@aut.ac.nz.

Whom do you contact for further information about this research? Researcher Contact Details: Marc Nazareth kfr6417@autuni.ac.nz or Nirmatha Arunthavam jcb9938@autuni.ac.nz

Project Supervisor Contact Details: Daniel Shepherd daniel.shepherd@aut.ac.nz Tel.: +64 9 921 9999 extn: 7238

Parent

Part One, please tell us a bit about yourself...

What sex are you?

Male

Female

Another Gender
(Please State):

What is your age in years?

Which ethnic group do you feel you most identify with?

European

Maori

Pasifika

Asian

Middle Eastern/Latin American/African

Other (please specify):

What is the highest level of education you have completed?

Primary School

Secondary School

Technical College or other professional training

University Degree

Other (please specify):

Are you currently (tick all that apply):

Single / a solo parent

Married

Previously divorced

Not married but living in a relationship

In a relationship but living independently

Child

Tell us about your child...

How old is your child with ASD (years old)?

What sex is your child's (please tick)?

Male

Female

How many other children (under 18 years of age) are currently in your care?

How old was your child when YOU first noticed their ASD-like behaviours?

Who first formally diagnosed your child with ASD?

My Doctor/ General Practitioner (GP)

Pediatrician

Psychologist

My child has never received a formal diagnosis

Other (please specify):

How old was your child when they received a formal diagnosis?

AIM_1

Tell us about your child's Autism

Please rate the impact that the following behaviours had on the daily functioning of the person with ASD in the <u>past 2 weeks:</u>

On a five point scale, how much do these behaviours interfere with your child's everyday functioning? (Note: Select "1" if the behaviour is absent)

	Not at all 1	Rarely 2	Moderately 3	Frequently 4	Severely 5
Shown fascination with parts of objects or toys rather than the whole object/toy	○	○	○	○	○
Lined things up	○	○	○	○	○
Had certain rituals or routines that have to be followed?	○	○	○	○	○
Shown strong attachments to unusual toys or objects?	○	○	○	○	○
Experienced problems with repetitive behaviours or restricted interests?	○	○	○	○	○
Avoided certain sounds, textures, or smells to an unusual extent?	○	○	○	○	○
Shown a preoccupation with one subject or area of interest?	○	○	○	○	○
Resisted changes in routines?	○	○	○	○	○

AIM_2

Tell us about your child's Autism

Please rate the impact that the following behaviours had on the daily functioning of the person with ASD in the <u>past 2 weeks:</u>

On a five point scale, how much do these behaviours interfere with your child's everyday functioning? (Note: Select "1" if the behaviour is absent)

	Not at all 1	**Rarely** 2	**Moderately** 3	**Frequently** 4	**Severely** 5
Had speech problems or been hard to understand?	○	○	○	○	○
Experienced problems in communicating with others	○	○	○	○	○
Had problems with pronouns (such as using "you" for "I")?	○	○	○	○	○
Not engaging in reciprocal conversation	○	○	○	○	○
Used a private or made-up language?	○	○	○	○	○

AIM_3

Tell us about your child's Autism

Please rate the impact that the following behaviours had on the daily functioning of the person with ASD in the <u>past 2 weeks:</u>

On a five point scale, how much do these behaviours interfere with your child's everyday functioning? (Note: Select "1" if the behaviour is absent)

	Not at all 1	**Rarely** 2	**Moderately** 3	**Frequently** 4	**Severely** 5
Responded oddly or inappropriately to others?	○	○	○	○	○
Experienced problems in social interactions?	○	○	○	○	○
Used odd or unusual pitch, volume, or tone when talking?	○	○	○	○	○
Had repetitive movements with his/her whole body (such as rocking or spinning)?	○	○	○	○	○
Shown repetitive hand or finger movements (such as finger flicking or hand flapping)?	○	○	○	○	○

AIM_4

Tell us about your child's Autism

Please rate the impact that the following behaviours had on the daily functioning of the person with ASD in the <u>past 2 weeks:</u>

On a five point scale, how much do the <u>ABSENCE</u> of these behaviors interfere with your child's everyday functioning?? (Note: Select "1" if the behaviour is absent)

	Not at all 1	**Rarely** 2	**Moderately** 3	**Frequently** 4	**Severely** 5
Used a number of different facial expressions (such as surprise, interest)?	○	○	○	○	○
Used gestures to communicate (such as nodding, waving goodbye, shrugging)?	○	○	○	○	○
Used a social smile to greet people or respond to them?	○	○	○	○	○
Brought/shown things to others just to share his/her interest (not just for help)?	○	○	○	○	○
Comforted others when they were upset?	○	○	○	○	○
Made eye contact with others?	○	○	○	○	○
Shared enjoyment	○	○	○	○	○

Checklist_1

Tell us about your child's everyday behaviour

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of your child's behaviour **over the last six months**.

