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ORIGINAL ARTICLE

Quality of Life and Its Associated Correlates of Parents of Children on the Autism Spectrum in Singapore

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Abstract

This cross-sectional study aimed to assess Quality of life (QoL) of parents of children on the autism spectrum in Singapore and identify its associated factors. Parents of children (age ≥ 5 years) completed the Quality of Life in Autism scale which measures parental self-rated QoL (higher scores denote greater QoL), and the perceived impact of the child's autism-related behaviors on parents (higher scores denote lesser impact). Information on the child's degree of autism (measured by the Social Responsiveness Scale, second edition [SRS-2]), community and social participation and cognitive and adaptive functioning were also obtained. Participants were 86 parents with mean child age 6.3 years (SD 1.0). Univariate analysis results revealed greater participation in community and social events to be two modifiable factors associated with higher parental QoL. However, these factors were not found to be significant in the multivariate model. Higher autism features (represented by higher parent-rated SRS scores) was associated with a greater perceived impact of the child's behaviors by parents in both univariate and multivariate analyses. Of note, child's cognitive or adaptive skills were not significantly associated with either QoL measure. Equipping parents to handle autism-related behaviors can be useful to reduce their impact on parental QoL. Facilitating community participation for these children may positively influence caregiver QoL as well.

Keywords Quality of life · Autism · Parents · Caregivers · Children

Autism is known to be a leading neurodevelopmental condition of childhood, resulting in a range of difficulties associated with social communication and behaviors (American Psychiatric Association, 2013). The nature of autism is such that several developmental domains, as well as adaptive skills, are involved with potential negative implications for daily functioning. In addition, it is also known that even amongst children on the autism spectrum without language or intellectual impairment, challenging behaviors can be prominent and interfere with adaptive skills and quality of life (Kanne et al., 2011; Wolff et al., 2014). Challenging behaviors in this context refer to repetitive behaviors, rigidity, and associated meltdowns related to challenges in emotional regulation.

Given the pervasive and chronic nature of autism, it is not surprising that caregivers of children on the autism spectrum experience greater levels of parental stress as well as mental health disorders (Dabrowska & Pisula, 2010; Hayes & Watson, 2013). Extant literature has also established a higher incidence of depression and anxiety in this subset of caregivers (Lai et al., 2015; Shepherd et al., 2021; Zablotsky et al., 2013). Specific factors known to be associated with caregiver stress include the presence and degree of challenging behaviors characteristic of autism, the presence of support networks, and parent coping strategies (Argumedes et al., 2018; Goh et al., 2021).

In this group of caregivers, a closely related but distinct construct is quality of life (QoL), defined as an individual's perception of their current life position concerning their cultural context, goals, value systems, and expectations (The

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Whoqol Group, 1998). QoL is a multi-dimensional concept and has generally been shown to be lower amongst caregivers of children on the autism spectrum as compared to typically developing children, including in a systematic review of 12 studies (Kuhlthau et al., 2014; Vasilopoulou & Nisbet, 2016). Much of this data comes from Western populations from countries such as Australia and the United States (Due et al., 2017; Eapen et al., 2014; Kuhlthau et al., 2014). QoL is influenced by multiple factors, including caregiver gender (mothers having lower QoL) (McStay et al., 2014), caregiver stress (Tung et al., 2014), child's challenging behaviors (Tung et al., 2014; Vasilopoulou & Nisbet, 2016), financial well-being (Khanna et al., 2011), availability of autism intervention services (Derguy et al., 2018; Due et al., 2017) and societal stigma and support networks (Derguy et al., 2018; Ilias et al., 2018). The literature is inconsistent regarding caregiver QoL and how it relates to features of autism, with some studies (Khanna et al., 2011; Tung et al., 2014; Zablotsky et al., 2013) suggesting that greater severity of autism negatively correlates with Qol while others show that QoL may be independent of severity of autism in the child (Due et al., 2017; Eapen et al., 2014). Awareness of the QoL of caregivers and factors that influence this, within a given community can contribute towards better support for this group of individuals. This can, in turn, facilitate the design of targeted measures to improve QoL in this vulnerable group of caregivers.

