

Behavioural Concerns of Children on the Autism Spectrum and the Impact on Parental Quality of Life

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Research Article

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Abstract

Purpose

This study aimed to determine the association between parental quality of life (QoL) and autism severity, child's cognitive level, adaptive behaviour and behavioural profile, and sociodemographic factors utilising the Quality of Life in Autism Questionnaire (QoLA).

Methods

Parents of children attending an autism specific preschool centre completed a sociodemographic questionnaire, the Quality of Life in Autism Questionnaire (QoLA), Vineland Adaptive Behaviour Scales 2nd edition (VABS) and Child Behaviour Checklist (CBCL). Trained researchers assessed autism severity with the Autism Diagnostic Observation Schedule-2 (ADOS-2) and the cognitive level with the Mullen Scales of Early Learning (MSEL).

Results

For parents of children on the autism spectrum, having other children without the condition buffered the potential negative effects on parental QoL. Lower levels of autism severity and internalising behaviours, and higher levels of daily living scores predicted greater perceived parental QoL. Parents perceived their child's autism-specific behaviour as less problematic when the child had higher socialisation scores. While lower levels of Attention Problems, Withdrawn Behaviour and lower scores on the Dysregulation Profile (Externalising Behaviours, Aggressive Behaviour and Anxious/Depressed) predicted greater perceived parental QoL, higher levels of Withdrawn Behaviour, Aggression and Externalising Behaviour predicted poorer perceived parental QoL. There were no significant findings for the relationship between parental QoL and cognitive level.

Conclusion

The present research establishes the complex effects of raising a child on the autism spectrum on parental QoL. Findings indicate a child's autism symptom severity, adaptive functioning and behavioural profile has greater impact on parental QoL than cognitive level.

Plain English Summary

Parenting a child with Autism Spectrum Disorder (ASD) can at times be challenging and impact a parents' and caregivers' quality of life (QoL). While previous studies have examined parental QoL in ASD, the unique impact of the autism symptoms such as not being able to form attachment relationships and engage in social interactions with family/carers and friends cannot be fully ascertained using general QoL measures. This study was therefore carried out using the Quality of Life in Autism Questionnaire (QoLA) which is specifically tailored to understanding the overall parental QoL and also the parental perceptions of the unique impact of the various autism specific symptoms and associated behaviours on their QoL. Our findings suggest that having siblings alongside a child with ASD had buffering effects on parental QoL. The finding that a child's higher socialisation scores and scores on interpersonal relationships, daily living skills and communication predicted greater parental QoL is in keeping with the known positive impact of social engagement in determining overall wellbeing and QoL. Further, our findings show that parental QoL is broadly impacted with autism symptom severity, Maladaptive Behaviours, Attention Problems, Withdrawn and Aggressive Behaviours and the Dysregulation Profile (Externalising Behaviours, Anxious/Depressed) all presenting as issues that are key for parental stress level and QoL. In addition to supports for autism symptom severity this suggests the need for targeted intervention of comorbid behavioural dysregulation and associated mental health challenges as part of the holistic assessment and management of ASD.

Introduction

Autism spectrum disorder (ASD) is characterised by difficulty in social interactions and communications, engagement in repetitive behaviours, and restricted interests with significant functional impairment [1]. The prevalence of autism is as high as 18.5 per 1000 (1 in 54) [2]. Despite early onset within the first two years of life [3], diagnosis can be delayed until 4 years or older [4, 5]. ASD is a lifelong condition with core symptoms and impairments persisting into adolescence and adulthood [6]. However, the course can be moderated by early behavioural interventions, educational inclusion, maternal positivity, and high-quality mother-child relationships [6-8], across infancy, adolescence [9], or adulthood [10].

Parents of children on the autism spectrum have been found to have lower subjective physical and mental health, decreased social functioning and less satisfaction with social environment in comparison to parents of typically developing children [11]. Mental and physical functioning can often be compromised by increased levels of stress, sleep deprivation and fatigue among parents of children on the spectrum [12, 13]. When compared to parents of typically developing children, parents of children on the autism spectrum report greater impairment in QoL across the domains of physical health, psychological, social relationships and their environment [14]. Restriction of social activities to prioritise caregiving tasks can negatively impact parents' emotional wellbeing and stress levels [15] and they can also overlook their own chronic conditions as they prioritise caregiving duties over their self-care [16]. Many parents also have to balance these additional caregiving tasks alongside care of other children and paid work [17]. The resulting impact on their wellbeing may impair their long-term caregiving ability [16].

The negative effects on physical health and increased experience of stress in parents of children on the autism spectrum is particularly prominent in mothers [18], likely explained by the greater burden for mothers due to their daily caretaking roles [11, 17]. Compared to fathers, mothers of children on the autism spectrum experience lower QoL and wellbeing [19], greater distress [20] and anxiety [21].

