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Using network analysis to identify factors influencing the heath-related quality of life of parents caring for an autistic child

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ABSTRACT

Background: Raising an autistic child is associated with increased parenting stress relative to raising typically developing children. Increased parenting stress is associated with lower parent wellbeing, which in turn can negatively impact child wellbeing.
Aims: The current study sought to quantify parenting stress and parent health-related quality of life (HRQOL) in the autism context, and further understand the relationship between them by employing a relatively novel statistical method, Network Analysis.
Methods and Procedures: This cross-sectional study involved 476 parents of an autistic child. Parents completed an online survey requesting information on parent and child characteristics, parent's perceptions of their autistic child's symptoms and problem behaviours, and assessed their parenting stress and HRQOL.
Outcomes and Results: Relative to normative data, parent HRQOL was significantly lower in terms of physical health and mental wellbeing. The structure extracted by the Network Analysis indicated that child age and externalising behaviours were the main contributors to parenting stress, and that externalising behaviours, ASD core behavioural symptoms, and parenting stress predicted HRQOL.
Conclusions and Implications: Parental responses to child-related factors likely determine parent HRQOL. Findings are discussed in relation to the transactional model, emphasising the importance of both parent and child wellbeing.

What this paper adds?

Parent-rated measures of their child's autism and challenging behaviours, and of their own parenting stress levels and health-related quality of life (HRQOL) were obtained from over 476 parents of an autistic child. The first finding of this study is the substantial numbers of parents reporting HRQOL scores that are lower than those reported in the general population. The second findings from the current study is that greater parenting stress and lower parent HRQOL results from a multiple of interacting factors, though the contribution of demographic factors may be only limited in comparison to the child's core autistic behaviours and comorbid problem behaviours. Child factors, such as gender and number of siblings, and parental factors such as gender, age, education and relationship status, were poor predictors of parent HRQOL, indicating that the challenges of raising a child with ASD are universal and affect parents irrespective of their personal circumstances. The third finding is to emphasise the importance of transactional effects

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and, on the basis of the bi-directional relationship between parent and child, argue for a holistic intervention approaches that include the quality of life of both parents and their autistic child.

1. Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterised by a constellation of symptoms that differ in severity across individuals conferred with the diagnosis. The most utilised diagnostic framework, the revised fifth edition of the Diagnostic and Statistical Manual (DSM-5TR: APA, 2022), documents symptoms in two broad areas: i) difficulties in social communication and interaction, and; ii) restricted, repetitive patterns of behaviour, interests, or activities. To further meet the criteria for an ASD diagnosis the symptoms must cause clinically significant impairment of daily function, and be present early in development, irrespective of age of diagnosis. Decades of research has consistently highlighted the challenges faced by autistic people when trying to integrate with the world they live in, and also the parenting challenges faced when raising an autistic child. For parents, caring for an autistic child entails additional time and financial demands that have been associated with reduced leisure and socialisation time, greater marital strain, reduced opportunities for employment, disruptions to work/life balance, and higher levels of parenting stress amplified by the need to attend their child's appointments and be the vanguard of their interventions (Davy et al., 2022; Karst & Van Hecke, 2012).

Parenting stress has been shown to be exacerbated when raising children exhibiting developmental challenges such as ASD (Barroso et al., 2018). However, it is important for parents to adjust to the challenges of raising an autistic child as negative parenting strategies can not only intensify their own stress but can also induce distress in their child (Hastings, 2002). Pertinently, higher levels of parenting stress predicts higher levels of self-rated psychiatric distress (Shepherd et al., 2021) and depression (Reed et al., 2016), which may negatively impact their child's wellbeing. Consequently, the bi-directional relationship between parent and child outcomes confers importance upon not only treating the ASD-related symptoms and the problem behaviours of the child, but also targeting the parents' mental health (Vasilopoulou & Nisbet, 2016). To this end, a multitude of studies have been undertaken in the last three decades attempting to understand how the characteristic traits of ASD influence parental wellbeing, of which only a few have examined how parenting stress mediates the relationship between them (Enea & Rusu, 2020). In terms of parent outcome measures, the wellbeing construct is typically medicalised as a condition or disorder (e.g., clinical depression, sleep disruption) or operationalised more subjectively, for example, as health-related quality of life.

Health-related quality of life (HRQOL), an indicator of overall wellbeing, came to prominence as an outcome tool in clinical and public health research following the World Health Organisation's (WHO) seminal definition of health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO, 1948). Such a definition gives a more holistic approach to health, as though objective medical measures such as blood pressure, limb function, or hearing acuity can give insights into an individual's biological functioning, a full and accurate measurement of their health entails subjective measures that ask individuals if they are satisfied with their health, irrespective of their organ functioning (Fallowfield, 1990). Thus HRQOL is a multifaceted concept that captures the impact of health status on quality of life, and as such is relevant to the ASD context where individual and family quality of life are typically reported to be degraded in families raising an autistic child (Turnage & Conner, 2022; Thomas et al., 2018; Hsiao, 2016).