It is also important to recognize that QoL of caregivers and the child goes beyond the child, but rather is nested within the ecosystem of the family including the cultural practices and societal norms within their community. For example, Wang et al. (2022) found that compared to western cultures, social support is an important factor in QoL for parents of children on the autism spectrum in eastern cultures. This is further substantiated by Kang-Yi et al. (2018) who highlighted that Asian families with a predominantly collectivist culture, find traditional forms of support such as community support useful. Thus, given that QoL is strongly influenced by culture and societal context (Eapen et al., 2023), studying it across cultures and communities is important to effectively support caregivers within each practice setting.

This study aimed first to examine the QoL of parents of children on the autism spectrum in Singapore, and second to identify factors associated with QoL. We hypothesized that reduced social participation/inclusion, more autism features in the child, and the presence of financial difficulties in the family would be associated with lower parental QoL.

Methods

Study Setting and Participants

Data for the study presented in this manuscript was obtained from a cross-sectional study conducted at a developmental-behavioral pediatrics (DBP) clinic situated within a tertiary academic center between June 2019 and March 2020 in Singapore. Singapore is a small multicultural city-country of 6 million inhabitants in South East Asia. Approximately 80% of the resident population is literate in English (Singapore Department of Statistics, 2011). It is one of the most densely populated countries in the world with no rural areas. Hence, most families will have to travel between 15 and 30 min to reach the clinic and similarly so for intervention services. The study clinic is one of two national DBP centers and serves primarily children from birth till 7 years old with both diagnostic and intervention services. The clinic evaluates children who are referred for any developmental, behavioral or emotional concern by primary care physicians. Following this first visit and subsequent visits whereby diagnostic assessments are done (for example, to determine a diagnosis of autism), children will be referred to therapy services either within the clinic (for children with short-term needs such as articulation or handwriting delays) or in the community for those who require longer term support/ services. The majority of children on the autism spectrum will receive community-based therapy services.

Inclusion criteria for the study included: 1. child older than or equal to 5 years, 2. child diagnosis of autism following clinical evaluation by a developmental pediatrician based on the Diagnostic and Statistical Manual of Mental Disorders (5th edition; DSM–5) (American Psychiatric Association, 2013), or following evaluation with both the Autism Diagnostic Observation Schedule-2nd edition (ADOS-2) (Lord et al., 2012) and Autism Diagnostic Interview-Revised (ADI-R) (Rutter et al., 2003), and 3. parent or legal guardian being able to speak and understand English; to complete study measures and questionnaires. Exclusion criteria included: 1. Parent's inability to comprehend questionnaire measures in English and, 2. presence of any serious chronic medical diseases (e.g., complex congenital cardiac disease) in the child. Parents completed the study measures at a review visit as part of their child's follow-up at the centre. Hence, the presence of autism would have been previously established and discussed with parents. Ethics approval was obtained from the relevant institutional research ethics board for the study and all its related procedures.

Procedure

Following informed consent by parents, research personnel recruited children into the study at their review visit at the medical clinic. All the study questionnaires were administered to parents/caregivers in the form of paper questionnaires by research personnel. The parents/caregivers completed the questionnaires independently, research personnel were available to clarify if parents/ caregivers had any questions. Information about cognitive and adaptive behavior and other medical data were abstracted from medical records as detailed below.

Study Measures

The following questionnaires were completed by parents/ caregivers at the point of recruitment for the study: Quality of Life in Autism (QoLA) scale, Social Responsiveness Scale-2nd edition (SRS-2), Repetitive Behavior Questionnaire-2nd edition (RBQ-2), Community and social participation questionnaire and, a demographic questionnaire.