Increased medical and psychiatric comorbidities in children on the autism spectrum have been linked to lower carer QoL and an absence of such comorbidities with better parental QoL [22, 23]. More than 70% of autistic individuals have one or more comorbid medical, developmental or psychiatric conditions [9] with comorbidities emerging from early years through to adulthood [10]. Common medical comorbidities include intellectual disorders, seizures, sleep disorders, gastrointestinal issues, metabolic disorders, and hormonal dysfunction [24, 25]. Psychiatric comorbidities in ASD include Attention Deficit Hyperactivity Disorder, Obsessive Compulsive Disorder, anxiety and depression, aggression and self-injurious behaviours, Tics and Tourette Syndrome, eating disorders, and psychosis [26]. Complex cases of ASD, with higher autism symptomology and greater number of psychiatric comorbidities, are associated with increased risk of maternal depression and lower maternal QoL [22, 23].

Parental stress and wellbeing are also influenced by characteristics of the child, such as problem behaviours or hyperactivity [27]. Externalising behaviours in particular have been found to significantly impact maternal parenting stress and psychological distress [28, 29], and also compromise family functioning, particularly social relationships, with impact on parenting and marriage. Internalising behaviours also impact family functioning [30] and maternal stress [31]. Pre-existing stress in the family dynamic could be further exacerbated by the need for chronic hypervigilance in the context of escape behaviours, property destruction [30].

Some studies have observed that factors outside of parental control such as autism severity, verbal ability or child's age can have no influence on parental stress or distress [32, 33]. This suggests parent's perceived control over a child's behavioural problems may influence experience of parental stress, alongside the disruptive and socially inappropriate nature of such behaviours and perceptions of others [32]. The impact of adaptive behaviours on parental QoL are mixed [34], as some studies have determined negative associations between adaptive behaviour and maternal stress [35] while others have found no correlation with parental stress or psychological distress [29].

Thus, parental QoL is intricately connected with characteristics of the child, and the overall functioning of the family. Parents that rate their emotional wellbeing higher tend to have higher scores on being warm, caring, and sympathetic towards their children, which elevates children's QoL and may foster closeness with child and family [32]. Parents who report higher parental stress and low QoL also tend to report lower levels of family functioning and believe they are not functioning optimally within the family dynamic [36]. Therefore, it is crucial to examine the interconnections between parental QoL and a child on the autism spectrum's behavioural and emotional characteristics, given that positive relations with the child and managing parental stress may cultivate improved levels of family function and parental QoL. The present study aims to determine the relationship between parental QoL and child autism severity and cognitive level, adaptive functioning and behavioural profile and the parental perception of the impact of autism specific symptoms and behaviours on their parental QoL.

Methods

Participants

Participants were parents and their children aged two to six enrolled in an early intervention program at KU Marcia Burgess Autism Specific Early Learning and Care Centre (ASELCC) in Liverpool, Sydney, Australia. At the time of enrolment, to reduce selection bias all, parents were offered participation in a research program and gave informed consent if they wished to participate. A total of 97 children and 97 parents who identified as the primary caregiver participated in this study. Child assessments were conducted within eight weeks of beginning the early intervention program at the ASELCC.

Child assessments included the Autism Diagnostic Observation Schedule – Second Edition (ADOS-2; [37]) and the Mullen Scales of Early Learning (MSEL; [38]). The ADOS-2 was used to assess autism symptoms and confirm the DSM-IV or 5 diagnosis of ASD at entry to the ASELCC. The ADOS-2 is a semi-structured, standardised diagnostic observational assessment of social interaction, communication, play, and imaginative use of materials. The standardised Calibrated Severity Score is calculated from the Social Affect and Restricted and Repetitive Behaviour domains, taking account of the language and age differences. Higher score refers to increased symptom severity in the domains and the calibrated score.

The MSEL was used to assess cognitive function. The MSEL evaluates development across key domains of language, motor, and perceptual abilities. Visual Reception, Fine Motor, Expressive Language, and Receptive Language scales were administered. A Development Quotient for each child was calculated by dividing the subscale age-equivalent score by the child's chronological age and multiplying by 100. Higher Development Quotient associates with better cognitive functioning.

Parents or caregivers completed questionnaires at enrolment that assessed child behaviour and parental QoL. The Vineland Adaptive Behaviour Scales 2nd edition (VABS; [39]) was used to assess adaptive/functional skill level in four broad domains of Communication, Daily Living Skills, Socialisation and Motor Skills, which comprise the Adaptive Behaviour Composite, and a fifth domain, the Maladaptive Behaviour Index (Figure 1). The subdomains comprise the following: Communication subdomains of Receptive, Expressive and Written; Daily Living Skills subdomains of Personal, Domestic and Community; Motor subdomains of Gross Motor and Fine Motor; and Maladaptive Behaviour Index subdomains of

Externalising and Internalising. For the subdomains, ν -Scale scores have a mean of 15, standard deviation of 3 and range from 1 to 24 [39]. The domain score is a norm-referenced standardised score with a mean of 100 and a standard deviation of 15, and the adaptive behaviour composite score is a sum of the standardised scores for the four domains. Higher scores refer to better adaptive behaviours and higher maladaptive behavioural problems.

The Child Behaviour Checklist (CBCL; [40]) was utilised as an additional behavioural comorbidity assessment. The Internalising scale measures emotional problems, whilst the Externalising scale assesses behavioural problems. The Dysregulation Profile combines Externalising scale and Anxious/Depressed subscale (Figure 1). The syndrome subscales are Emotionally Reactive, Anxious/Depressed, Somatic Complaints, Withdrawn, Sleep Problems, Attention Problems and Aggressive Behaviour (Figure 1). T scores above 63 are in the borderline range and above 70 are in the clinical range [41]. A higher score refers to more behavioural problems.

