

Parental Quality of Life in Autism Spectrum Disorder: Current Status and Future Directions

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Abstract

Parents of children with Autism Spectrum Disorder (ASD) take on responsibilities of diagnosis, advocacy, and daily care. There is evidence that this impacts upon their Quality of Life (QOL). This systematic review examined the impact of parenting a child with ASD on parental QOL. Available evidence overwhelmingly suggests that poorer parental QOL exists in this group of parents when compared to parents of both typically developing children and children with other disabilities. Several factors have been identified as having an impact on parental QOL including the severity of the core features of ASD, presence of comorbidities and in particular maladaptive behaviours such as hyperactivity, oppositional defiant and conduct problems, anxiety and emotional symptoms, as well as the level of general developmental delay and impairment in activities of daily living. However, the studies examined in this review have conflicting findings as to the contribution of these on QOL. It is worth noting that methodological issues may have contributed to the discrepancy in findings such as the differences in the age of the children studied and the different measures used to assess QOL with no autism specific QOL tool being available till the recent development of the Quality of Life in Autism (QOLA) scale. Further research is indicated to better understand the determinants and predictors of negative quality of life in autism both for the patients and their caregivers.

Keywords: Autism; Autism spectrum disorder; Parent; Quality of life; Wellbeing; Parent-child relationship

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Introduction


Autism Spectrum Disorder is a neurodevelopmental disorder characterised by two domains as per Diagnostic and Statistical Manual, 5th edition (DSM-5): deficits in social interaction and communication, and restricted, repetitive behavioural patterns and activities, such that impairment of functioning occurs [1]. ASD has a prevalence of approximately 1% [2]. Due to the heterogenous nature of ASD, its aetiology and pathophysiology have been difficult to determine; current research suggests the involvement of complex interactions between genetic and environmental factors [3].

Comorbid conditions are common in ASD occurring in as many as 70% and 26-38% of individuals with ASD also have intellectual disability, a decrease from previous rates of 70% due to increased awareness of high-functioning ASD [2, 4, 5]. Commonly encountered psychiatric co-morbidities in ASD subjects include

anxiety disorders (including generalised anxiety disorder, panic disorder and social anxiety disorder), ADHD, and oppositional defiant disorder [6]. Maladaptive behaviours, such as aggression, self-injury, and destructive behaviours, have a prevalence of 82-93.7% in children with ASD [7, 8]. Children with autism are more at risk for developing such behaviours than typically developing children and other developmentally delayed children [9], possibly due to expressive communication difficulties [10-12]. Activities of daily living may also be impaired. Feeding problems, such as difficulty in solid uptake and food restrictions, may occur due to sensory processing differences (for example not able to tolerate certain consistency of food such as sticky items) or due to communication difficulties [13]. Toilet training may be challenging due to an overall developmental delay or due to child's sensory issues or focus of attention elsewhere [14]. Dominick et al. [15] observed abnormal sleep patterns in two-thirds of children with autism. Sivertsen et al. [16] found a lower prevalence of 39.3%;

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however, even this rate of occurrence is ten times higher than that of the control group.

As caregivers of a child with autism, parents take on responsibilities associated with diagnosis, health, behaviour and assisting their child in everyday life. It is thus reasonable to examine the impact of this role on their QOL. QOL is a multidimensional concept encompassing various domains of functioning. The World Health Organisation has defined QOL as the “perception of [an individual’s] position in life... in relation to their goals, expectations, standards and concerns” [17]. Schalock et al. [18] proposed a model for assessing QOL in the context of disabilities with eight core domains: personal development, self-determination, interpersonal relations, social inclusion, rights, emotional wellbeing, physical wellbeing, and material wellbeing.

Materials and Method

A systematic literature search was conducted on the electronic databases Medline, PsycInfo, and Scopus, using ‘autism spectrum disorder’ ‘quality of life’ and ‘parent’ as search terms. No restrictions were placed on publication year. Titles were screened and non-relevant studies, such as those examining QOL in individuals with ASD, were excluded. Abstracts of remaining articles were then screened for relevancy. It should be noted that ASD as defined in the DSM-5 includes children diagnosed with “Autistic Disorder”, “Asperger’s Disorder” and “Pervasive Developmental Disorder” described previous editions of the DSM; studies which examined parental QOL in children with these DSM-4 diagnoses were thus also included. A manual search of references was then conducted to ensure inclusion of all relevant studies. This generated 20 studies which specifically examined QOL in parents of children with ASD. These studies are summarised in **Table 1** and will now be further discussed in sequence of publication.

Results

Allik et al. [19] examined the health related QOL (HRQOL) in 31 mothers and 30 fathers of children with Asperger Syndrome (AS) or high-functioning autism (HFA) in comparison to a control group of mothers and fathers of age-matched typically developing (TD) children. Parental HRQOL was measured by the 12 Item Short Form Health Survey (SF-12), which produces a Physical Component Summary score, describing physical health, and a Mental Component Summary score, describing mental health. Child behaviour was measured with the High Functioning Autism Spectrum Screening Questionnaire (ASSQ) and the Strengths and Difficulties Questionnaire (SDQ), completed by both parents and the child’s teacher. The ASSQ measures autism-related symptoms in the domains of social interaction impairment, restricted and repetitive behaviour, communication problems, and motor clumsiness and associated symptoms. The SDQ is a measure of social competence and psychological attributes, with the subscales of pro-social behaviour, hyperactivity, emotional symptoms, conduct problems and peer problems. Comparisons between the groups were performed through linear regression, controlling for parent age, child age, and child gender. It was found that mothers of AS/HFA children have poorer physical health