Quality of Life in Autism (QoLA) Scale

The primary study measure was the Quality of Life in Autism (QoLA) scale (Eapen et al., 2014). The QoLA has a parent-version to be completed by parents/caregivers of children on the autism spectrum (who are ≥ 5 years of age) and a self-reported version meant for older individuals on the autism spectrum. The QoLA parent-version was used in this study and this contains questions related to caregiver's quality of life and the child's behaviors answered via a 5-point Likert scale. The scale contains 2 subscales: Part A measures parental self-rated QoL (score range 28–140, higher scores denote greater perceived QoL) with questions like 'I am satisfied with my life' and 'I feel in control of my life'. Part B measures how much of an impact the child's autism-related behavior has on the parents (score range 20–100, higher scores denote fewer perceived problems due to behavior) with questions like 'How much of a problem has this been for you: needing to stick to a routine'. The two subscales are meant to be scored and analyzed separately and interpreted as a continuum with no threshold or categorical scores e.g., a range that would indicate high or low QoL. The validation study of the QoLA showed that it had excellent internal consistency as well as good known-groups validity between parents of children on the autism spectrum and those who were typically developing (Eapen et al., 2014). The QoLA also showed good convergent validity with other QoL measures and autism symptom severity, respectively.

Social Responsiveness Scale-2nd Edition (SRS-2)

Parents also completed the Social Responsiveness Scale-2nd edition (SRS-2) (Constantino & Gruber, 2012), which is a well-used measure of difficulties related to symptoms of autism, namely in the domains of social communication and restricted behaviors. The SRS-2 scale provides a total composite score, which was used for analysis and represented an objective measure of autism symptoms.

Repetitive Behavior Questionnaire-2nd Edition (RBQ-2)

The Repetitive Behavior Questionnaire-2nd edition (RBQ-2) was completed by parents (Leekam et al., 2007). This questionnaire measures the frequency and intensity of repetitive behaviors, which may be associated with autism and provides a total repetitive behavior score. Results from the original study showed that the RBQ-2 has good internal consistency and validity, indicating that it is a reliable instrument for measuring a range of repetitive behaviors. We selected this tool as it can be used in children as young as 15 months of age, which was appropriate for use in our (other) clinical studies compared to other tools to measure RRBs, for example, the RBS-R which was for children aged 6 and above (Lam & Aman, 2007).

Community and Social Participation Questionnaire

We developed a 4-item community and social participation questionnaire based on the 'satisfaction with participation in social roles' domain of the PROMIS® short form measure (Cella et al., 2019). The questionnaire, which was completed by caregivers at the point of recruitment, contained questions related to the activities of the child in the community and in terms of social events. From this questionnaire, two questions (namely: 'How often do you and your child participate in invited social events?' and 'How often do you and your child participate in community events which are fun? (e.g. community center events)') were used to represent social and community participation of children. Respondents rated the frequency of participation as 'Never', 'Less than once a month', or 'More than once a month' and responses based on these categories were used in statistical analysis.

Demographic Questionnaire

All caregivers completed a demographic questionnaire, which asked questions regarding family history of autism, presence of siblings, parental education and whether the family was receiving government-administered financial subsidies. In Singapore, stringent criteria including a family's per capita household income is used to determine eligibility for financial subsidies (Ministry of Health & Singapore, 2021). Financial subsidies are used to reduce cost of outpatient specialist care, and varies in amount and duration according to a tiered approach. Within our clinic setting, the majority of families (except high income relative to national income profiles) are expected to receive financial subsidies to varying degrees, hence those who did receive subsidies are expected to be in the low income and middle-income group. In our study, we classified all families who received any amount of subsidy as 'receiving financial subsidies'. This was used as a proxy for family socio-economic status.