Examination of the literature suggests that two self-report HRQoL tools predominate in the parenting stress literature (Eapen & Guan, 2016), the Short-form Health Survey (SF-36) and the World Health Organisation's family of quality of life (QoL) instruments (WHOQOL). This dominance likely reflects the availability of these measures in multiple language versions that have undergone intensive validation a priori, as-well-as access to clinical and non-clinical normative datasets across the globe. In addition, family-specific instruments (e.g., the Family Quality of Life Scale: FQOL) have also been used, with the focus removed from the individual and instead placed upon the larger family unit. A number of meta-analyses and reviews have been undertaken to summarise the general findings presented in the autism literature, and irrespective of measure it has been reported that parenting an autistic child is associated with a greater risk of lower HRQoR compared to parents of typically developing children (e.g., Enea & Rusu, 2020; Yorke et al., 2018; Vasilopoulou & Nisbet, 2016; Ooi et al., 2016; Yirmiya & Shaked, 2005). This finding holds across the main dimensions of HRQoL, including physical health, psychological well-being, social and spiritual relationships, and environmental QoL (Turnage & Conner, 2022). This given, the impact that reduced parent HRQoL may have on the parent-child dyad also needs to be considered, with degraded parent-child attachments capable of adversely affecting child functioning and QoL (Teague et al., 2018).

In the ASD context the dominant predictor of parent HRQOL is parenting stress (Tung et al., 2014). General stress is often conceptualised by Lazarus and Folkman's (1984) Transactional Model of Stress and Coping in which an individual appraises potential stress-inducing events and deploys coping strategies. Adaptive coping strategies minimise stress, while maladaptive strategies allow the potential stressor to overwhelm the individual and induce a state of stress. More definitively, parenting stress is defined as feelings of distress or discomfort arising from the demands associated with raising a child (Watson et al., 2013). There are numerous models specific to parenting stress and include the Double ABCX Model (McCubbin & Patterson, 1983), the ecologically-based Process Model (Belsky, 1984), and Abidin's (1992) transactional model of parenting behaviours. All three approaches consider parenting stress to be a function of both the parent (e.g., age, gender, relationship status, education) and child (gender, age, behaviours) characteristics, and how these characteristics interact with social factors.

To date, studies identifying the risk factors of parenting stress in the ASD context have been inconclusive (Enea & Rusu, 2020). In terms of demographic factors, the literature is conflicting, with different studies reporting evidence both for and against the influence of parent and child age, and parent gender, education, and relationship status, upon parenting stress (e.g., Meads et al., 2022; Yorke et al., 2018). Intuitively, researchers have primarily focused on child characteristics such as ASD core symptoms or comorbid

conditions such as problem behaviours. Despite this being topical in the research space, these findings are inconsistent, with some reporting strong positive correlations between child core symptoms and parenting stress (e.g., Lecavalier et al., 2006; Shepherd et al., 2018), while others have not found such associations (e.g., Falk et al., 2014). Furthermore, there is greater inconsistency in results when core symptoms are examined in finer detail, with some reporting no linkages between parenting stress and either child language/communication difficulties or stereo-typed behaviours (e.g., Davis & Carter, 2008; Tomanik et al., 2004), in contrast to other studies (e.g., Shepherd et al., 2018).

Some have argued that the child's externalising behaviours are a more reliable risk factor of parenting stress (Huang et al., 2014; Karst & Van Hecke, 2012), and parent reports of their autistic child's behaviours indicate higher levels of externalising behaviours than those reported by parents of typically developing children (Siu et al., 2019). Externalising behaviours are behaviours projected outward to others, such as impulsivity, hyperactivity, aggression, and conduct issues, and in the ASD context a number of studies have indicated positive associations between child externalising behaviours and parenting stress (e.g., Lovell & Wetherell, 2016). In contrast, internalising behaviours are those privately experienced by the individual (e.g., emotional dysregulation, anxiety), and while not considered core ASD symptoms they are a prevalent commodity in autistic children, and are known contributors to parenting stress (Lin et al., 2021).

Additionally, many of the risk factors identified as predictors of parenting stress have a direct effect on parent quality of life (Davy et al., 2022). For example, core ASD symptoms (Landon et al., 2018) and child behaviour problems (Frazier et al., 2020) have been shown to predict lower quality of life. However, as with parenting stress, the literature presents contradictory evidence for these associations. Some studies report links between child ASD symptom severity and psychological wellbeing (e.g., Zhou et al., 2019; Falk et al., 2014; Duarte et al., 2005) despite other studies not finding this relationship (e.g., Salomone et al., 2018; Reed et al., 2016; Davis & Carter, 2008). Despite these inconsistencies, however, Frazier et al. (2020) argued that a child's core ASD symptoms and behaviour problems contribute, to some degree, independently to family quality of life, and identifying child externalising behaviours as the strongest predictor of lower quality of life of parents.