than mothers of children in the control group; however, there were no differences in reported mental health, in addition to no differences in the mental or physical health between the fathers of the AS/HFA and control groups. Maternal physical health was poorer than paternal physical health in the AS/HFA group. Parental HRQOL was not found to be related to the child’s autism symptom severity as measured by parent or teacher, while higher maternal physical health was related to higher teacher-reported pro-social behaviours, and higher maternal mental health was related to higher parent-reported pro-social behaviour and lower parent-reported hyperactivity and conduct problems. It was concluded that mothers of children with AS/HFA are more likely to experience impairment of HRQOL than mothers of typically developing children, and child behaviour problems in AS/HFA are associated with poorer maternal mental health.

Mugno et al. [20] undertook a study in 212 parents of children with PDDs, cerebral palsy and intellectual disability, aiming to evaluate the QOL in these parents in comparison to a control group of 77 parents of TD children, as well as to compare QOL between the disability groups. QOL was measured by the World Health Organization Quality of Life Assessment-BREF (WHOQOL-BREF), which assesses physical, psychological, social, and environmental health, as well as overall QOL perception, with higher scores indicating higher HRQOL. Independent t-tests analyses demonstrated that mothers and fathers of children with PDD reported poorer perception of overall QOL, health, social relationships and psychological wellbeing in comparison to the parents in the control, cerebral palsy, and intellectual disability groups. When the PDD group was analysed separately as AS/HFA, AD and PDD-NOS groups, comparison to the control group found the same. When comparing these PDD groups with one-way ANOVA and post-hoc comparison, no significant differences emerged except for lower perceived overall health in fathers of HFA/AS children than PDD-NOS children. The results of this study thus suggest parents of children with PDD were more likely to perceive poorer QOL than parents of children with other disabilities or TD children.

Lee et al. [21] compared the HRQOL in 89 parents of children with high-functioning ASD to that of a control group of 46 parents of TD children. Possible psychosocial predictors were measured with three tools: Family Crisis-Oriented Personal Evaluation (FC-OPE), Family Inventory of Resources for Management (FIRM) and the Parenting Stress Inventory-Short Form (PSI-SF). The FC-OPE examines coping with the five subscales of acquiring social support, reframing, seeking spiritual support, mobilising family to acquire and accept help, and passive appraisal. FIRM measures the amount of resources the families perceive themselves to have, consisting of four subscales: esteem and communication, mastery and health, extended family support, and financial wellbeing. The PSI-SF measures the domains of parenting distress, parent-child dysfunctional interaction, and difficult child. HRQOL itself was measured with the 36-Item Short-Form Health Survey (SF-36), similar to the SF-12, generating physical and mental health component scores.

Independent t-tests were used to analyse the differences in HRQOL between the study and control groups, finding that both

Table 1 Summary of studies on Quality of Life in Autism.

Study	Country	N	Mean ages of parent; child	Diagnosis	Setting	QOL Measure	Main findings	Limitations
Allik et al., 2006	Sweden	61 (31 Mo, 30 Fa) +59 TD (30 Mo, 29 Fa)	Mo 42.4 (28-54) Fa 45.6 (25-64) Ch 10.8 (8-12)	AS/HFA	PDD-habilitation centres	SF-12	1. Mothers of AS/HFA children have poorer physical health than mothers of TD children, however there is no difference in mental health 2. Mothers of AS/HFA children have poorer physical health than fathers 3. Better maternal mental health is related to better behaviour in children with AS/HFA	1. Small sample size 2. Socio-demographic factors not controlled for 3. Parental physical health was subjectively measured 4. Inclusion criteria may restrict the external applicability of this study 5. Cross sectional study
Mugno et al., 2007	Italy	69 (39 Mo, 30 Fa) PDD +89 MR (49 Mo, 40 Fa) +54 CP (27 Mo, 27 Fa) +77 TD (42 Mo, 35 Fa)	37 (± 12.7) Ch 7.5 (3-17)	37 AD 32 AS/HFA 10 PDD-NOS	Child neurology and psychiatry centre	WHOQOL-BREF	1. Parents of children with PDD have poorer QOL than parents of children with other impairments and TD children	1. Social factors (e.g. income) not controlled for 2. Psychiatric comorbidities in children were not assessed 3. Small sample size 4. Age of diagnosis and gender of children not analysed 5. Cross sectional study
Lee et al., 2009	USA	89 (65 Mo, 24 Fa) + 46 TD	42.2 (± 6.2)	HFA	Summer Program for children with HFA	SF-36	1. Parents of children with HFA have poorer HRQOL than parents of TD children 2. Income and stress are significant contributors to both physical and mental health in these parents	1. Small sample size 2. Cross-sectional study 3. Mostly wealthy 4. Results cannot be generalised to parents of lower-functioning children
Montalban and Roccella 2009	Italy	108 (54 Mo, 54 Fa)	Mo (28-58) Fa (29-67) Ch 11.2 (4-28, ± 5.7)	43 AD 2 CDD 3 AD 6 PDD-NOS	Autism societies and schools	ICIS	1. Parental and family QOL is affected in PDD 2. There are no significant differences between perceptions of QOL between parents	1. Cross-sectional study 2. Only a limited number of QOL factors were explored 3. Sociodemographic, symptom severity and behavioural factors we're not controlled for