Other Study Data

Apart from the study questionnaires above, information on the child's diagnosis, presence of medical illnesses, adaptive and cognitive functioning was extracted using a standardized data extraction form from medical records. Specifically, adaptive functioning is measured (as part of the standard clinical workflow in the clinic) using the Vineland Adaptive Behavior Scales-3rd edition (VABS-III), which is a well-validated and widely used assessment that measures everyday functioning in the domains of communication, social, daily living and motor skills (Sparrow et al., 2005). Cognitive functioning was determined using standardized Weschler scales of intelligence tests (Wechsler, 1999), administered by trained and research reliable psychologists. Results of both these assessments were abstracted from the medical records; these assessments are typically performed between 5 and 6.5 years in our clinic, as dictated by clinical workflows.

Statistical Analysis

All analyses were carried out using SPSS Version 28.0. Descriptive statistics for QoLA scores, as well as child factors including cognitive functioning, adaptive functioning, Social Responsiveness Scale scores were presented as mean (standard deviation) for normally distributed variables, otherwise median and interquartile range will be presented. Parental education was dichotomized into 2 groups (diploma and below, and university education and above) for analysis, while family's receipt of financial subsidies was used as a dichotomous variable. Community and social participation were coded into categories based on frequency of participation in events as rated by parents as noted above; the category of 'never' was used as the reference category in regression analysis and the pairwise comparisons were Bonferroni-adjusted. Univariate linear regression was done to examine for variables associated with QoLA Part A and Part B scores. Subsequently, multivariate analysis was done in separate models for Part A and Part B scores, using variables which were $p < 0.1$ from the corresponding univariate analysis.

Results

The study sample comprised 86 children (mean age 6 years and 3 months, SD 1.0 year). Table 1 depicts the demographic variables of the sample. The majority of children were of male gender ($n = 72$, 83.7%) and about half ($n = 38$, 44.2%) were the only child in their family. The majority ($n = 65$, 75.6%) of families were receiving financial subsidies within the public health care system. The cognitive profile of the child sample showed a good range with mean full-scale IQ score of 84.5, SD 23.9 (median 78.0, interquartile range 69.8–100.0). Adaptive behavior profile showed a mean adaptive behavior composite of 71.3, SD 9.7 (median 74.0, interquartile range 65.0–78.8) across the children. The mean QoLA Part A score (parental self-rated QoL) was 104.0 (SD 17.5) and that for Part B (parental rating of impact of child's autism-related behavior on themselves) score was 66.2 (SD 22.4).

Table 2 shows the univariate relationships of variables with the QoLA Part A and Part B scores while Table 3 shows the same for multivariate regression. Univariate significant predictors for higher QoLA Part A score (parental self-rated QoL) included higher maternal education ($b = 12.76$, 95% CI 0.32 to 25.20, $p = 0.045$), presence of sibling(s) ($b = 10.02$, 95% CI 2.11 to 17.93, $p = 0.014$), more frequent community participation (i.e., more than once a month) as compared to no community participation ($b = 14.71$, 95% CI 2.56 to 26.87, $p = 0.018$) and more frequent social participation (i.e., more than once a month) as compared to no social participation ($b = 9.47$, 95% CI 0.68 to 18.23, $p = 0.035$). Inversely, infrequent participation in social events (i.e., less than once a month) as compared to no social participation, was associated with lower Part A scores ($b = -13.85$, 95% CI − 26.89 to − 0.81, $p = 0.038$), together with having a family history of autism ($b = -11.05$, 95% CI − 23.13 to 1.05, $p = 0.073$). However, multivariate linear regression analysis (Table 3), did not yield any significant variables associated with the QoLA Part A scores.