	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	○	○	○
Restless, overactive, cannot stay still for long	○	○	○
Often complains of headaches, stomach-aches, or sickness	○	○	○
Shares readily with other children, for example toys, treats, tablets	○	○	○
Often has temper tantrums or hot tempers	○	○	○
Comforted others when they were upset?	○	○	○
Rather solitary, prefers to play alone	○	○	○

Checklist_2

Tell us about your child's everyday behaviour

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of your child's behaviour **over the last six months**.

	Not True	Somewhat True	Certainly True
Many worries, often seems worried	○	○	○
Restless, overactive, cannot stay still for long	○	○	○
Helpful if someone is hurt, upset or feeling ill	○	○	○
Constantly fidgeting or squirming	○	○	○
Has at least one good friend	○	○	○
Often fights with other children or bullies them	○	○	○

Checklist_3

Tell us about your child's everyday behaviour

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of your child's behaviour **over the last six months**.

	Not True	Somewhat True	Certainly True
Easily distracted, concentration wanders	○	○	○
Nervous or clingy in new situations, easily loses confidence	○	○	○
Kind to younger children	○	○	○
Often lies or cheats	○	○	○
Picked on or bullied by other children	○	○	○
Often volunteers to help others (parents, teachers, children)	○	○	○
Thinks things out before acting	○	○	○

Checklist_4

Tell us about your child's everyday behaviour

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of your child's behaviour **over the last six months**.

	Not True	Somewhat True	Certainly True
Steals from home, school or elsewhere	○	○	○
Gets along better with adults than with other children	○	○	○
Many fears, easily scared	○	○	○
Good attention span, sees chores, homework, tasks through to the end	○	○	○
Generally liked by other children	○	○	○
Generally well behaved, usually does what adults request	○	○	○

Parenting_1

How do you cope parenting a child with autism?

The following statements describe feelings and perceptions about the experience of being a parent of a child with ASD. Think of each of the items in terms of how your relationship with your child or children typically is.

Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.:

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree
I am happy in my role as a parent	○	○	○	○	○
There is little or nothing I wouldn't do for my child if it was necessary.	○	○	○	○	○
Caring for my child sometimes takes more time and energy than I have to give.	○	○	○	○	○
I sometimes worry whether I am doing enough for my child.	○	○	○	○	○
I feel close to my child.	○	○	○	○	○
I enjoy spending time with my child.	○	○	○	○	○
My child is an important source of affection for me.	○	○	○	○	○
Parenting this child gives me a more certain and optimistic view for the future.	○	○	○	○	○
The major source of stress in my life is my child.	○	○	○	○	○

Parenting_2

How do you cope parenting a child with autism?

The following statements describe feelings and perceptions about the experience of being a parent of a child with ASD. Think of each of the items in terms of how your relationship with your child or children typically is.

Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.:

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree
Parenting this child leaves little time and flexibility in my life.	○	○	○	○	○
Parenting this child has been a financial burden.	○	○	○	○	○
It is difficult to balance different responsibilities because of my child.	○	○	○	○	○
The behaviour of my child is often embarrassing or stressful to me.	○	○	○	○	○
If I had it to do over again, I might decide not to have children.	○	○	○	○	○
I feel overwhelmed by the responsibility of being a parent.	○	○	○	○	○
Parenting this child has meant having too few choices and too little control over my life.	○	○	○	○	○
I am satisfied as a parent	○	○	○	○	○
I find my child enjoyable	○	○	○	○	○

Anxiety

Does your child experience anxiety?

Yes

No

Has your child's anxiety been formally diagnosed and acknowledged?

Yes

No

How much does your child's anxiety interfere with their everyday functioning?

Very mildly Mildly Moderately Severely Very Severely

How much does your child's anxiety contribute to your levels of parenting stress?

Not at all Slightly Moderately Quite a bit Extremely

ADHD

Does your child experience ADHD?