Benjak 2010	Croatia	178 (105 Mo, 73 Fa) +169 TD	46 (28-84) Ch 15 (3-45, ± 9.9)	ASD	Croatian autism centres and education centres	PWI	1. Parents of children with autism have poorer subjective quality of life 2. Parents of children with autism have poorer self-perceived general health	1. Sampling bias 2. Results may not be generalisable to countries with differing political and socioeconomic situations 3. Cross-sectional study
Johnson et al., 2011	USA	128 (64 Mo, 64 Fa)	Mo 39.2 (29-69) Fa 42 (25-64) Ch 7.8 (2-24)	ASD	Internet recruitment	SF-36	1. In mothers, caregiving stress is associated with physical health but not mental health 2. In fathers, personal and family stress is associated with mental and physical health 3. Discrepancy between perceived and desired family functioning contributes to poorer maternal and paternal mental health	1. Lack of verification of ASD diagnosis and completion by both parents 2. Cross-sectional study 3. No control group
Khan et al., 2011	USA	304 (283 Mo, 28 Fa)	38.9 (± 8)	158 ASD 77 AS 65 PDD-NOS	West virginia autism training centre	SF-12	1. Maternal HRQOL is poorer than that of general US caregiver population 2. Poor child functioning, social support, and maladaptive coping predicted poorer parent mental health 3. Child behaviour problems and decreased social support predicted poorer parent physical health	1. Cross-sectional design 2. Large proportion of female subjects 3. No control group
Kheir et al., 2012	Qatar	56 (33 Mo, 23 Fa) + 42 TD (38 Mo, 4 Fa)	Not reported	ASD	Paediatric rehabilitation clinics	SF-36	1. No significant differences in the mental or physical health in parents of children with ASD or parents of TD children	1. Low response rate and small sample size 2. Cross sectional study 3. Higher proportion of fathers in ASD group 4. Reporting bias—parent may not have been primary caregiver

Yamada et al., 2012	Japan	269 (147 Mo, 122 Fa)	Mo 38.3 (± 4.6) Fa 40 (± 5.7)	42 AD 35 AS 81 PDD-NOS	Outpatient paediatric neuropsychiatry clinic	SF-36	1. More QOL areas were impacted (in comparison to the general population) in mothers than in fathers 2. Neuroticism personality trait was associated with poorer mental component of QOL in parents of children with autism 3. Relationship quality between the parents impacts on QOL in both mothers and fathers	1. Cross sectional study 2. Socioeconomic and marital status not controlled for 3. Sampling bias 4. No control group
Zablotsky et al., 2013	USA	1110 (Mo) 570 Non-depressed 540 Depressed	Ch of Non-depressed mothers 8.67 (± 3.87) Ch of Depressed mothers 8.9 (± 3.97)	535 AD 228 AS 347 Other ASD	Interactive autism network online registry	PDHQ	1. Children with more severe autism symptomatology and children with comorbid psychiatric condition are more likely to have a mother with depression 2. Mothers with depression are more likely to experience negative impact on various QOL spheres than mothers without depression 3. More severe autism symptomatology and existence of two or more psychiatric comorbidities is related to negative impact on all QOL domains in both depressed and non-depressed mothers.	1. Sampling bias 2. Cross-sectional study 3. Reporting bias
Baghdadi et al., 2014	France	152 Mo	Mo median 46 (IQR 42; 49.5) Ch mean 15 (± 1.6)	ASD	Autism evaluation clinics	Par-DD-Qol	1. Poorer adaptive behaviours and psychological development, increased aberrant behaviour and increased autism symptomatology are related to a moderate or high impact on parental QOL 2. Externalising behaviour and hyperactivity are risk factors for high impact on QOL, while independent functioning and higher cognitive ability are protective 3. Increased hours of intervention per week is a risk factor for moderate or high impact on QOL	1. Data collection bias as original data from a larger study 2. Type of intervention not controlled for 3. Cross-sectional study 4. No control group

Dardas & Ahmad 2014 (i)	Jordan	184 (114 Mo, 70 Fa)	37 (21-69) Mo 35.4 (21-57) Fa 39.9 (25-69) Ch 6.3 (2-12)	ASD	ASD special education centres	WHOQOL-BREF	1. No significant differences between maternal and paternal parenting stress or QOL 2. All domains of parenting stress, as well as accepting responsibility problem solving and escape avoidance coping are correlated with QOL in both mothers and fathers	1. Sampling bias 2. Cross-sectional study 3. Environmental factor findings maybe specific to predominant culture 4. No control group
Dardas & Ahmad 2014 (ii)	Jordan	184 (114 Mo, 70 Fa)	37 (21-69) Mo 35.4 (21-57) Fa 39.9 (25-69) Ch 6.3 (2-12)	A±	ASD special education centres	WHOQOL-BREF	1. No significant differences between maternal and paternal parenting stress or QOL 2. Increased parenting distress is predictive of poorer QOL in fathers 3. Increased parenting distress and difficult child behaviour is predictive of poorer QOL in mothers 4. Higher household income and more siblings of the child were protective for maternal QOL	1. Sampling bias 2. Cross-sectional study 3. Environmental factor findings maybe specific to predominant culture 4. No control group
Hoefman et al., 2014	USA	224 (200 Mo, 24 Fa)	39.4 (± 8.3) Ch 8.4 (± 3.5)	A±	Autism treatment network sites	Carer QOL	1. 97% of parents found fulfillment in caring for their child 2. The majority of parents found difficulty in balancing daily activities with caregiving tasks, as well as reporting mental and physical health problems 3. Higher reported fulfillment and support is associated with lower burden of caring, and better parent and child health	1. No control group 2. High proportion of educated working mothers 3. Sampling bias
Kuhlthau et al., 2014	USA	224 (200 Mo, 24 Fa)	39.4 (± 8.3) Ch 8.4 (± 3.5)	ASD	Autism speaks autism treatment network clinics	SF-6D EQ-5D	1. HRQOL in these parents is significantly lower than general US population 2. Child diagnosis and severity were not associated with parental QOL	1. No control group 2. Sampling bias 3. Cross sectional
Pozo et al., 2014	Spain	118 (59 Mo, 59 Fa)	Mo 44.6 (28-69) Fa 46.7	43 A± 1 AS 5 Rett's 10 PDD-NOS	Schools	FQOL	1. Poorer QOL and psychological wellbeing was correlated with more severe autism	1. Small participants to parameters ratio 2. Cross sectional 3. No control group