As for the QoLA Part B score (impact of child's autism-related behavior with higher scores denoting lesser impact), the following factors were associated with greater impact of the child's behaviors in univariate analysis: higher SRS-2 score ($b = -0.74$, 95% CI − 1.32 to − 0.17, $p = 0.013$) and older age of child ($b = -6.18$, 95% CI − 10.59 to − 1.78, $p = 0.007$). The family being in receipt of financial subsidies was associated with lesser impact of the child's behaviors ($b = 22.36$, 95% CI 12.22 to 32.50, $p < 0.001$). On multivariate linear regression analysis (Table 3), the QoLA Part B model ($R^2 = 0.235$) showed that higher SRS-2 score was still associated with greater impact of child's behaviors ($b = -0.63$, 95% CI − 1.20 to − 0.05, $p = 0.034$).

Discussion

The main goal of this study was to examine the QoL of caregivers of children on the autism spectrum in Singapore and identify child and family-related factors associated with

Table 1 Demographic and clinical characteristics of participants (*n* = 86)

Characteristics	Value
Age of parent (years), mean ± SD (range)	38.5 ± 6.6 (25–62)
Age of child (years), mean ± SD (range)	6.3 ± 1.0 (5–10)
Maternal education, *n* (%)	
High school and below	15 (38.5)
University and above	24 (61.5)
Paternal education, *n* (%)	
High school and below	20 (47.6)
University and above	22 (52.4)
Gender of child, *n* (%)	
Female	14 (16.3)
Male	72 (83.7)
Having one or more sibling, *n* (%)	48 (55.8)
Family history of autism, *n* (%)	9 (10.5)
Receipt of financial subsidies, *n* (%)	65 (75.6)
QoLA Part A score, mean ± SD (range)	104.0 ± 17.5 (58 to 138)
QoLA Part B score, mean ± SD (range)	66.2 ± 22.4 (20 to 100)
IQ score, mean ± SD (range)	84.5 ± 23.9 (35 to 134)
VABS adaptive behavior composite score, mean ± SD (range)	71.3 ± 9.7 (47 to 89)
RBQ total repetitive behavior score, mean ± SD (range)	29.9 ± 6.0 (20 to 48)
Parent-rated SRS score, mean ± SD (range)	62.7 ± 10.2 (39 to 85)
Community participation, *n* (%)	
Never	36 (43.4)
Less than once a month	38 (45.8)
More than once a month	9 (10.8)
Social participation, *n* (%)	
Never	7 (8.4)
Less than once a month	58 (69.9)
More than once a month	18 (21.7)

IQ intelligence quotient, *QoLA* quality of life in autism, *RBQ* repetitive behavior questionnaire, *SRS* Social Responsiveness Scale, *VABS* Vineland III Adaptive Behavior Scales

QoL. To the best of our knowledge, our study is the first to examine factors associated with self-reported parental QoL scores of parents of children on the autism spectrum within our country. We found that greater severity of autism features in the child was associated with greater perceived impact of the child's autism related behaviors on the parents. Our study findings also suggest that participation in community and social events, having other children apart from the child on the autism spectrum and higher maternal education were all associated with higher parental QoL, although these were not significant on multivariate analysis. Further, older age of the child, and family being in receipt of financial subsidies were both associated with greater perceived impact of the child's autism related behaviors on the parents, but only on univariate analysis.

Parental self-reported QoL as found in this cohort was higher (104.3) as compared to that reported in other western countries (e.g., 98.3 in Australia and 95.8 in United Kingdom), as well as that in Malaysia (92.2), a neighboring country in Southeast Asia (Eapen et al., 2023). In children on the autism spectrum, early diagnosis and prompt specialized care, adequate educational and community resources and a social support network that facilitates inclusion, have been reported to affect family's QoL (Kuhlthau et al., 2014; Lindsey & Barry, 2018). The relatively higher scores in our sample could be related to improvements in Singapore's disability landscape targeting the above-mentioned areas over the last 20 years (Goh et al., 2023). This includes the Compulsory Education Act in 2000 (Ministry of Education & Singapore, 2021) (in which schooling provisions was made available to all children including those with moderate to severe special educational needs), and the Enabling Masterplan (Ministry of Social & Family Development, Singapore, 2022) (national roadmap to create a more inclusive nation) since 2007. These government-initiated far-reaching measures may have contributed to our population's QoL ratings.