The Quality of Life in Autism (QoLA) questionnaire [42] for parents and caregivers of children on the autism spectrum is a 48 item questionnaire assessing two subscales – parents' QoL (Part A), and a parent report of how problematic their child's ASD symptoms are for the parent (Part B). For both the scales higher score associates with better QoL.

An additional questionnaire completed by parents or caregivers at their child's enrolment to the ASELCC consisted of family sociodemographic questions.

Study data were collected on record forms or in questionnaires. The data was then converted into an electronic format and managed using REDCap (Research Electronic Data Capture) [43].

Statistical Analysis

Descriptive statistics were used to present the sociodemographic and clinical characteristics of participants. Bivariate and correlational analyses were conducted to explore associations between sociodemographic variables, baseline scores from parental reported QoLA Parts A and B, CBCL behavioural profile scores, and VABS adaptive behaviour scores. Correlation analyses confirmed that relationships between each of these instruments and the QoLA subscales should be performed separately (see Supplementary 1, Table 1). The conceptual approach taken to ensure that variables from the VABS and CBCL instruments were not subject to category errors associated with cross-level analysis is detailed in Table 1. Complete case analysis was not possible however due to substantial missingness associated with the CBCL (see Supplementary 1, Table 2 for full details). In total 37 of 61 (60.7%) records had complete data. Data loss was considered missing-at-random. Consequently, multiple imputation using chained equations (MICE) was applied to analyse these data [44]. Incomplete variables were imputed under fully conditional specification and combined using Rubin's rules [45]. Continuous variables (e.g., age in months) were estimated using weighted predictive mean matching; dichotomous variables (e.g., Culturally and Linguistically diverse – (CALD) status) using logistic regression; and ordered categorical variables (e.g., level of parental income) using a proportional odds model. Scores for variables higher than Level 3 (i.e., CBCL: Internalising) were recalculated using imputed estimates. Full specification and code available in Supplementary 2.

Following van Buuren [46] a majority method approach was taken to variable selection using linear modelling [47-49]. In cases where this approach did not yield clear results, the D1 multivariate Wald test was used to include only those variables significantly different from zero [48, 50]. Linear regression modelling was then performed for each level of analysis as described in Figure 1; though, for Level 1 analyses VABS Maladaptive Behaviour Index was included as a comparator against VABS Adaptive Behaviour Composite to align planned analyses between the two target instruments (i.e. VABS, CBCL). All analyses were performed using SPSS v24 [51] and the R language v3.6.1 [52] within the RStudio IDE [53] (session details available in Supplementary 2).

Results

The sample included parents of 97 children; the majority of children were male (85.57%), born in Australia (88.42%), many families were culturally and linguistically diverse (74.16%), and three percent of children were indigenous. All families were either Australian Citizens (89.25%) or Permanent Residents (10.75%). Most parents had tertiary level education or higher (76.34%). More detailed child and parental characteristics can be found in Table 1

Mean QoLA score for Part A was 98.36 (SD 21.68) and Part B was 71.58 (SD 18.9) (Table 2). All of the mean scores for domains that comprised the VABS Adaptive Behaviour Composite subdomain measures were below the standard mean of 15. However mean scores for domains representing problematic behaviours, such as, the Maladaptive Behaviour Index and Internalising, and Externalising subdomains, were above mean scores. For behavioural problems such as Withdrawn, Attention Problem, and Internalising subscales measured by the CBCL, the mean score of the participants was above the borderline range of T-scores ≥ 63 . The mean score for the dysregulation profile was (178.33, SD=18.71), which is close to the stringent cutoff of T-scores ≥ 180 [54].

Parents with more than one child reported a higher QoLA Part A score than a parent with only one child ($p < 0.01$) (Table 3). No other demographic variables were associated with either QoLA Parts A or B at the significance level in the correlation analysis.

Correlation analyses were performed to investigate the association of the autism severity, child cognitive and behavioural measurements with parent reported QoLA Part A and Part B scores (Table 4). Autism symptom severity was negatively correlated with QoLA Part A scores (Calibrated Severity Score, $p=0.02$; Restricted Repetitive Behaviour, $p<0.01$). The VABS Community subdomain ($p=0.01$) and the Daily Living Skills domain ($p=0.04$) were positively correlated with scores for QoLA Part A. The VABS Internalising subdomain was negatively correlated with scores for QoLA Part A ($p=0.05$). Positive associations were observed for QoLA Part B scores with the Socialisation domain ($p<0.01$), three subdomains of the Socialisation domain (Interpersonal Relationship, $p=0.02$; Play & Leisure Skills, $p<0.01$; Coping, $p=0.04$) and the Community subdomain ($p=0.01$). CBCL subscales reflecting behavioural problems were negatively correlated with scores for QoLA Part A (Anxious Depressed, $p=0.04$; Withdrawn, $p=0.05$; Attention Problems, $p=0.01$; Externalising, $p=0.02$; Dysregulation Profile, $p=0.01$). Higher QoLA Part B scores were negatively correlated with CBCL Anxious Depressed ($p=0.05$), Withdrawn ($p=0.02$), Aggressive Behaviour ($p=0.01$) and Externalising subscales ($p=0.02$) and the Dysregulation Profile ($p=0.02$).