In the ASD literature a number of studies have operationalised psychological HRQOL using anxiety, depression, or psychiatric distress measures (e.g., Falk et al., 2014), and by utilising path analyses, have reported that parenting stress fully mediates the relationship between child ASD core symptoms and parent psychological wellbeing (Tomeny, 2016; Shepherd et al., 2021). However, while there is an intuitive link between parenting stress and HRQOL, it is unlikely to be unidirectional (Yorke et al., 2018). As much as a causal link likely exists between parenting stress and parent mental health (Dardas & Ahmad, 2015; Gallagher & Hannigan, 2014) there is also the potential for parent mental health to impact parenting stress. Statistically modelling the relationships and pathways between parent and child demographics, ASD-related factors such as symptom severity and problem behaviours, parenting stress, and parent HRQOL is an ongoing endeavour. As univariate and bivariate methods reach their limits and give way to multivariate approaches, the predictors of parent HRQOL become better understood. However, multivariate methods also have their limits, being vulnerable to unmet assumptions and overfitting, and difficulty modelling systems where relationships among variables are bidirectional or non-linear. Alternative approaches capable of accounting for both inter-relationships and proximal or distal effects in multivariate datasets have emerged, and a more contemporary approach to elucidating the underlying structures of complex systems is symptom networks identified through Network Analysis (NA).

Symptom networks are a novel paradigm of modelling the complex relationships between symptoms and assume that symptoms cause, or are associated with, the expression of other symptoms and related variables (Borsboom, 2017). Bayesian networks are powerful tools to decompose the joint probability distribution of variables and identify dependence and conditional independence relationships between random variables (Parviainen & Kaski, 2017). Recently, Bayesian networks have been used to explore the complex relationships between symptoms and related variables of one or more mental illnesses (Briganti et al., 2023). Bayesian networks differs from confirmatory factor analysis by not specifying a model a priori. Instead, the model is data-driven and thus inductive in nature. Similar to implementing a confirmatory factor analysis on the result of a principal components analysis, a locally optimal Bayesian network can be expressed as a structural equation model (SEM) and information on the significance of the relationships (i.e., path coefficients) within the network can be estimated. Essentially, Bayesian networks are based on conditional probability relationships and an SEM is a frequentist approach to Bayesian networks. As discussed by Kline (2023), directed acyclic graphs, such as Bayesian networks, are one type of SEM, and these are named structural causal models. Using structural causal models of symptoms is a relatively new approach to symptom networks, although there has been a steep increase in the use of Bayesian SEMs in other areas of psychology (Smid et al., 2020).

1.1. The current study

The current study seeks to understand how raising an autistic child impacts parent HRQOL, an important endeavour as higher parent HRQOL will likely foster better parenting and therefore improved child outcomes. Davy et al. (2022) reported that research into quality of life outcomes in the ASD context has "…been identified as an important research priority by the autism and developmental disabilities community" (p. 1917). This study has two aims, both of which fill substantial gaps in the literature (Enea & Rusou, 2020). First, to estimate the HRQOL of parents caring for an autistic child. Second, to apply recently developed analytical approaches (i.e., NA), to model the relationship between individual parent and child characteristics, parenting stress, and parent HRQOL. The NA will then be used to inform a structural equation model, whose output allows the strength of the relationships to be estimated, as well as the model's goodness-of-fit.

2. Method

2.1. Participants

An online survey was made available to New Zealand parents of an autistic child via Qualtrics©. The study was advertised with the assistance of New Zealand's largest national autism organisation, who promoted the survey. A total of 54 male ($M_{age} = 32.9$, $SD = 9.5$) and 422 females ($M_{age} = 27.7$, $SD = 9.2$) participated in this cross-sectional study, and all satisfied the study's inclusion criterion of being over 18 years of age, residing in New Zealand, and parenting a child with a formal diagnosis of ASD. Participants reported that their autistic children were predominantly male ($n = 361$) and that the majority received a formal diagnosis before the age five years ($n = 253$; 54.8 %). Demographic information, as entered into the study's statistical models, is presented in Table 1. The study was approved by the Author's institutional ethics committee (**Blinded For Review**).

Measures.

2.2. Health-related quality of life

The Short-Form Medical Outcomes Scale (SF-36) was used to assess HRQOL (Ware & Sherbourne, 1992). The SF-36 consists of 36 items which reduce to eight domains that can be further condensed into a Physical Component Summary (PCS: Physical Function (PF), Role Physical (RP), Bodily Pain (BP), General Health (GH)) and Mental Component Summary (MCS: Vitality (V), Social Function (SF), Role Emotion (RE), Mental Health (MH)). Depending on the domain, participants are required to answer a mix of yes-no questions, or three-point and five-point Likert scale questions. For each participant the eight domain scores are transformed to range between 0 (worst health) and 100 (best health). Each of the two summary measures (i.e., the PCS and MCS) were calculated using standardised scoring algorithms (Ware, Koskinski & Keller, 1994) and, following normalisation, PCS and MCS scores below 50 are taken to indicate below average HRQOL while scores above 50 represent above average HRQOL.

2.3. Severity of child autism

Child autism symptoms were documented using the parent-rated Autism Impact Measure (AIM) as presented by Kanne et al., (2014,

Table 1
Demographic profile of the sample.