			(2-72) Ch 12.4 (4-38)				symptoms for mothers, and more behavioural problems for fathers 2. Increased social support and sense of coherence is associated with improved family QOL 3. Behavioural problems affected SOC, leading to poorer perceived QOL 4. Severity of autism had no relationship with psychological wellbeing in mothers or fathers, while behavioural problems had an indirect relationship with psychological wellbeing	
Tung et al., 2014	Taiwan	82	38.65 (± 4.62)	A±	Hospitals, paediatric clinics, developmental centre	WHOQOL-BREF	1. Parents in this group have a poorer QOL when compared with the general population 2. Only parental distress, and not child characteristics, were correlated with the four domains of QOL, with more distress correlated to lower QOL	1. Small sample size 2. Cross sectional 3. Only parent and child factors examined 4. No control group
Dardas & Ahmad 2015	Jordan	184 (114 Mo, 70 Fa)	37 (21-69) Mo 35.4 (21-57) Fa 39.9 (25-69) Ch 6.3 (2-12)	A±	Special education centres	WHOQOL-BREF	1. Accepting responsibility was the only mediator between stress and QOL 2. Seeking social support and escape avoidance were moderators between stress and QOL	1. Sampling bias 1. Cross-sectional study 2. Environmental factor findings may be specific to predominant culture of study population 3. No control group
Dardas & Ahmad 2015	Jordan	101 Fa	29.3 (25-69) Ch 5.9 (2-13)	A±	Disability diagnostic and education centres	WHOQOL-BREF	1. No coping strategies were found to be mediators of the effect of stress on QOL	1. Difference in paternal primary caregiver status not controlled for 2. Cross-sectional study 3. Sampling bias 4. Environmental factor findings may be specific to predominant culture of study population 5. No control group
Suzumura, 2015	Japan	30 (Mo) +30 TD (Mo)	37.7 (28-47) Ch 5 (3-6)	12 HFA 4 AS 14 HF PDD-NOS	Child psychiatry outpatients clinics	SF-36	1. Mothers of children with PDDs had poorer mental health but not physical health 2. Mental and physical health in mothers of children with PDDs is affected by child behaviour, rather than autism symptoms	1. Small sample size 2. Using DSM criteria may not be accurate measure of symptom severity 3. Cross-sectional 4. Health was self-reported

Van Tongerlo et al., 2015	Netherlands	28 (22 Mo, 3 Fa, 4 pairs)	Mo 40.9 (± 4.4) Fa 43.5 (± 5.4) Boy Ch 14.1 (± 4.4) Girl Ch 13.4 (± 4.2)	A±	General practice database	Qualitative interviews SF-12	1. Feelings of overburdening and guilt are experienced by many parents 2. Many parents experience lack of adequate support	1. Small sample size
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AD = Autistic Disorder
AS/HFA = Asperger Syndrome/High Functioning Autism
CDD = Childhood disintegrative disorder
PDD (-NOS) = Pervasive Developmental Disorder (Not Otherwise Specified)
TD = Typically Developing
Fa = Father
Mo = Mother
Ch = Child

mental and physical domains were significantly poorer in parents of children with HFA. Similarly, stress, coping and resources were found to be poorer in the study group when compared to that of the control group. Hierarchical regression analyses were then used to measure the contribution of psychosocial and demographic factors to QOL. Higher income was found to predict better mental and physical health. After controlling for this, stress was the only psychosocial factor found to significantly contribute to parental physical and mental health. The authors concluded that caring for a child with HFA has significant impacts on parental QOL, with income and its associated resources a possible buffer to stress.

Montalbano and Roccella [22] examined the impact on QOL of the families of 54 children with PDD. QOL was measured by the Impact of Childhood Illness Scale (ICIS), which comprises the four domains of impact of illness and its treatment, impact on development and child's adjustment, impact on parents, and impact on family. In each question, the participant is able to rate frequency and importance of each problem. Frequency analyses demonstrated that both mothers and fathers felt that their lives had been impacted, with 59.3% of fathers and 51.9% of mothers indicating that their social contacts were affected, 66.7% of fathers and 72.2% of mothers indicating that family activities were affected, 46.3% of fathers and 50% of mothers indicating more arguments at home. No significant differences between maternal and paternal concerns were found. The authors concluded that the approach to children with PDD should be holistic, as parental and sibling relationships may be affected, resulting in psychological problems in other family members.