Results from the multivariate analyses are reported, in full, in Table 5. In Level 1 analysis, while no predictors were found to be significant, the VABS Maladaptive Behaviour Index was marginally predictive of overall lower parental quality of life (Part A; $\beta=-1.94$, $p=0.08$) and how problematic their child's ASD symptoms are for them (Part B; $\beta=-1.74$, $p=0.08$). In Level 2 analysis VABS Socialisation ($\beta=0.91$; $p<0.001$) was found to be positively associated with Part B. Moreover, the CBCL Dysregulation Profile (Anxious/Depressed, Attention Problems, and Aggressive Behaviour subscales) was negatively associated with both Part A ($\beta=-0.33$; $p=0.01$) and Part B ($\beta=-0.23$; $p=0.05$). In Level 3 analysis VABS Internalising Behaviours ($\beta=-2.29$; $p=0.03$) and CBCL Attention Problems ($\beta=-0.72$; $p=0.02$) were negatively associated and VABS Communication domain ($\beta=3.03$; $p=0.01$) was strongly positively associated with Part A. VABS Play & Leisure Skills were strongly positively associated with Part B ($\beta=4.78$; $p<0.001$) while VABS Interpersonal Relationships ($\beta=-1.73$; $p=0.05$) and CBCL Aggressive Behaviour ($\beta=-0.54$; $p=0.05$) were marginally negatively predictive of Part B.

Discussion

The primary aims of the study were to examine the relationship between parental QoL and autism symptom severity using the QoLA questionnaire [42], which has been developed to specifically measure the QoL of parents of children on the autism spectrum. Furthermore, we sought to determine whether this relationship can be explained by sociodemographic factors, a child's cognitive level, or the child's behavioural profile. The parents of children on the autism spectrum who had at least one sibling were found to have a better overall perception of their QoL. This finding implies there may be a buffering effect on parental QoL when the child on the autism spectrum has at least one other sibling who does not have autism. This is in keeping with previous research, which had reported a protective effect on parental emotional QoL when the child on the autism spectrum had siblings without ASD [55]. It is possible that parental expectations and therefore parental disappointments would be much greater if the child on the autism spectrum was the only child, thereby having a more pronounced impact on parental QoL [56]. Further, the presence of siblings may buffer the limited bonding/attachment and reciprocal social interactions that can be present when a child is on the autism spectrum which in turn may significantly impact the parental sense of validation of themselves as a provider of nurturing care and their role as parents [57]. In this regard, having other children who do not have ASD might counter this negative self-evaluation of parents about their parenting capacity and confidence [58]. Further, enhanced levels of physical health QoL has been identified in parents who have other children to potentially assist with caretaking responsibilities and temporarily alleviating parents of caretaking duties [59]. However, the effects of having siblings who do not have ASD on parents is mixed in the literature, although this may be due to cultural differences, as studies conducted in Jordan, which possesses a shared, collectivist culture wherein domestic and caretaking tasks are shared amongst the children, report similar buffering effects on maternal QoL [60].

Autism severity was negatively correlated with parental perception of their QoL. Previous research has also demonstrated that greater severity of autism symptoms are associated with decreased parental QoL [61]. Mothers of children with more autism symptomology had a higher risk of having depression and were more likely to report a negative life impact on relationships with partners, extended family, and friends [23]. Higher autism severity can often increase caretaking and educational needs of a child, which can compromise parents' social engagement with friends and family [62] and their career [63]. However, while autism severity may negatively impact parental quality of life, parental optimism mediates this relationship, which holds promise for development of interventions that focus on cultivating parental optimism to buffer the potential negative impacts of increased autism severity in children [64].

Internalising behaviour problems influenced parental perception of their QoL and also the parents' perception of how problematic their child's autism-specific difficulties are for them. Increased internalising behaviour problems (as measured by the VABS) were associated with lower parental perception of their QoL. Higher rates of problems related to anxiety/depressed and withdrawn/depressed (CBCL) were also associated with lower parental perception of their QoL and with increased parents' perception of how problematic their child's autism-specific difficulties are for them. As previous literature has shown parental stress is at heightened levels with increasing internalising behaviours, this may exert a diminishing effect on parental QoL [65]. Moreover, maternal parenting stress has been shown to increase with increasing internalising behaviours, namely anxious and depressive symptoms, which is aligned with the present findings as greater internalising behaviours are associated with increases in how problematic parents feel their child's autism-specific behaviour is [31]. Given increases in parental stress can result from greater severity of maladaptive behaviours [66] and internalising behaviours [31] this may be the driving factor behind compromised parental QoL in the present work.