Demographic	N	%	Missing
Sex (Parent)			1
Male	54	11.3	
Female	422	88.7	
Sex (Child)			6
Male	361	76.6	
Female	110	23.4	
Age (Parent)			1
< 45	235	49.4	
45 +	241	50.6	
Age (Child)			5
< 13	260	55.1	
13 +	212	44.9	
Ethnicity (Parent)			0
European	383	80.3	
Maori	46	9.6	
Other	48	10.1	
Education (Parent)			1
No University Degree	222	46.6	
University Degree	254	53.4	
Marital Status (Parent)			11
Single	101	21.7	
Relationship	365	78.3	
Number of Children (Parent)			10
1	164	35.1	
2 +	303	64.9	
Age of ASD Behaviour			1
< 2	232	48.7	
2 +	244	51.3	
Age at diagnosis			15
< 5	253	54.8	
5 +	209	45.2	
Diagnosing Clinician			0
Paediatrician	272	57	
Psychologist	130	27.3	
Other	75	15.7	

p. 175). Though the original AIM included both the frequency and impact of core ASD symptoms, this study only utilised the 25-item impact measure on account of collinearity between the two. The AIM impact dimension presents 25 clinical features of ASD, each on a 5 point Likert-type scale ranging from 1 (Not at All) to 5 (Severe), and asks parents how each impacts their autistic child's everyday functioning. In keeping with the clinical features detailed in the DSM-5, the 25-items are structured into four subscales: Restricted/Ritualized Behaviours (8 items), Odd/Atypical Behaviours (5 items), Communication/Language Impairment (5 items), and Social-Emotional Reciprocity deficits (7 items).

2.4. Child behaviour problems

Behavioural and emotional problems in children and adolescents were estimated using the Strengths and Difficulties Questionnaire (SDQ: Goodman & Goodman, 2009), and was also parent-rated. The SDQ probes parent's perceptions of their child's everyday behaviour using a three-category response scale: "not true", "somewhat true", or "certainly true". Hyperactivity (e.g., restlessness, easily distracted), Emotional Symptoms (e.g., worry, tearfulness), Conduct Problems (e.g., disobedience, dishonesty), Prosocial Behaviours (e.g., empathy, sharing), and Peer Problems subscales were calculated. Note that one item from the emotional symptoms subscale ("Often unhappy, down-hearted or tearful") was not analysed due to an error in the online survey, and this subscale was computed without this item. The SDQ subscales are further reducing to an Externalising score, by combing the Conduct Problems and Hyperactivity subscales, and an Internalising score, by combining the Peer Problems and Emotional Symptoms subscales.

2.5. Parenting stress

The 18-item Parenting Stress Scale (PSS: Berry & Jones, 1995) was used to measure the impact of raising an autistic child, and embodies both the positive (e.g., personal growth and emotional benefits) and negative (restricted lifestyle and strains on resources) aspects of parenthood. Each item is addressed using a 5 point Likert-type scale (1 = strongly disagree to 5 = strongly agree), and the responses yield four subscales: Parental Stressors, Parental Satisfaction, Lack of Control, and Lack of Rewards (Berry & Jones, 1995; Zelman & Ferro, 2018). These four subscales are then added to produce a PSS total score.

2.6. Data analysis

Preliminary analyses, deriving descriptive statistics and comparing mean SF-36 scores to population norms were undertaken in SPSS v.26. All multivariate analyses were conducted in R version 4.3.2, and structural equation modelling through the R package lavaan (v. 0.6–16, Rosseel, 2012). Only individuals who completed more than 50 % of the items were retained in the NA, with descriptive statistics compiled using non-imputed data and NA statistics obtained using imputed data based on the random forests algorithm in R.

The SF-36 domain scores were calculated using the steps detailed in the SF-36 Manual and Interpretation Guide (Ware et al., 1993). Firstly, selected items were reversed encoded to ensure that higher ratings on these items equated to higher perceptions of HRQoL. Secondly, SF-36 domain scores were calculated by summating each of the responses to each item belonging to a domain. The final step involves transforming domain scores so they all sit on a 0 - 100 scale. This is undertaken by multiplying the following by 100: (actual raw domain score - lowest possible domain score)/ possible raw domain score range (see Table 6.11, Ware et al., 1993).

In NA the reconstructed networks are comprised of nodes (variables) and edges (associations between variables), where edges may be directed from a parent node (predictor) to a child node (response), partially directed, or undirected. A Bayesian network encodes conditional probability relationships into a directed acyclic graph, using the hill climbing method to estimate the graph topology. Hill climbing starts with an empty graph to which edges between nodes are added, deleted, or reversed until no improvement is made to the 'score' function (e.g., the Bayesian Information Criterion (BIC)). The parameters of the network are learned at each step of the iteration, by either specifying a global distribution for all parameters in the network, or by specifying local distributions for the relationships between variables. Once the network structure and parameters are learned and estimated, information from the network can be extracted from either how central a node is in the network, from the edges or associations between variables, or from consideration of conditional probability relationships between variables. Probability queries can be obtained by treating the network as an expert system to obtain conditional probabilities between nodes such as predictor (parent variable) and response (child variable) relationships.