Yes
No

Has your child's ADHD been formally diagnosed and acknowledged?

Yes
No

How much does your child's ADHD interfere with *their* everyday functioning?

Very mildly Mildly Moderately Severely Very Severely

How much does your child's ADHD contribute to your levels of parenting stress?

Not at all Slightly Moderately Quite a bit Extremely

Disability

Does your child experience intellectual diability?

Yes
No

Has your child's intellectual disability been formally diagnosed and acknowledged?

Yes
No

How much does your child's intellectual disability interfere with *their* everyday functioning?

Very mildly Mildly Moderately Severely Very Severely

How much does your child's intellectual disability contribute to your levels of parenting stress?

Not at all Slightly Moderately Quite a bit Extremely

Gastro

Does your child experience gastrointestinal (gut / tummy) problems?

Yes
No

Has your child's gastrointestinal problems been formally diagnosed and acknowledged?

Yes
No

How much does your child's gastrointestinal problems interfere with *their* everyday functioning?

Very mildly Mildly Moderately Severely Very Severely

How much does your child's gastrointestinal problems contribute to your levels of parenting stress?

Not at all Slightly Moderately Quite a bit Extremely

Sleep

Does your child experience sleep difficulties?

Yes
No

Has your child's sleep difficulties been formally diagnosed and acknowledged?

Yes

No

How much does your child's sleep difficulties interfere with *their* everyday functioning?

Very mildly	Mildly	Moderately	Severely	Very Severely

How much does your child's sleep difficulties contribute to your levels of parenting stress?

Not at all	Slightly	Moderately	Quite a bit	Extremely

Health_1

Finally, as a parent of a child with autism we'd like to hear what you think about your health and wellbeing.

We would like to know about how your health has been over the two weeks. Please answer the following questions by selecting the answer which you think most nearly applies to you.

In general, would you say your health is:

Excellent	Very Good	Good	Fair	Poor

Compared to one year ago, how would you rate your health in general now?

Much better now than one year ago

Somewhat better now than one year ago

About the same as one year ago

Somewhat worse now than one year ago

Much worse now than one year ago

Health_2

We would like to know about how your health has been over the past two weeks. Please answer the following questions by selecting the answer which you think most nearly applies to you.

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	○	○	○
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○	○	○
Lifting or carrying groceries	○	○	○
Climbing several flights of stairs	○	○	○
Climbing one flight of stairs	○	○	○

Health_3

We would like to know about how your health has been over the past two weeks. Please answer the following questions by selecting the answer which you think most nearly applies to you.

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Bending, kneeling, or stooping	○	○	○
Walking more than a kilometer	○	○	○
Walking several 100 meters	○	○	○
Walking 100 meters	○	○	○
Bathing or dressing yourself	○	○	○

Health_4

We would like to know about how your health has been over the past two weeks. Please answer the following questions by selecting the answer which you think most nearly applies to you.

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	No
Cut down on the amount of time you spent on work or other activities	○	○
Accomplished less than you would like	○	○
Were limited in the kind of work or other activities	○	○
Had difficulty performing the work or other activities (for example, it took extra effort)	○	○

How much bodily pain have you had during the past 4 weeks?

None	Very Mild	Moderately	Quite a bit	Extremely

During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely

Health_5

We would like to know about how your health has been over the past two weeks. Please answer the following questions by selecting the answer which you think most nearly applies to you.

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	No
Cut down on the amount of time you spent on work or other activities	○	○
Accomplished less than you would like	○	○
Did work or other activities less carefully than usual	○	○

During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

Not at all	Slightly	Moderately	Quite a bit	Extremely

During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time

Health_6

We would like to know about how your health has been over the past two weeks. Please answer the following questions by selecting the answer which you think most nearly applies to you.

These questions are about how you feel and how things have been with you during the past two weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Did you feel full of life?	○	○	○	○	○	○
Have you been a very nervous person?	○	○	○	○	○	○
Have you felt so down in the dumps that nothing could cheer you up?	○	○	○	○	○	○
Have you felt calm and peaceful?	○	○	○	○	○	○
Did you have a lot of energy?	○	○	○	○	○	○
Have you felt downhearted and sad?	○	○	○	○	○	○
Did you feel worn out?	○	○	○	○	○	○
Have you been a happy person?	○	○	○	○	○	○
Did you feel sleepy?	○	○	○	○	○	○

Health_7

We would like to know about how your health has been over the past two weeks. Please answer the following questions by selecting the answer which you think most nearly applies to you.