A dysregulated behavioural profile was associated with both lower parental perception of their QoL and increased parents' perception of how problematic their child's autism-specific difficulties are for them. These findings build upon previous literature which determined greater use of

externalising behaviour by children on the autism spectrum correlated with lower overall family QoL and heightened maternal and parental stress [32, 67, 68]. Moreover, externalising behaviours, such as emotional outbursts, and reduced use of passive comforting strategies impact family and parental QoL in a negative manner [69], which may be attributed to the fact that externalising behaviours are more visible and salient. Externalising, hyperactive behaviour can exacerbate parenting stress levels, which may be attributed to potential external disapproval garnered from behaviours that are socially inappropriate or disruptive [70]. Parental emotional coaching may be a valuable tool in buffering the potential negative effects of externalising behaviours, as it has been found to mitigate the effects of externalising behaviours on parents of children on the autism spectrum [71].

Specifically, attention problems, a subscale of the dysregulated profile, were associated with lower parental perception of their QoL, which may be due to the fact that a greater number of psychiatric comorbidities, like attention problems, in children on the autism spectrum can place increased stress on parents, which has been shown to reduce QoL and increase risk for depression in mothers [25]. Increased attention problems have also been associated with parents feeling a dysfunction in the relationship with their child and greater levels of stress, illuminating the heightened stress and issues in the parent-child interaction that may result from greater attentional issues [68]. Greater levels of maternal stress has been shown to be associated with more emotionally reactive and withdrawn children, and those who have more attention problems [72]. Poorer parental QoL therefore may be as a result of increased stress and issues in the parent-child dynamic when managing multiple psychiatric issues.

Another component of a dysregulated profile, aggressive behaviour, was associated with increased parents' perception of how problematic their child's autism-specific difficulties are for them. The negative impact of autistic behaviours on the parent with increased levels of aggressive behaviour may be due to the fact that aggressive behaviours and conduct problems predict higher levels of parental stress [73] which in turn may deteriorate parental QoL. Furthermore, aggressive behaviours in children on the autism spectrum can deteriorate the family dynamic, as it impacts daily routine and well-being of family, and can lead to financial strain and issues with engaging with already limited mental health services [74].

Parents of children on the autism spectrum with increased socialisation skills reported higher perception of their QoL. This is in line previous findings, wherein social impairment in children on the autism spectrum was associated with lower parental QoL and higher maternal stress [75]. This may be due to increased fatigue with more severe social impairment, or stigma in social situations, or potential social isolation and decreased socialisation of the family to accommodate for the needs of the child [76]. The findings of the influence of interpersonal relationships on how problematic a child's autism-specific difficulties are perceived by the parent were mixed. While higher scores on interpersonal relationships were associated with lower parents' perception of how problematic their child's autism-specific difficulties are for them for unadjusted estimates, this finding was reversed when adjusted for play and leisure skills. While literature has found impaired social ability is associated with decreased parental QoL, and in the case of mothers, this relationship is mediated by childcare burden [75], the present mixed findings suggest further research is warranted.

Communication was shown to be positively correlated with parental perceptions of QoL in the present research, which echoes past research determining increases in communication were shown to have protective effects on parents reported QoL [55]. Many parents of children on the autism spectrum express concern and stress regarding their communication with their child [77], it may be that improvements in the realms of communication alleviates parental stress and therefore improves perceived QoL.

We found no significant association between parental QoL and cognitive level, however, there was a positive relationship between communication and parental QoL. Previous findings in the literature identify that, much more than cognitive and communication level, it is the behavioural issues that are key for the family's stress level and QoL [68]. Given that behavioural issues have such a profound impact on parental QoL, this has significant implications for the need for targeted intervention of comorbid mental health challenges as part of the holistic assessment and management of ASD. Targeted intervention for comorbid behavioural dysregulation and associated mental health challenges is critical in the holistic assessment and management of children with ASD as parental stress and QoL were found to be integrally linked to children's behavioural regulation profile. In this regard, it is noteworthy the association between better QoL and child's higher socialisation scores.

Parental QoL also did not vary as a function of the child's age. It is possible that the care requirements of children on the autism spectrum may remain high. Previous research has identified that the care requirements of children with complex care needs does not follow the trajectory of care requirements of typically developing children as the care requirements of children with complex needs may remain high [78].

Limitations of the present research must be considered when evaluating findings. Given parent self-report measures were used to measure adaptive functioning and behavioural profile rather than a standardised measure administered by a trained professional, this may have influenced the results. Moreover, the QoLA was only administered to parents of children on the autism spectrum below school age, and it is yet undetermined whether parental QoL may fluctuate over a child's lifetime. Future research should implement more objective, standardised testing administered by a trained professional to minimise the influence of parental perceptions of their child and examine the fluctuations in parental QoL over the child's lifetime.

Conclusion

Parenting children on the autism spectrum presents unique challenges. Therefore, using a tailored measure like the QoLA may prove especially useful to gauge the QoL specific to those caring for children on the autism spectrum. The negative association between parental QoL and higher scores on maladaptive behaviours and internalising behaviours on VABS which is a measure of the adaptive functioning of the child is not

unexpected as these are critical to the child's daily functioning. Previous research has shown a close link between the child's behavioural profile and QoL and in this regard, the specific link observed between QoL and attention problems, the dysregulation profile (externalising behaviours, anxious, depressed) and aggressive behaviour as measured by the CBCL is not surprising. Our finding that parents of children who had more severe autism symptoms, internalising and externalising behavioural problems and were more dysregulated showed decreased QoL suggests that careful assessment of comorbid behavioural challenges as part of the holistic assessment of ASD is critical. This would need to be combined with targeted intervention for comorbid behavioural dysregulation and associated mental health challenges.