For the NA, three hybrid Bayesian networks were implemented using the score-based Hill climbing algorithm, which searches the structure and parameter space of possible networks to converge to a locally optimum solution (Scutari et al., 2019). Hill climbing starts with an empty network, and at each step adds, deletes, or changes the direction of an edge until no improvement can be found in the network score. The Bayesian information criterion (BIC) index was used as the score criterion in this study. Hybrid Bayesian networks afford the inclusion of both discrete and continuous variables in the model, however, discrete variables are not permitted to be 'daughter' nodes of continuous variables and therefore all demographics were discretized, as logistic and multinomial regressions (with a discrete outcome variable) were not conducted in the networks of our study. Gender was coded as Female (1) and Male (2), age (of parent) was younger than 45 (1) and 45 or older (2), child age as younger than 13 (1) and 13 or older (2), and age at diagnosis as younger than six (1) and six and older (2), marital status as relationship (1) and single (2) and number of children as 1 child (1) and two or more children (2). Consequently, there is a blacklist containing edges that are not permitted in the model. It also makes sense to ensure demographic variables are not response variables of the clinical assessment subscales (predictors) in our analysis. In addition, as the main outcome variables, the PCS and MCS were forced to be leaf nodes and added to the blacklist, eliminating any possible edges

from these nodes to other others while still allowing edges between the two. Additionally, demographic variables were removed from the model if the demographic variable was a leaf node, or if it did not lead to a leaf node that was not a clinical assessment variable. Hence, demographic variables were removed if the clinical assessment variables were not dependent on them, directly or through a third variable.

All networks we constructed using the bnlearn package by Scutari (2010), with the assumption that the distribution between model nodes were conditional Gaussian. Further, networks can be averaged by reconstructing a network on a bootstrapped sample many times and averaging the results. Averaged networks tend to have higher predictive validity than a network reconstructed on the entire sample (Nagarajan et al., 2013), and thus bootstrapping was employed in the current study.

The centrality statistics generated by the NA identify how central a node is in the network, with nodes that are more central being considered to have the greatest influence over the network (Bringmann et al., 2019). Three centrality indices were extracted to reflect which variables in the sample were most important (Hevey, 2018): *Betweenness*, the importance of a node in the average pathway between other pairs of nodes; *Closeness*, the relationship to all other nodes in the network, taking the shortest distance from that node to all other nodes in the network, and; *Degree*, the number of edges of each node. We standardised the metrics betweenness and closeness to a z-score in this study. Further, Bayesian networks can be queried on the strength of relationships between variables in the networks. Here, the reconstructed network is treated as an expert system and questions are made about the probability of an occurrence given the event of two or more variables (Briganti et al., 2022). An example query from this study may be formulated as, given that the child with autism is aged 13 or older, what is the probability that the child scores above the median of the sample for scores on the externalising dimension of the SDQ? The results of these queries can then be made to make an inference about the predictor-response relationships between two or more variables.

Following the reconstruction of the networks a structural equation model was created, allowing further estimation of model parameters and providing fit statistics. This was performed in R using the Lavaan package by Rosseel (2012). As both discrete and continuous variables populated the model, diagonally weighted least squares parameter estimates were obtained, entailing the need to calculate some fit statistics (i.e., Likelihood, Akaike information criterion (AIC), and BIC) using the bnlearn package. Lower values of AIC and BIC suggests a better model for the data and values above.95 for CFI and TLI and below approximately.06 for RMSEA indicates a good fit of the model to the data (Hu & Bentler, 2009). We also conducted a hypothesis test on each of the models to identify whether the observed variance covariance matrix is significantly different to the model implied variance covariance matrix, using a chi-square test of model fit.

3. Results

3.1. Descriptive statistics

Summary statistics for the scalar measures utilised in the NA are presented in Table 2 and in more detail in supplementary materials (*re*: Supplementary Table 1), including minimum and maximum values, and reliability statistics (Cronbach's alpha). The mean total score for the AIM is close to estimates reported in a previous study analysing data from an equivalent New Zealand sample ($M = 75.19$, $SD = 16.27$: Shepherd et al., 2021). Finally, Grasso et al. (2022) presented a similar SDQ mean score for the externalising behavioural domain for children with ASD, and all subscale scores were significantly different (*re*: supplementary materials) from a sample of non-autistic New Zealand children (Kercher et al., 2024), with the current sample exhibiting greater behavioural and social challenges. Finally, the parenting stress scale (PSS) total score calculated in the current study was higher than those reported in an international study looking at parents caring for young children with language delays ($M = 30.9$: Kotsis et al., 2023).

3.2. SF-36 scores

Normalised SF-36 domain scores are presented in Fig. 1 alongside New Zealand norms (Frieling et al., 2013). A battery of independent-samples *t*-tests revealed that all pairwise comparisons with the normative data were significant (all $p < .001$), with larger effect sizes obtained with the SF-36 mental health domains (*re*: Supplementary Table 2). The eight SF-36 domain scores were further condensed into the Physical Component Score (PCS) and the Mental Component Score (MCS), with histograms for each displayed in Figs. 2a and b. Using the weightings published by Frieling : Table 6) et al. (2013), the mean PCS and MCS values for the current study were 46.27 and 33.43, respectively, compared to the New Zealand normative values of 47.87 and 53.04, respectively. With reference

Table 2
Summary statistics.