Benjak [23] investigated the subjective quality of life (SQOL) and health status of 177 parents of 105 children with autism who were primary caregivers, in comparison to 169 parents of children with no disability (matched for the sex and age of the child, sex and age of parents, education level of parents, and municipality of residence). It was intended that both mothers and fathers would participate in the study, however only 73 of 105 fathers responded. The SQOL was assessed with the seven item Personal Wellbeing Index (PWI), which measures the domains of standard of living, health, life achievements, relationships, safety,

community connectedness and future security. The overall PWI score is an average across these seven domains, and the parental scores were divided into "high" and "low" categories. Parents' perception of their own health was rated on a five-point Likert scale. 38% of parents of children with ASD had high SQOL, while 62% had low SQOL. Following multiple logistic regression and bivariate analysis, parents of children with ASD were found to have poorer SQOL than control group parents in all domains of SQOL. The results of Pearson's chi-squared test showed that parents of children with ASD report poorer general health. The author concluded that parents of children with ASD are a vulnerable population group at risk of poorer SQOL and self-perceived health.

Johnson et al. [24] examined the relationships between family functioning, stress, and HRQOL in the mothers and fathers of children with ASD. Parenting stress was measured by the Parenting Stress Scale: Autism (PSSA), which consists of the subscales of behaviours and communication, parental caregiving, advocating, and personal and family life that are summed for a total score. Family functioning was measured by the Feetham Family Functioning Survey (FFFS), which includes the domains of relationship between the family and broader society, the subsystems within the family, and the relationships between the individuals in a family. The FFFS also provides a discrepancy score, which is the difference between the respondent's perception of "what is" and "what should be". The HRQOL was measured by the SF-36, as described previously. Pearson's correlations were performed to identify relationships between the study variables. Stepwise regressions on the most statistically significant correlations found that caregiving stress is associated with maternal physical health but not mental health, while in fathers, personal and family life stress was associated with mental health and physical health. Higher discrepancy in perceived and desired family functioning was negatively associated with both mental healths in both parents. Mediation analyses found that the discrepancy score mediated the effect of personal/family stress on paternal mental, but not physical health, and did not mediate the relationship between maternal caregiving stress and health.

A Wilcoxin test to compare discrepancy scores between mothers and fathers found that mothers had a higher discrepancy score, suggesting that maternal expectations of family functioning were not being met. The authors concluded that the discrepancy between expectations and the reality of family functioning contributed to poor mental health in parents, impacting upon HRQOL, and recommended that parental expectations should be discussed and supported by clinicians.

Khanna et al. [25] compared the HRQOL of 304 parents who were main caregivers of children with autism to that of caregivers in the general US population, in addition to examining the factors contributing to QOL. HRQOL was measured with the SF-12. The contributing factors measured were caregiver burden, social support, family functioning, coping, functioning (autism symptomatology) and behaviour of the child. Compared to age-matched counterparts, mothers of children with autism had significantly lower mental health but not physical health. Hierarchical regression analyses and Structural Equation Modelling were performed to test for predictors of mental and physical health-related quality of life. Poorer child functioning, social support, maladaptive coping and increased burden were found to predict poorer caregiver mental health. Increased child behaviour problems and decreased social support were significant predictors of poorer caregiver physical health. The authors concluded that caring for a child with ASD has a significant impact upon QOL, which intervention approaches need to address.

Kheir et al. [26] assessed the QOL of 56 parents of children with autism. A control group of 42 parents of typically developing children were also recruited. The Standard Recall SF-36v2, an interview-based questionnaire, was used to measure QOL; similar to the SF-12, this generates a mental health component score and a physical component score. T-tests were used to analyse the differences in QOL between the study and control groups. Parents of children with autism were significantly more likely to rate their health as poor, but there was no statistically significant difference between the groups in physical and mental health component scores. However, it was found that mothers were significantly more likely to suffer bodily pain, fatigue, tiredness and poorer mental health; thus, the higher proportion of fathers in the autism group as compared to the TD group (41% vs. 10%) may have masked the difference.

Yamada et al. [27] examined the QOL in 269 mothers and fathers of children with PDDs. The QOL was measured by the SF-36. The Intimate Bond Measure with the domains of Care and Control was used to assess the relationship between the parent partners, and NEO Five Factor Inventory was used to measure the five domains of personality (neuroticism, extraversion, openness, agreeableness and conscientiousness). Independent t-tests were performed to compare the SF-36 scores of mothers and fathers to general population scores. In mothers, a range of QOL domains were found to be significantly poorer than that of the general population, including role physical, general health perception, vitality, social functioning, role emotional, mental health, as well as overall mental component summary. In fathers, however, only vitality was found to be poorer than that of the general population. When using correlations and multiple regressions

to analyse the effect of relationship features and personality traits on reported mental and physical QOL, it was found that neuroticism was associated with poorer mental health in both mothers and fathers. Lower levels of care in the relationship were associated with poorer maternal physical health, while higher levels of control were associated with both poorer maternal mental health and paternal physical health. Increased work hours in fathers was associated with better physical health, while increased time spent with children was associated with better paternal mental health. While many other studies have shown that QOL is poorer in parents of children with PDDs, this is the only study reviewed which has considered the effect of parental personality traits, which the authors suggest may be used to personalise interventions.