Declarations

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Conflicts of interest: All authors declare that they have no competing interest.

Availability of data: Deidentified data can be made available upon request made to the authors.

Code availability: Full reproducible code is available upon request.

Authors' contributions: VE contributed to the design of the data collection and conceived the paper. VE and AM supervised the data collection and analysis. SIA and LK analysed the data. VE, AM and RI, RI, SIA, LK and AM drafted the paper and revised the paper critically for important intellectual content at all stages. VE revised the paper for intellectual content. All authors contributed to the final version of the manuscript.

Ethics approval: This study was performed in line with the principles of the Declaration of Helsinki. UNSW Sydney Human Research Ethics Committee (HREC) approved the study (HC14267).

Consent to participate: All participants have provided written informed consent to participate in the study.

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Tables

Table 1
Demographic Information – Child and Parents (n = 97)

	N	%
Child Age*	50.48	6.83
Child Sex		
Male	83	85.57
Female	14	14.43
Child Country of Birth		
Australia	84	88.42
Others	11	11.58
Child Indigenous origin		
Aboriginal	2	2.56
Non Indigenous	76	97.44
Any Siblings		
Yes	70	75.27
No	23	24.73
Child Birth Order		
First Child	52	54.74
Second Child	26	27.37
Third Child or Higher	17	17.89
Family Residency		
Australian Citizen	83	89.25
Permanent Resident	10	10.75
Culturally and Linguistically Diverse		
Yes	66	74.16
No	23	25.84
Parents Education		
Secondary or less	22	23.65
Tertiary	43	46.24
Postgraduate	28	30.11
Parent Occupation		
Professional/Clerical & Retail/Self-employed	41	47.13
Home Carer/Duties	36	41.38
Unemployed/retired	10	11.49
Parent Income		
Less than 40,000	21	29.17
40,000-100,000	32	44.44
Over 100,000	19	20.88

Note. *Mean and standard deviation reported

Table 2
 Parents QoLA score and Child ADOS-2, Mullen, VABS
 and adaptive and behavioural profile (n = 97).

Measure	Mean	SD
QoLA		
Part A	98.36	21.68
Part B	71.58	18.90
ADOS-2		
Calibrated Severity Score	7.24	1.56
Social Affect	14.36	3.40
Restricted Repetitive Behaviour	5.04	1.76
Mullen*		
Visual Reception	39.61	17.30
Fine Motor	47.05	14.74
Receptive Language	30.71	17.60
Expressive Language	31.46	17.87
VABS#		
Adaptive Behaviour Composite	254.58	39.51
Communication^	59.53	15.50
Receptive	6.70	3.05
Expressive	6.45	2.35
Written	12.48	3.64
Daily Living Skills^	61.96	13.33
Personal	8.12	2.58
Domestic	10.29	2.30
Community	8.80	2.46
Socialisation ^	62.45	9.47
Relationships	7.21	1.98
Play and Leisure Time	7.73	1.76
Coping Skills	10.01	2.23
Motor Skills ^	71.39	11.88
Gross Motor	11.08	2.31
Fine Motor	9.47	2.37
Maladaptive Behaviour Index	19.64	2.02
Internalising	20.21	2.35
Externalising	16.91	2.41
CBCL**		
Emotionally Reactive	62.33	11.28
Anxious Depressed	56.92	8.60
Somatic Complaints	60.90	8.18
Withdrawn	76.00	9.75

Measure	Mean	SD
Sleep Problem	59.43	9.19
Attention Problem	64.47	7.87
Aggressive Behaviour	57.57	8.27
Externalising	57.72	9.26
Internalising	67.19	8.59
Dysregulation Profile	178.33	18.71

Note. *Developmental Quotient scores, #v-Scale scores, ^ Domain standard score, **T-scores

Table 3
Differences of QoLA scores on the demographic variables (n = 97).

	QoLA Part A			QoLA Part B		
	Mean	SD	p-value	Mean	SD	p-value
Child Sex						
Male	98.47	21.54	0.91	72.17	18.33	0.53
Female	97.71	23.32		68.07	22.42	
Any Siblings						
Yes	101.96	21.74	< 0.01	71.64	21.74	0.86
No	88.17	19.73		70.96	19.73	
Child Birth Order						
First Child	95.75	22.19	0.24	71.60	20.68	0.67
Second Child	101.15	20.53		69.38	16.55	
Third Child or Higher	101.82	23.00		75.18	17.91	
CALD						
Yes	101.02	21.37	0.10	71.17	19.25	0.83
No	91.52	24.09		72.17	18.95	
Parents Education						
Secondary or less	95.27	24.45	0.70	72.05	21.42	0.90
Tertiary	100.00	19.87		72.05	18.31	
Postgraduate	99.29	23.10		70.68	19.25	
Parent Occupation						
Professional/ Clerical & Retail/Self-employed/	98.71	23.37	0.38	73.20	17.94	0.85
Home Carer/Duties	100.47	20.11		71.33	21.40	
Unemployed/retired	87.20	22.06		69.40	21.74	
Parent Income						
Less than 40,000	93.57	23.71	0.09	75.48	18.54	0.30
40,000-100,000	104.69	22.47		70.56	20.81	
Over 100,000	102.37	16.52		72.37	19.84	

Notes. Abbreviations: CALD; Culturally and Linguistically Diverse. Emboldened indices reflect significance at an alpha threshold of $p < .05$.