	# Items	*M*	*SD*	Min	Max	Cronbachs
AIM Total Score	25	75.98	15.61	31	118	.819
SDQ Internalising Total Score*	9	9.89	3.41	1	17	.613
SDQ Externalising Total Score	10	9.42	3.99	0	19	.786
Parental Stress Total Score	18	45.77	12.17	16	77	.905
SF−36 PCS	36	46.27	10.15	10	65	.915
SF−36 MCS	36	33.43	16.68	4	63	.907

Note: * = Item 3 not available for this subscale

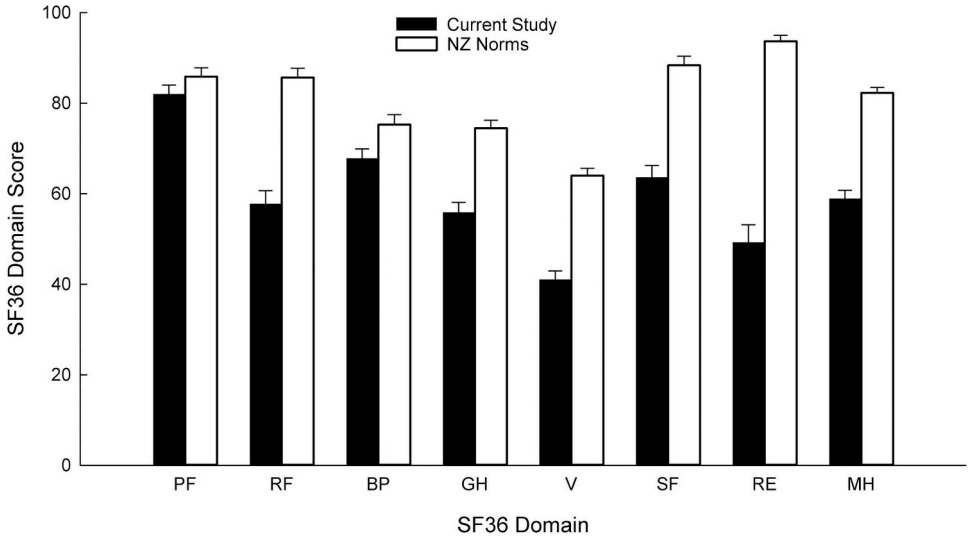

Fig. 1. Average domain scores (filled bars) accompanied with population norms (open bars). Whiskers are 95 % confidence intervals, and abbreviated domain names are detailed in Table 2.

to Ware et al. (1994), component scores below 44 represent below average wellbeing and health. As shown in Fig. 2a, 182 of participants had PCS scores below 44, which inflated to 335 participants when considering the MCS values (*re*: Fig. 2b).

3.3. Network analysis model

Table 3 below shows the model fit statistics for three Bayesian network models attempted in this study. Although the blacklist applied constraints upon the network, it in fact returned better fit statistics, indicating that the model without a blacklist terminated at a locally optimised solution that was suboptimal compared to the network with the blacklist. Because the network with a blacklist had the best-fit statistics, we report the network (Fig. 3) and the SEM (Fig. 5) for this network below. Additionally, the averaged (bootstrapped) network had the poorest fit to the data. It may, however, have stronger predictive validity. The model with the blacklist was non-significant which indicates the model implied variance covariance matrix was not significantly different to the observed variance covariance matrix. Hence, either there is insufficient power to identify significance, or this is the true underlying model that generated the data.

Fig. 3 shows the Bayesian network structure for the blacklisted network, while the network without a blacklist and the averaged network can be found in the Supplementary Materials. The results in Fig. 3 suggest that PCS is dependent on both the MCS and the AIM's Restricted and Ritualised Behaviour subscale. Furthermore, the MCS mediates the relationship between both the Internalising and Externalising subscale of the SDQ and the PCS, and between the PSS and the PCS. In turn, the MCS is dependent on the Restricted and Ritualised Behaviour subscale of the AIM, the Internalising and Externalising subscale of the SDQ, and the PSS. The SDQ Internalising subscale mediates the relationship between child age at diagnosis and the MCS, while the MCS is also independent of the age of the child given the effect of the mediator variable SDQ's Externalising subscale. Parenting stress is also dependant on externalising behaviour and child age. Lastly, the network in Fig. 3 also shows that the SF-36′s PCS and the AIM's Socioemotional Reciprocity subscale are leaf nodes, meaning that they are outcome variables and therefore nothing in this network depends on the score of these two variables.

Fig. 4 presents the three centrality statistics, betweenness, closeness, and degree, for the network in Fig. 3. The MCS had the highest betweenness estimate, indicating that many edges, with strong associations, pass through this variable to the PCS. In terms of closeness, child age, the AIM's Odd Behaviour, and child age at diagnosis had a smaller distance to all other nodes in the network, indicating it is tightly connected to all other nodes in the network. In terms of degree, the variables with the highest number of edges in Fig. 3 were the MCS and the SDQ's Externalising subscale, with the MCS having the most incoming edges in the network.

Table 4 presents the queries to the network, with each variable in the query being dichotomised using sample medians. The probability of the PCS being less than the sample median (*Med* = 59.8) when the MCS is less than the sample median (*Med* = 44) is $p = .765$. Similarly, the probability of the PCS being less than the sample median when the Restricted and Ritualised Behaviour subscale is greater than the sample median (*Med* = 28) is $p = .661$. For the MCS, the probability that it is less than the median is.706 when the PSS is greater than the median (*Med* = 46), and is $p = .663$ when SDQ externalising subscale greater than the median (*Med* = 10).