Zablotsky et al. [28] investigated the effect of child autism symptomatology and comorbid psychiatric conditions (depression, anxiety, bipolar disorder, ADHD), as well as maternal depression diagnosis, on maternal QOL. Autism symptomatology was measured by the Social Responsiveness Scale, which has three domains of social impairment, communication impairment, and repetitive/stereotyped behaviours. The Parental Depression History Questionnaire was used to collect information on maternal depressive illness diagnoses as well as the impact of raising a child with ASD on five areas of life (relationship with partner, relationship with extended family, friendships and social network, career or education, and financial situation). It was found that children with more severe autism symptomatology and at least one comorbid psychiatric condition, and younger children, were more likely to have a mother with depression. Multiple regression analyses found that mothers with depression were more likely to experience negative impact on their partner and extended family relationships as well as their financial situation and career. More severe autism symptomatology and two or more comorbid conditions in the child was related to negative impact on all five areas of maternal QOL. The authors suggested that child characteristics may be used as a screening tool for maternal depression and poorer QOL, allowing for early detection and targeted intervention.

Baghdadli et al. [29] assessed the impact of caring for an adolescent with ASD (mean age 15) on the quality of life of 152 mothers. QOL was measured with the Parental- developmental disorder-quality of life scale (Par-DD-QoL), which generates scores for the emotional and daily disturbance subdomains, as well as a global QOL score. Higher scores indicate lower QOL. Symptom severity was measured by the Childhood Autism Rating Scale (CARS), which uses ratings of child behaviours to yield a composite score that allows the categorisation into non-autistic, mild, moderate, and severely autistic. Adaptive behaviours were measured with the Vineland Adaptive Behaviour subscales of communication, daily living skills, and socialisation. Behavioural problems were measured with the four Aberrant Behaviour Checklist (ABC) domains of irritability and aggressiveness, social withdrawal and passiveness, stereotypy and self-injury, and hyperactivity and lack of cooperation. Expressive speech was assigned one of three categories (spontaneous, functional speech with sentences; speech including at least five different words; use of fewer than five words) based on observational data. Psychological

development was assessed through the two functional areas of object-related cognition functioning and person-related cognition functioning. The Par-DD-QoL scores were divided into three categories based on terciles from a sample of patients with severe chronic diseases (no impact, moderate, high impact). Poorer adaptive behaviours and psychological development were related to a perceived moderate or high impact. High impact was also associated increased aberrant behaviour and autism symptomatology. When polytomic logistic regressions were used to compare QoL outcome for parents based on child characteristics, it was found that externalising behaviour and hyperactivity were significant risk factors for parent-perceived high impact on QoL, while independent functioning and higher cognitive ability reduced the risk. Increased number of hours of intervention per week was also found to be a risk factor for perceived moderate or high impact on QoL, which persisted when autism severity was controlled for. The authors hypothesised that this could be due to increased amount of intervention because of poorer parental QoL, or the lack of adaptation of intervention to family needs. The authors concluded that perceived parental QoL is impacted by child characteristics across behaviour, autism symptomatology, and adaptive skills.

Dardas and Ahmad [30] examined the differences between QoL in 114 mothers and 70 fathers. Stress was measured with the PSI-SF. Coping strategies were measured with the Ways of Coping Checklist-Revised (WCC-R), which measures the coping mechanisms of positive reappraisal, confrontive coping, problem-solving, seeking social support, distancing, self-control escape-avoidance, and accepting responsibility. QoL was measured by the WHOQoL-BREF. No differences in overall QoL or its subscales were found between mothers and fathers on independent t-test analyses. Bootstrapped Pearson's correlations showed that all domains of parenting stress, as well as the coping strategies of accepting responsibility, escape avoidance and problem solving were correlated with QoL in both parents. Distancing and positive reappraisal were correlated with QoL in fathers but not mothers, while family income and employment were correlated with QoL in mothers but not fathers. Hierarchical regression equations were then performed to examine any effect of moderation of coping strategies on the relationship between stress and QoL. The coping methods of escape avoidance and seeking social support were found to be amplifiers. The authors concluded that autism is found to impact upon QoL in non-western societies, and QoL may be associated with parental coping and stress.

Dardas and Ahmad [31] examined predictors of QoL in the same sample population, using the same measures. The predictors analysed were the three domains of the PSI-SF, income, child age and number of siblings of the child. No significant differences between maternal and paternal QoL and parenting stress were found following a MANOVA test. Following multiple regression analyses, it was found that increased parenting distress was the only predictor for poorer QoL in fathers. In mothers, increased parenting distress and a more difficult child predicted poorer QoL, while higher household income and more siblings of the child were protective. It was concluded that because parental stress and other environmental factors play a role in predicting parental QoL, holistic management

plans which take these into account would ensure optimum results for both parents and child.