In our study, higher SRS-2 scores (indicating more symptoms of autism) were associated with greater negative impact

Table 2 Results of the univariate linear regression conducted to determine variables associated with QoLA Part A and Part B scores

Variables	QoLA Part A			QoLA Part B		
	b	95% CI	p-value	b	95% CI	p-value
Age of parent (years)	0.17	−0.40 to 0.74	0.559	0.54	−0.18 to 1.27	0.141
Age of child (years)	−1.55	−5.13 to 2.03	0.391	**−6.18**	**−10.59 to −1.78**	**0.007**
Maternal education: University and above vs. High school and below	**12.76**	**0.32 to 25.20**	**0.045**	0.33	−14.44 to 15.09	0.965
Paternal education: University and above vs. High school and below	9.13	−2.56 to 20.83	0.122	4.05	−10.17 to 18.27	0.568
Gender of child: female vs. male	−2.56	−12.77 to 7.65	0.619	4.58	−8.45 to 17.63	0.486
Having one or more sibling	**10.02**	**2.11 to 17.93**	**0.014**	−2.62	−13.16 to 7.91	0.622
Family history of autism	**−11.05**	**−23.13 to 1.05**	**0.073**	−2.62	−18.38 to 13.15	0.742
Receipt of financial subsidies	−0.56	−9.35 to 8.22	0.898	**22.36**	**12.22 to 32.50**	**<0.001**
IQ score	0.01	−0.25 to 0.2	0.951	−0.06	−0.41 to 0.30	0.745
VABS adaptive behavior composite score	−0.08	−0.50 to 0.35	0.725	−0.17	−0.71 to 0.38	0.539
RBQ total repetitive behavior score	−0.06	−0.68 to 0.56	0.852	−0.40	−1.19 to 0.39	0.312
Parent-rated SRS score	−0.26	−0.77 to 0.25	0.305	**−0.74**	**−1.32 to −0.17**	**0.013**
Community participation[a]						
Less than once a month	0.81	−6.81 to 8.44	0.832	2.31	−7.83 to 12.44	0.652
More than once a month	**14.71**	**2.56 to 26.87**	**0.018**	−4.67	−20.83 to 11.49	0.567
Social participation[a]						
Less than once a month	**−13.85**	**−26.89 to -0.81**	**0.038**	−2.74	−20.19 to 14.20	0.755
More than once a month	**9.47**	**0.68 to 18.23**	**0.035**	−2.54	−14.50 to 9.23	0.669

IQ intelligence quotient, *QoLA* quality of life in autism, *RBQ* repetitive behavior questionnaire, *SRS* Social Responsiveness Scale, *VABS* Vineland III Adaptive Behavior Scales

[a] Indicates Bonferroni adjusted *p*-values

Table 3 Results of the multivariate analysis[a] conducted to determine factors[b] associated with QoLA Part A and Part B scores

Variables	QoLA Part A ($R^2=0.245$)			QoLA Part B ($R^2=0.235$)		
	b	95% CI	p-value	b	95% CI	*p*-value
Age of child				−2.01	−114.5 to 177.87	0.668
Maternal education: University and above vs. high school and below	11.88	−2.54 to 26.29	0.102			
Having one or more sibling	10.13	−4.7 to 24.33	0.155			
Family history of autism	−4.27	−23.08 to 14.53	0.644			
Receipt of financial subsidies				18.04	−1.46 to 37.52	0.069
Parent-rated SRS score				**−0.63**	**−1.20 to −0.05**	**0.034**
Community participation[c]						
Less than once a month	4.49	−10.05 to 19.01	0.531			
More than once a month	17.51	−16.31 to 51.33	0.298			
Social participation[c]						
Less than once a month	−11.88	−32.38 to 8.61	0.245			
More than once a month	−0.80	−18.33 to 16.74	0.926			