3.4. Structural equation model

Fig. 5 has the same structure characteristics as that presented in Fig. 3, however, the standardised coefficients and their associated

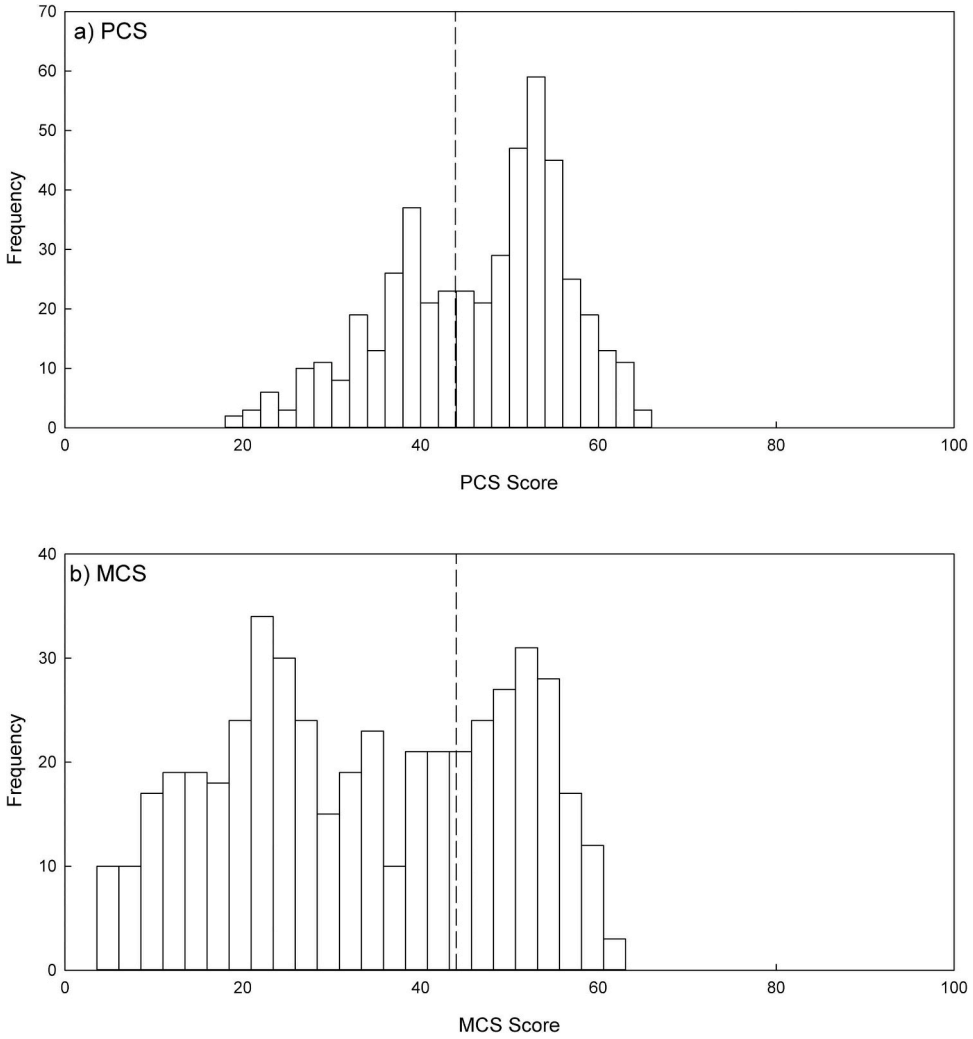

Fig. 2. Histogram's displaying the frequency distribution of PCS (top) and MCS (bottom) scores. The dashed vertical lines represents the cut-off point between those reporting physical (a) or mental (b) health challenges (to the left of the line), and those reporting an absence of chronic physical limitations and psychological distress (to the right of the line).

Table 3
Model Fit Statistics for Bayesian Networks. CFI, TLI, Chi-square, and RMSEA were derived from the lavaan package, while Log-likelihood, BIC and AIC indices were derived from the bnlearn package.

Model	CFI	TLI	RMSEA	Chi-Square	*df*	*p*	Log-Likelihood	BIC	AIC
No Blacklist	.986	.983	.028	105.06	77	.019	−14875.0	30113.9	29868.0
With Blacklist	.992	.990	.024	71.50	56	.079	−14364.0	29073.4	28840.0
Averaged Network	**.891**	**.891**	**.065**	**107.96**	**36**	**< .001**	−14397.5	**29097.1**	**28892.9**

significance were derived from a structural equation model. The results suggest that the strongest predictor response relationship was between the Odd Behaviour and Restricted and Ritualised Behaviour subscales from the AIM ($\beta = .68$, $p < .001$). Of interest, externalising behaviours were positively associated with high parenting stress ($\beta = .46$, $p < .001$). Child age was also a significant predictor of parenting stress, with ages greater than 5 years of age being associated with higher parenting stress ($\beta = .15$, $p = .004$). There was a negative relationship between child age and externalising behaviours ($\beta = -.42$, $p < .001$). Additionally, age of diagnosis was a significant predictor of externalising behaviours ($\beta = .33$, $p < .001$), and age of diagnosis was also negatively associated with communication and language impairments ($\beta = -.46$, $p < .001$). In terms of MCS and PCS, the outcome variables of this study, the MCS was a mediating variable of externalising behaviours ($\beta = -.2$, $p < .001$) and parenting stress ($\beta = -.41$, $p < .001$) on PCS, and although internalising behaviours was dependant on MCS in the network, this relationship was non-significant. Restricted and ritualised behaviour was also a significant predictor of both MCS ($\beta = -.11$, $p < .020$) and PCS ($\beta = -.11$, $p < .021$). The structure of the