Hoefman et al. [32] assessed the impact of caregiving on the QoL of 224 parents of children with ASD alongside investigation of the construct validity of the Carer QoL. QoL was measured with the Carer QoL, Self-rated Burden scale (SRB), and the Family Quality of Life Scale (FQLS). The Carer QoL specifically examines caregiving burden through the domains of fulfilment, support, relational problems with the dependent, mental health problems, daily activities problems, financial problems, physical health problems, and general happiness, to produce a weighted total score. The SRB is a single item measure which scores the subject's feelings of burden on a measure of 0 to 100. The FQLS examines the domains of family interaction, parenting, emotional wellbeing, physical wellbeing and disability-related support, and produces a total score. Descriptive analyses of Carer QoL responses showed that 97% of parents found fulfilment in caring for their child. However, 61% found difficulty in performing daily activities alongside carer tasks, 58% reported mental health problems, and 52% reported physical health problems. In analysing the discriminative validity of the Carer QoL, it was found that higher reported fulfilment and support is associated with a lower reported burden of caring as well as better child and parent mental and physical health. The authors concluded that caregiving for a child with ASD affected several domains of parental QoL.

Kuhlthau et al. [33] aimed to assess the HRQoL, its influences, and areas of its importance of the same 224 parents of children with ASD using a mixed qualitative and quantitative study. HRQoL was measured with the Six Dimension Short-Form Health Survey (SF-6D), a modified version of the SF-12, as well as the Five Dimension EuroQoL (EQ-5D), which consists of five domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The qualitative component of the study was conducted through focus groups. Wilcoxin-Man-Whitney tests were used to detect differences between the study samples and previously published scores of the general U.S. population. While the quality of life as measured by the EQ-5D was not significantly different to that of the general population, the QoL as found by the SF-6D was significantly lower. From the child characteristics of age, IQ, diagnosis, severity on ADOS, and time since diagnosis, only time since diagnosis was associated with QoL scores: parents of children diagnosed between one and two years previously reported increased caregiving burden than the groups diagnosed less than one year or more than two years ago. Qualitative analyses on focus group themes found that the most important areas of experience as parents of children with ASD were mental health and stress, social support, relationships, financial burden and physical health. The authors concluded that caring for a child with ASD had a substantial and varied impact on parental QoL.

Pozo et al. [34] used the double ABCX model to examine the influence of severity of the disorder, behavioural problems in the child, and parental sense of coherence and social support on family QoL and parent psychological wellbeing. The severity of autism was measured with CARS. Behavioural problems were measured by the Behavioural Problems Inventory, which includes the subscales of self-injurious, stereotyped behaviours, and

aggressive/destructive behaviour. Social support was measured by the Checklist of Supports for Parents of the Handicapped. Sense of Coherence was assessed with the Sense of Coherence Questionnaire. The Brief Coping orientation of Problems Experience questionnaire was used to measure coping strategies, with two factors used in analysis: positive/problem-focused coping and avoidance coping. Overall parental psychological wellbeing was measured by the Brief Psychological Wellbeing questionnaire. The FQLS (described above) was used to measure parents' perception of quality of life. Pearson's correlations were performed and it was found that in mothers, more severe autism symptoms were correlated with poorer QOL and psychological wellbeing, while in fathers, behavioural problems were correlated with the same. Increased social support was found to be associated with better family QOL. Modelling for influences on family QOL showed that increased sense of coherence and support were both directly related to family QOL, and behavioural problems had an indirect effect through poorer parental sense of coherence leading to poorer perceived QOL. The severity of autism was related to poorer family QOL in the mother, and improved family QOL in the father; the authors hypothesised that this was due to the differing experiences of mothers and fathers of the child's disorder, with a more severe disorder possibly allowing fathers to adjust their expectations of the child's development. In the psychological wellbeing model, it was found that autism severity had no direct or indirect relationship on psychological wellbeing in mothers or fathers. Behavioural problems had an indirect negative relationship with psychological wellbeing through sense of coherence. The authors concluded that raising a child with autism impacted on parental SOC, which in turn influenced the parental perception of QOL and psychological wellbeing.

Tung et al. [35] aimed to examine the correlation between HRQOL in carers of children with autism and autism severity, behavioural problems, and parenting stress, as well as to evaluate the parents' perception of importance of the HRQOL domains. HRQOL was measured by the WHOQOL-BREF, stress was measured by PSI-SF, autism severity was measured by CARS, and behavioural problems were measured by SDQ. One sample t-test analysis was used to compare the QOL domains of the study group and the Taiwan general population norms, finding that carers of children with autism had significantly lower scores in the physical, psychological and social domains. In addition, it was found that the domains ranked from most to least important by the parents were in the sequence of physical, psychological, social and environmental. Following correlation analyses and multiple regression, it was found that only parental distress, and not child characteristics, was significantly correlated the four QOL domains, with increased stress resulting in poorer perceived QOL. The authors concluded that parental stress is a key target for improvement of carer QOL.

Dardas and Ahmad [36] examined the role of coping strategies as moderators of the relationship between stress and quality of life in the same sample of 184 parents from the two 2014 studies discussed previously. The same measures were used. Multiple sets of regressions found accepting responsibility to be the only mediator between stress and QOL, and seeking social support and escape avoidance as moderators which amplified the relationship

between stress and quality of life. The authors hypothesised that accepting responsibility allowed parents a greater sense of control and that escape avoidance provided a "buffer" for stress, leading to higher QOL.

Dardas and Ahmad [37] examined the effect of coping strategies on the relationship between parenting-related stress and QOL in 101 fathers of children with autism. Stress was measured with the PSI-SF and coping strategies with the WCC-R. QOL was measured by the WHOQOL-BREF. Following multiple regression analyses, mediation analyses with the bootstrapping method and modelling, none of the coping strategies measured by the WCC-R were found to be mediators or moderators in the relationship between stress and QOL. The authors hypothesised that this may have been due to the loss of coping strategies due to multiple stressors, or factors influencing QOL that were not accounted for by the study's framework.