IQ intelligence quotient, *QoLA* quality of life in autism, *RBQ* repetitive behavior questionnaire, *SRS* Social Responsiveness Scale, *VABS* Vineland III Adaptive Behavior Scales

[a] Multivariate analysis was done in separate models for Part A and Part B scores

[b] Variables $p<0.1$ from the corresponding univariate analysis in Table 2

[C] Indicates Bonferroni adjusted *p*-values of the child's autism-related behaviors as perceived by their parents. This is similar to studies which showed that unpredictable behaviors of the child are deemed as problematic by caregivers and results in caregiver burnout, chronic stress and psychosocial burden (Shrestha et al., 2023; Smith et al., 2010; Woodgate et al., 2015). However, the lack of impact of SRS-2 scores on overall QoL (as indicated by the multivariate analysis) was surprising as literature traditionally has reported a significant role of the degree of autism symptoms in parental QoL (Khanna et al., 2011; Tung et al., 2014; Wang et al., 2018). Our findings may be explained by other mediating factors such as caregiver fulfilment in caring for the child, resilience, mental and physical health, which were not measured in this study (Hoopen et al., 2020). Alternatively, our finding could also be related to the QoL construct that we used in this study that separated parental QoL (part A) from the perceived impact of the child's autism-related behaviors (part B), which allowed us to tease apart the area of impact of SRS-2 scores, as opposed to the singular construct used in past literature. Examination of the results of the QoLA in larger samples to assess for replication of these findings can further clarify this difference. SRS-2 used as a marker for autism symptoms in the child can possibly aid the identification of caregivers with greater difficulty in managing the child's behaviors within a clinical setting. Given that this is a potentially modifiable factor with appropriate intervention, these caregivers may benefit from targeted support to address these areas. Literature findings of the impact of the child's autism symptoms on caregiver QoL (Hastings et al., 2006; Peters-Scheffer et al., 2012) emphasize the importance of equipping parents with problem-focused and emotion-focused strategies to enable them to better manage their child's unique behaviors and needs (Chin et al., 2023; Luther et al., 2005; Twoy et al., 2007; Wilson et al., 2013).

Results of the univariate analysis suggest that greater community and social participation was associated with higher parental QoL, although these were not statistically significant on multivariate analysis. This could be related to reduced statistical power to detect a significance when controlling for other variables. Nonetheless, these findings are important as this is a potentially modifiable factor that may be leveraged on as opposed to the other secondary findings. These results are consistent with findings from previous studies (Khanna et al., 2011; McStay et al., 2014). Community and social participation reflect a society's inclusiveness and caregiver's receptiveness to engage with others. The former encompasses factors like social stigma and physical provisions for these families. The latter, i.e., caregiver receptiveness could be influenced by intrinsic resilience and motivation for their child on the autism spectrum to engage socially. Greater social participation suggests greater engagement between the child, caregivers, and their community and would explain the better QoL reported. Previous literature from Singapore has highlighted societal stigma as a prominent part of the parenting experience of children on the autism spectrum (Goh et al., 2021). Indeed, social acceptance and inclusion were identified as one of the key factors influencing the quality of life of typically developing children and youth within the country in a recent large study (National Council of Social Service & Singapore, 2022). This same study also reported that children and youth with health or developmental conditions faced challenges in social inclusion due to their condition. These findings mirror that identified among caregivers in our sample and highlight the need to facilitate societal efforts towards inclusion in the country. Overall, future research will be important to study this contrast further and understand its impact on parental QoL, especially within our cultural context.