Table 4
Correlation of child behavioural and cognitive measures with QoLA scores (n = 97).

	QoLA Part A			QoLA Part B	
	N	R	p-value	R	p-value
ADOS-2					
Calibrated Severity Score	95	-0.24	0.02	-0.12	0.24
Social Affect	94	-0.18	0.08	-0.16	0.12
Restricted Repetitive Behaviour	94	-0.33	< 0.01	-0.11	0.26
Mullen*					
Visual Reception	93	0.02	0.89	-0.02	0.84
Fine Motor	94	0.07	0.53	-0.02	0.83
Receptive Language	94	0.06	0.55	-0.01	0.92
Expressive Language	95	0.14	0.17	0.07	0.51
VABS#					
Adaptive Behaviour Composite	86	0.20	0.07	0.11	0.32
Communication^	91	0.14	0.19	0.08	0.45
Receptive	91	0.05	0.62	0.10	0.34
Expressive	91	0.16	0.14	0.14	0.20
Written	92	0.14	0.18	-0.01	0.90
Daily Living Skills^	89	0.22	0.04	0.10	0.35
Personal	89	0.16	0.13	-0.04	0.73
Domestic	91	0.18	0.09	0.08	0.43
Community	91	0.27	0.01	0.26	0.01
Socialisation^	89	0.19	0.07	0.32	0.00
Interpersonal Relationships	90	0.17	0.10	0.24	0.02
Play & Leisure Skills	89	0.18	0.09	0.36	0.00
Coping Skills	89	0.16	0.13	0.22	0.04
Motor Skills^	88	0.18	0.09	0.04	0.69
Gross Motor	88	0.13	0.23	0.02	0.85
Fine Motor	89	0.18	0.10	0.07	0.51
Maladaptive Behaviour Index	91	-0.17	0.10	-0.20	0.06
Internalising	91	-0.21	0.05	-0.14	0.20
Externalising	91	-0.08	0.43	-0.09	0.42
CBCL**					
Emotionally Reactive	40	-0.22	0.18	-0.08	0.60
Anxious Depressed	86	-0.22	0.04	-0.21	0.05
Somatic Complaints	42	-0.23	0.15	-0.12	0.46
Withdrawn	86	-0.21	0.05	-0.25	0.02
Sleep Problems	56	-0.24	0.08	-0.16	0.24
Attention Problems	85	-0.28	0.01	-0.10	0.37

	QoLA Part A			QoLA Part B	
Aggressive Behaviour	77	-0.22	0.06	-0.31	0.01
Externalising	76	-0.28	0.02	-0.26	0.02
Internalising	37	-0.26	0.12	-0.19	0.26
Dysregulation Profile	76	-0.31	0.01	-0.27	0.02

Note. *Developmental Quotient scores, #v-Scale scores, ^Domain standard score, **T-scores. Emboldened indices reflect significance at an alpha threshold of $p < .05$.

Table 5

Results for planned multivariate models (n = 5) run for each level of analysis regressing measures of adaptive functioning (VABS) and behaviour (CBCL scores) on QoLA scores (Part A, B).

Intercept		95% CI											
		Estimate	p	R ² ^a	LL	UL	Instrument	Predictor	β	SE	t-value	df	p
Level 1	QoLA Part A	129.60	<.001	0.05	0.00	0.16	Sociodemographic	CALD	9.36	5.01	1.87	88.36	0.07
							VABS	Maladaptive Behaviour Index	-1.94	1.10	-1.76	86.48	0.08
	QoLA Part B	105.83	<.001	0.02	0.00	0.12	VABS	Maladaptive Behaviour Index	-1.74	0.97	-1.80	88.45	0.08
Level 2	QoLA Part A	108.10	<.001	0.07	0.00	0.21	Sociodemographic	CALD	8.60	4.98	1.73	88.20	0.09
							VABS	Communication	0.28	0.17	1.66	64.44	0.10
							VABS	Maladaptive Behaviour Index	-1.69	1.11	-1.53	82.08	0.13
		156.81	<.001	0.07	0.00	0.20	CBCL	Dysregulation profile	-0.33	0.13	-2.58	76.75	0.01
	QoLA Part B	33.07	0.01	0.11	0.01	0.25	VABS	Daily Living Skills	-0.30	0.20	-1.50	79.95	0.14
							VABS	Socialisation	0.91	0.28	3.26	78.90	<.001
	112.71	<.001	0.05	0.00	0.18	CBCL	Dysregulation profile	-0.23	0.12	-1.98	69.74	0.05	
Level 3	QoLA Part A	128.41	<.001	0.10	0.01	0.24	VABS	Communication	3.03	1.09	2.78	76.28	0.01
							VABS	Receptive	-1.56	0.93	-1.67	77.85	0.10
							VABS	Internalising	-2.29	1.01	-2.27	83.86	0.03
			144.94	<.001	0.06	0.00	0.19	CBCL	Attention Problems	-0.72	0.29	-2.49	80.63
	QoLA Part B	48.56	<.001	0.14	0.03	0.30	VABS	Play & Leisure Skills	4.78	1.25	3.84	75.29	<.001
							VABS	Interpersonal Relationships	-1.73	0.85	-2.02	75.01	0.05
			102.47	<.001	0.04	0.00	0.19	CBCL	Aggressive Behaviour	-0.54	0.27	-2.00	59.96