How TRUE or FALSE is each of the following statements for you?

	Definitely True	Mostly true	Don't Know	Mostly False	Definitely False
I seem to get sick a little easier than other people	○	○	○	○	○
I am as healthy as anybody I know	○	○	○	○	○
I expect my health to get worse	○	○	○	○	○
My health is excellent	○	○	○	○	○

Finish!

This is the end! Thank you for sharing your experiences with us. These results are important to us and the ASD community. We would be grateful if you could pass on this link to other parents of children with ASD so we can obtain the results that best reflect the overall experience of New Zealand parents.

If you have any further comments relating to the support you receive as a parent of a child with ASD, or about this survey in general, then we'd be interested to hear them:

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Appendix B

Means (M), Standard Deviations (SD),Corrected Item-Total Correlation, and Cronbach's Alpha (α_c) if Item Deleted for the Individual Subscale Items of the AIM

Item	*M*	*SD*	Corrected Item-Total Correlation	α_c if Item Deleted
Restricted/Ritualised behaviour				
AIM_R1: Fascination with parts	2.7	1.3	.48	.791
AIM_R2: Lined up objects	2.5	1.3	.41	.801
AIM_R3: Rituals or routines	3.8	1.0	.58	.775
AIM_R4: Attached to certain objects	3.3	1.3	.58	.773
AIM_R5: Repetitive Behaviours	3.8	1.0	.60	.772
AIM_R6: Avoidance of textures/smells/sounds	3.6	1.2	.53	.780
AIM_R7: Restricted interest	3.9	1.0	.49	.787
AIM_R8: Resistant to change	3.7	1.1	.52	.783
Communication/Language				
AIM_C1: Speech difficulties	2.9	1.5	.74	.807
AIM_C2: Communication difficulties	3.6	1.2	.72	.819
AIM_C3: Difficulties with pronouns	2.6	1.6	.75	.803
AIM_C4: Engagement in reciprocal conversation	3.5	1.2	.64	.834
AIM_C5: Uses made-up language	2.1	1.4	.54	.859
Odd/Atypical behaviour				
AIM_O1: Odd approach	3.2	1.0	.58	.755
AIM_O2: Problem with social interaction	3.8	0.9	.57	.762
AIM_O3: Odd pitch/tone	3.1	1.3	.52	.773
AIM_O4: Repetitive movements with full body	2.8	1.4	.66	.723
AIM_O5: Repetitive movements with hands or fingers	2.7	1.4	.58	.754
Social-emotional reciprocity				
AIM_S1: Range of facial expressions	2.6	1.1	.62	.452
AIM_S2: Gesture usage	2.6	1.1	.64	.483
AIM_S3: Appropriate smiling	2.6	1.1	.66	.451
AIM_S4: Shared interests	2.6	1.2	.60	.392
AIM_S5: Comforts others	2.4	1.1	.52	.308
AIM_S6: Makes eye contact	2.6	1.0	.58	.384
AIM_S7: Shared enjoyment	2.7	1.0	.63	.426

Appendix C

Means (M), Standard Deviations (SD), Corrected Item-Total Correlation, and Cronbach's Alpha (α_c) if Item Deleted for the SDQ

Item	*M*	*SD*	Corrected Item-Total Correlation	α_c if Item Deleted
Emotional symptoms				
SDQ_E_1: Complains of headaches and ills	0.6	0.8	.37	.758
SDQ_E_2: Is often worried	1.2	0.8	.34	.760
SDQ_E_3: Nervous, low confidence	1.3	0.8	.39	.757
SDQ_E_4: Many fears, scared easily	1.0	0.8	.39	.757
Hyperactivity				
SDQ_H_1: Restless, overactive	1.2	0.8	.39	.756
SDQ_H_2: Constantly fidgets	1.1	0.8	.47	.750
SDQ_H_3: Easily distracted	1.3	0.7	.47	.751
SDQ_H_4: Thinks before acts (R)	1.4	0.7	.27	.765
SDQ_H_5: Sees tasks through (R)	1.5	0.7	.41	.755
Peer problems				
SDQ_P_1: Solitary, plays alone	1.5	0.7	.06	.779
SDQ_P_3: Generally liked by other children	0.8	0.8	.33	.761
SDQ_P_4: Picked on or bullied	1.1	0.8	.13	.776
SDQ_P_5: Gets along better with adults than children (R)	1.1	0.7	.30	.763
Conduct issues				.764
SDQ_C_1: Often has hot tempers or tantrums	1.1	0.8	.50	.772
SDQ_C_2: Generally obedient	0.4	0.6	.39	.747
SDQ_C_3: Often fights with other children	0.3	0.6	.32	.757
SDQ_C_4: Often lies or cheats	0.2	0.4	.29	.762
SDQ_C_5: Steals things (R)	0.9	0.7	.44	.765
SDQ summated scale items	17.9	5.78	–	.770