Our other results suggest that the presence of children other than the child on the autism spectrum was associated with better parental QoL, while a family history of autism was associated with poorer QoL. This is consistent with existing literature which shows that presence of neurotypical children increased parental QoL, while having more than one child on the autism spectrum had the opposite effect (Baghdadli et al., 2014; Eapen et al., 2022). It is possible that having neurotypical children allows parents to partake in typical parenting activities, including social events. The neurotypical sibling may also be a source of companionship for the child on the autism spectrum, thus alleviating a portion of caregiving by the parents. While we did not differentiate the specific family member with autism in the family history, it is possible that additional caregiving responsibilities related to having more than one child on the autism spectrum could contribute to this lower QoL. In this sample, higher maternal education was also associated with higher parental QoL. While this has not been directly studied before, previous studies (Dardas & Ahmad, 2014; Vasilopoulou & Nisbet, 2016) have shown a positive effect of employment on parental QoL, including specifically in mothers (Bourke-Taylor et al., 2012). Although we did not specifically study employment status in this sample, this could be related to higher educational status. Receiving financial subsidies for medical expenses was associated with parents reporting lesser impact of the child's autism-related behaviors. This could be due to parents feeling better supported financially and hence having a more receptive approach towards the child's behaviors. Older age of the child was also associated with parents reporting a greater impact of the child's autism-related behavior. This could be due to increasing and more apparent differences between the child on the autism spectrum and his/her neurotypical peers in terms of behavior, as age increases and expectations for appropriate behavior become more defined. However, given that these factors were not significant in multi-variate analysis, they require more research in other samples to establish and understand further.

It is also worthy to note that in our study, child cognition and adaptive skill measures were not significantly associated with parental QoL, adding to existing observations that QoL and cognitive functioning are not necessarily interrelated. In our study, this could be due to the fact that these measures were obtained at different time-points from the QoL measures and doing so may reveal otherwise. Nonetheless, this is important in that it alludes to the presence of many other modifiable factors which may be more easily targeted by intervention strategies that go beyond just the child alone, e.g., social inclusion and community support for the child and their family. This finding also supports the need to examine QoL as a separate marker of outcome in children on the autism spectrum and their families, apart from the traditional cognitive and adaptive skill markers.

Strengths and Limitations

Strengths of our study include the detailed examination of parental QoL and its related factors within a group of children in an Asian-based multicultural context. In addition, this was a clinical sample that is better representative of the intended study population as opposed to a research cohort. We also used several methods to assess child functioning, including standardized assessments and caregiver-completed measures of autism symptoms. However, our study has several limitations. Firstly, we did not collect information on parental stress, which can influence perceived QoL and is a distinct entity that is influenced by factors independent of those that influence QoL (Giovagnoli et al., 2015). It would thus be important to include parental stress in the evaluation of parental QoL and will be included in our future studies. In addition, other societal and systemic factors, including (but not limited to) availability of intervention services, social stigma, and support groups, can all influence perceived QoL but we were unable to quantify or measure these as part of this study. Qualitative data can be used in future studies to capture these factors better. Second, we only measured QoL at a single time point, which may not capture changes in QoL over time, with the child's age and trajectory of autism across childhood. Longitudinal studies of parental QoL will be able to address this. Thirdly, the use of a single question to assess community and social participation (i.e., Questions 3 and 4 in the community and social participation questionnaire) may limit the reliability of these constructs. Lastly, this data is from parents who attended a review visit at a single study site; this may also further limit the generalizability of these results.

Conclusion

Quality of life is an important dimension to consider in supporting families of children on the autism spectrum. It is likely that a myriad of factors affects caregivers' QoL given the complexity and heterogeneity of autism. The current study findings show the association between the child's autism-related symptoms and parental QoL and also suggest that community participation may be important in influencing caregiver QoL. These two factors are modifiable factors amidst other ones that can influence parental QoL. However, interventions facilitating community participation require commitment and expertise beyond the medical fraternity and addressing cultural stigma and inclusion. Hence apart from medical care in terms of addressing symptoms of autism, we advocate for a more inclusive society, which facilitates community participation of these children and their families, which may then lead to better QoL in these families.

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Declarations

Competing Interests The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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