Notes. ^aR² Adjusted. Abbreviations: CALD, Culturally and Linguistically Diverse; CBCL, Child Behaviour Checklist; VABS, Vineland Adaptive Behaviour Scales-II. For each planned level of analysis (Figure 1), only candidate variables that improved overall model saturation were retained in the final analysis as per the majority method approach. Emboldened indices reflect significance at an alpha threshold of $p < .05$

Figures

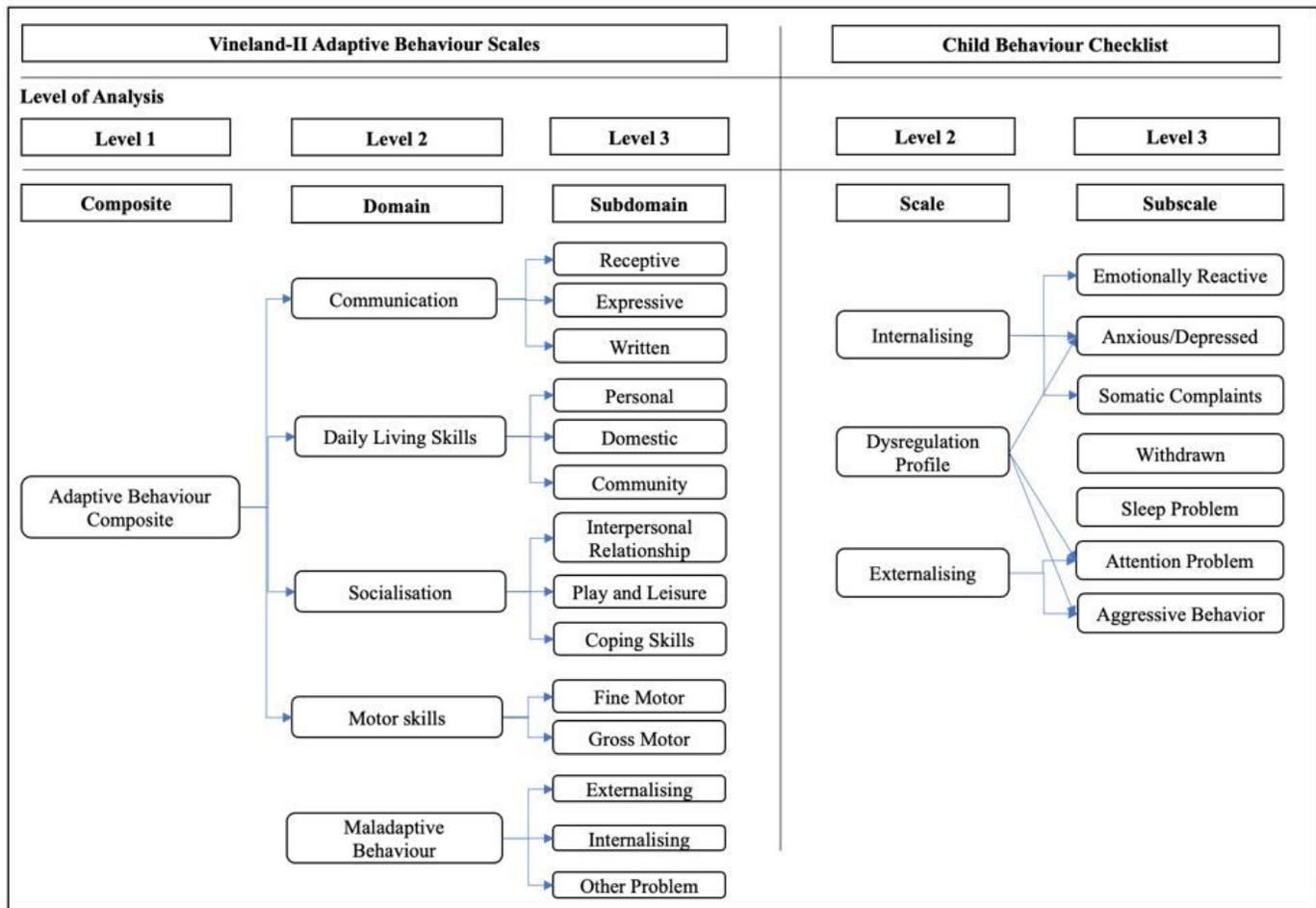


Figure 1

The Dysregulation Profile combines Externalising scale and Anxious/Depressed subscale (Figure 1). The syndrome subscales are Emotionally Reactive, Anxious/Depressed, Somatic Complaints, Withdrawn, Sleep Problems, Attention Problems and Aggressive Behaviour (Figure 1).

Supplementary Files

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