Note: Item reverse-coded (R)

Appendix D

Means (M), Standard Deviations (SD), Corrected Item-Total Correlation, and Cronbach's Alpha (α_c) if Item Deleted for the PSS

Item	*M*	*SD*	Corrected Item-Total Correlation	α_c if Item Deleted
PSS_1: Happy in role as parent	2.3	1.1	.70	.896
PSS_2: Would do anything for child	1.3	0.7	.20	.908
PSS_3: Time and energy of care	4.2	1.1	.53	.901
PSS_4: Doing enough for child	4.4	0.9	.21	.909
PSS_5: Close to child	1.8	1.0	.52	.902
PSS_6: Spending time with child	1.9	0.9	.60	.900
PSS_7: Child is source of affection	2.3	1.2	.40	.905
PSS_8: Optimistic future view	3.2	1.2	.60	.899
PSS_9: Child is major stressor	3.4	1.3	.60	.899
PSS_10: Little flexibility and time	3.8	1.2	.59	.899
PSS_11: Financial burden of parenting	3.2	1.3	.47	.903
PSS_12: Difficulty balancing responsibilities	3.8	1.1	.66	.897
PSS_13: Embarrassing behaviours	3.4	1.3	.60	.899
PSS_14: Not having children again	2.1	1.3	.58	.900
PSS_15: Overwhelmed by parenting	3.1	1.3	.65	.897
PSS_16: Lack of choice and control	3.1	1.3	.74	.894
PSS_17: Satisfied as parent	2.4	1.1	.72	.896
PSS_18: Child is enjoyable	2.0	0.9	.64	.899
PSS Summated Scale Items	51.6	12.6	–	.905

Appendix E

Means (M), Standard Deviations (SD),Corrected Item-Total Correlation, and Cronbach's Alpha (α_c) if Item Deleted Values for the MCS domain of the SF-36

Item	*M*	*SD*	Corrected Item-Total Correlation	α_c if Item Deleted
SF36_19: Cut down on activities	1.5	0.5	.59	.905
SF36_20: Accomplished less	1.3	0.5	.57	.905
SF36_21: Did activities less carefully	1.6	0.5	.51	.906
SF36_22: Social interference (R)	3.7	1.1	.69	.898
SF36_23: Extent of social interferences	3.5	1.3	.49	.906
SF36_24: Lively (R)	3.1	1.2	.69	.897
SF36_25: Nervousness	4.2	1.4	.53	.905
SF36_26: Extremely down	4.7	1.3	.71	.896
SF36_27: Calm (R)	3.1	1.3	.71	.896
SF36_28: Energy (R)	2.9	1.3	.67	.898
SF36_29: Depressed	4.1	1.2	.72	.896
SF36_30: Worn out	3.0	1.4	.69	.897
SF36_31: Happy (R)	3.7	1.2	.68	.898
SF36_32: Tiredness	3.2	1.3	.58	.902
SF36 Summated MCS Scale Items	43.3	10.8	–	.907

Note: Item reverse-coded (R)

Appendix F

Means (M), Standard Deviations (SD), Corrected Item-Total Correlation, and Cronbach's Alpha (α_c) if Item Deleted Values for the PCS domain of the SF-36