Suzumura [38] evaluated the HRQOL in 30 mothers of children with high-functioning PDD in comparison to a control group of 30 mothers of TD children, in addition to the child characteristics which contributed to QOL. The health-related QOL was measured by the SF-36, child behaviour was measured with the SDQ, and autism severity was quantified by the number of DSM-IV criteria met. Independent t-test analyses showed that mothers in the PDD group had poorer general health, vitality, social functioning, and overall mental health than the mothers in the control group, but no difference in overall physical health. On stepwise regression, it was found that increased difficult behaviours, rather than child IQ or autism severity, contributed to poorer physical and mental health-related QOL. The authors concluded that caring for a child with high-functioning PDD had an impact on maternal health-related quality of life, which is influenced by child behaviours rather than autism symptomatology.

Van Tongerloo et al. [39] undertook a mixed-methods study, with qualitative data collected from interviews, as well as quantitative data on QOL as measured by the SF-12. The main themes which emerged from the semi-structured interviews performed were feelings of overburdening and guilt resulting from perceived failure as caregivers. Another main concern of parents was the length of time for diagnosis of ASD and the lack of support from health services following the diagnosis. The authors concluded that these results point to the need for more outreach and home visit services, in addition to the education of general practitioners in a holistic approach to the family with a child with ASD.

Discussion

It is clear that reports from across countries and cultures suggest that caring for a child with ASD impacts significantly on the parent or care giver's QOL. Parents of children with ASD have poorer QOL than the age-matched general population, parents of typically developing children, and parents of children with other disabilities. It is likely that parental QOL is poorer than parents of typically developing children due to the emotional, physical, social and financial stresses of caring for a child with a disability. There are a number of possible explanations for poorer parental QOL than parents of children with other disabilities. The core features of ASD, such as social deficits and repetitive behaviours, may

cause more parental distress. These features may also negatively impact the ability of parents to maintain support networks, such as difficulties attending social or family engagements with affected children. Decreased social support for parents may then result in poorer QOL, as reported in the Khanna et al. [25] and Pozo et al. [34] studies reviewed. Another possible reason for poorer QOL in parents of children with autism is that parents who perceive and thus report poorer QOL may be more likely to have a child with ASD due to genetic or environmental factors. It is thus important that a holistic family-oriented approach in managing a child with ASD is used, with targeted intervention for parental QOL also warranted.

As described above, in addition to the core features of ASD, much comorbidity occur including maladaptive behaviours, general developmental delay and impairment of skills of daily functioning. The studies examined in this review have conflicting findings as to the impact of such comorbidities on parental QOL in comparison to core ASD symptomatology and severity. Khulthau et al. [33] found that parental QOL was not associated with severity of autism; additionally, Suzumura et al. [38] and Allik et al. [19] found that maladaptive behaviour affects parental QOL while autism severity does not. However, Zablotsky et al. [28] and Baghdadli et al. [29] found an association between both psychiatric comorbidities and autism symptomatology with parental QOL. It is possible that mothers and fathers are affected differently due to differing caring roles or expectations, as in the Pozo et al. [34] study which found that poorer QOL in mothers were associated with ASD severity, while paternal QOL was affected by behavioural problems. The Tung et al. [35] study suggests that neither ASD severity nor maladaptive behaviours are correlated with QOL, and rather, it is parental distress as the result of other factors, such as poor coping, which most affect perceived QOL. This is thus an area for further research.

Existing evidence suggests that within two-parent families, maternal QOL is consistently more affected than paternal QOL; this is likely because the child caring role is often assumed by mothers or it may be that there are the differences between genders in coping [40]. Further, several studies focused only on mothers, and it is possible that this was due to the lack of paternal

participation or responses, as in the Baghdadli et al. study which excluded the few paternal responses received. A possible alternative for future studies is to divide parental responses into "primary caregiver" and "secondary caregiver" so that paternal primary caregiver data is also considered. This would clarify if the difference between mothers and fathers is due to differing caring roles, or if there is a difference due to gender itself.

There are several limitations to the studies examined above. All are limited by small sample size. In addition, the majority of studies recruited from centres and clinics which provided services for children with ASD, resulting in sampling bias, as the parents of these children are already seeking support. It is possible that the relationship between QOL and parenting a child with ASD differs in those families who are not linked into health or social services. Future studies which recruit from the community settings may overcome these limitations.

Another limitation includes the variety of instruments used in assessing QOL in these studies. None of these measures were specific for use in ASD. As there is evidence that parents of children with ASD face unique challenges in providing care, it is reasonable that a quality of life measure specific to autism be considered for use in the assessment of QOL in these parents, such as the QOLA, developed by Eapen et al. [41]. The QOL contains two subscales: Part A, with questions pertaining to overall perceptions of QOL, and Part B, with questions asking parents to rate the impact of autism-specific symptoms of their child on parental daily activities. A preliminary study showed good psychometric properties with strong internal consistency and convergent validity [41].

Further limitation results from the lack of longitudinal studies. All studies discussed in this review are of cross-sectional design; while these studies are valuable in demonstrating associations, no unidirectional causative relationships may be concluded. For example, it is possible that parental psychosocial concerns related to lower QOL cause or exacerbate maladaptive behaviours in children with ASD. Future studies of longitudinal design are needed to further understand the relationship between child characteristics and parental QOL.

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