Item	*M*	*SD*	Corrected Item-Total Correlation	α_c if Item Deleted
SF36_3: Vigorous activities	2.1	0.8	.56	.906
SF36_4: Moderate activities	2.6	0.6	.65	.908
SF36_5: Lifting groceries	2.7	0.6	.64	.909
SF36_6: Climbing several flights of stairs	2.5	0.7	.66	.906
SF36_7: Climbing one flight of stairs	2.8	0.5	.66	.909
SF36_8: Bending, kneeling, stooping	2.5	0.7	.45	.908
SF36_9: Walking more than a Kilometre	2.6	0.7	.64	.906
SF36_10: Walking several 100 meters	2.8	0.6	.81	.908
SF36_11: Walking 100 meters	2.8	0.5	.75	.910
SF36_12: Bathing or dressing	2.9	0.4	.31	.912
SF36_13: Cut down on work or activities	1.7	0.5	.53	.910
SF36_14: Accomplished less	1.4	0.5	.56	.909
SF36_15: Limited in work or activities	1.6	0.5	.65	.909
SF36_16: Difficulty doing activities	1.6	0.5	.63	.909
SF36_17: Bodily pain (R)	3.5	1.1	.67	.906
SF36_18: Pain interference (R)	3.9	1.1	.73	.904
SF36_33: Get sick easily	3.6	1.3	.39	.912
SF36_34: Health comparison (R)	3.6	1.3	.68	.905
SF36_35: Worsening of health	3.2	1.2	.30	.913
SF36_36: Excellent health (R)	3.0	1.3	.68	.905
SF36 Summated PCS Scale Items	52.8	10.0	–	.912

Note: Item reverse-coded (R)

Appendix G

Correlations of Subscale Total Scores Between Caregiver Stress, HRQoL, and Child Factors

	Scale	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1	AIM ritualised	–																
2	AIM language	**.45*****	–															
3	AIM odd	**.59*****	**.65****	–														
4	AIM social	**.20*****	**.10***	**.23****	–													
5	SDQ emotional	**.23****	**-.11***	**.13****	.06	–												
6	SDQ peer	**.25****	**.21****	**.31****	.07	**.24****	–											
7	SDQ conduct	**.22****	.04	**.27****	.07	**.29****	**.17****	–										
8	SDQ hyperactivity	**.34****	**.31****	**.45****	**.09***	**.19****	**.13****	**.40****	–									
9	SF36 physical	**-.17****	-.07	**-.13****	.02	-.06	**-.16****	**-.10***	-.03	–								
10	SF36 role physical	**-.27****	**-.17****	**-.16****	.00	**-.13****	**-.18****	**-.20****	**-.18****	**.49****	–							
11	SF36 bodily pain	**-.19****	-.06	**-.12***	.02	-.08	**-.18****	**-.14****	**-.09***	**.60****	**.55****	–						
12	SF36 general health	**-.19****	-.07	**-.16****	.00	**-.21****	**-.12****	**-.17****	**-.18****	**.48****	**.44****	**.49****	–					
13	SF36 vitality	**-.24****	-.05	**-.20****	.03	**-.26****	**-.18****	**-.31****	**-.29****	**.37****	**.44****	**.37****	**.51****	–				
14	SF36 social functioning	.08	-.03	.07	**.11***	**.13****	.09	**.15****	**.10***	-.06	**-.12****	**-.15****	**-.12****	**-.25****	–			
15	SF36 role emotional	**-.18****	**-.10***	**-.14****	-.04	**-.21****	**-.20****	**-.25****	**-.18****	**.25****	**.55****	**.25****	**.39****	**.52****	**-.18****	–		
16	SF36 mental health	**-.19****	-.03	**-.19****	-.01	**-.30****	**-.18****	**-.31****	**-.26****	**.31****	**.35****	**.27****	**.48****	**.81****	**-.23****	**.52****	–	

(Appendix continues)

Appendix G, continued

	Scale	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
17	Parenting stress	**.16****	.06	**.18****	-.02	**.29****	**.27****	**.45****	**.29****	**-.17****	**-.27****	**-.17****	**-.25****	**-.50****	**.17****	**-.39****	**-.57****	–

Note: This table displays Pearson correlation coefficients for subscales used. AIM subscale contained data from 494 participants. With the following participant numbers included in the analyses of each subscale correlation: SDQ emotional (n = 484), SDQ peer (n = 480), hyperactivity (n = 479), SF-36 physical (n = 450), SF-36 role physical (n = 450), SF-36 bodily pain (n = 456), SF-36 general health (n = 450), SF-36 vitality (n = 447), SF-36 social functioning (n = 451), SF-36 role functioning (n = 445), SF-36 mental health (n = 451), and parenting stress (n = 465).

* p = ≤ .05 (two-tailed). ** p = ≤ .01 (two-tailed). *** p = ≤ .001 (two-tailed)