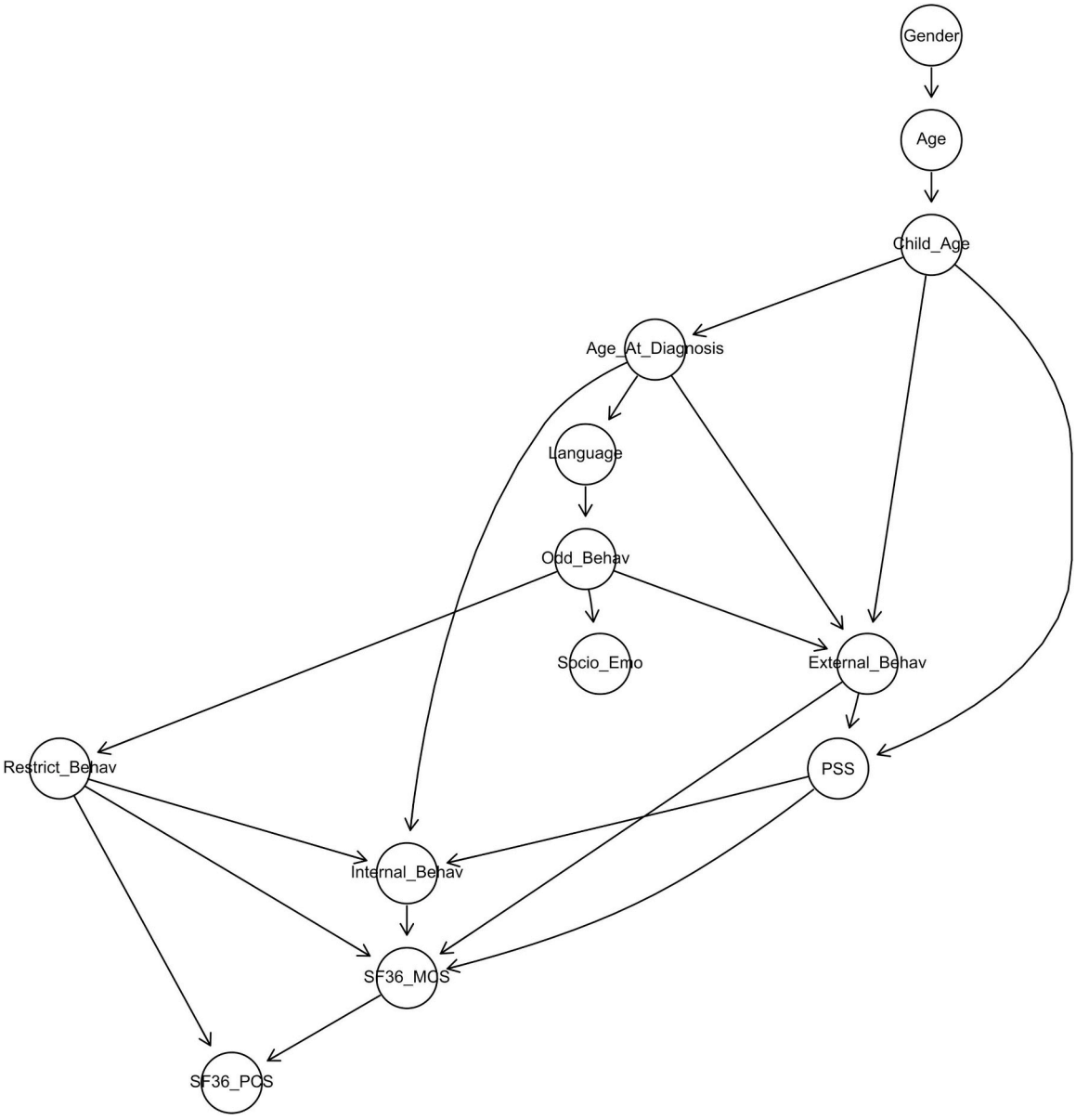

Fig. 3. Hybrid Bayesian Network with blacklist.

network in Fig. 5 retains the dependencies and independencies encoded in the Bayesian network identified in Fig. 3, hence externalising behaviours and parenting stress are independent of PCS given the values of MCS.

4. Discussion

The current study sought to document the HRQOL of parents caring for an autistic child, and to apply Network Analyses to further elucidate the relationships between child and parent factors. The findings of this study indicate that parent HRQOL is relatively low, but more so for psychological than physical HRQOL. The Network Analysis indicated that, with reference to research hitherto reporting that child problem behaviours is the dominant risk factor for elevated parenting stress and degraded HRQOL mental health, child core autistic behaviours are also potent predictors. Relationships between HRQOL physical health and parenting stress and child problem behaviours is mediated by HRQOL mental health.

4.1. Health status of the sample

The demands of raising children typically induce care-related stress in parents (Tadema & Vlaskamp, 2010), whether it be acute or

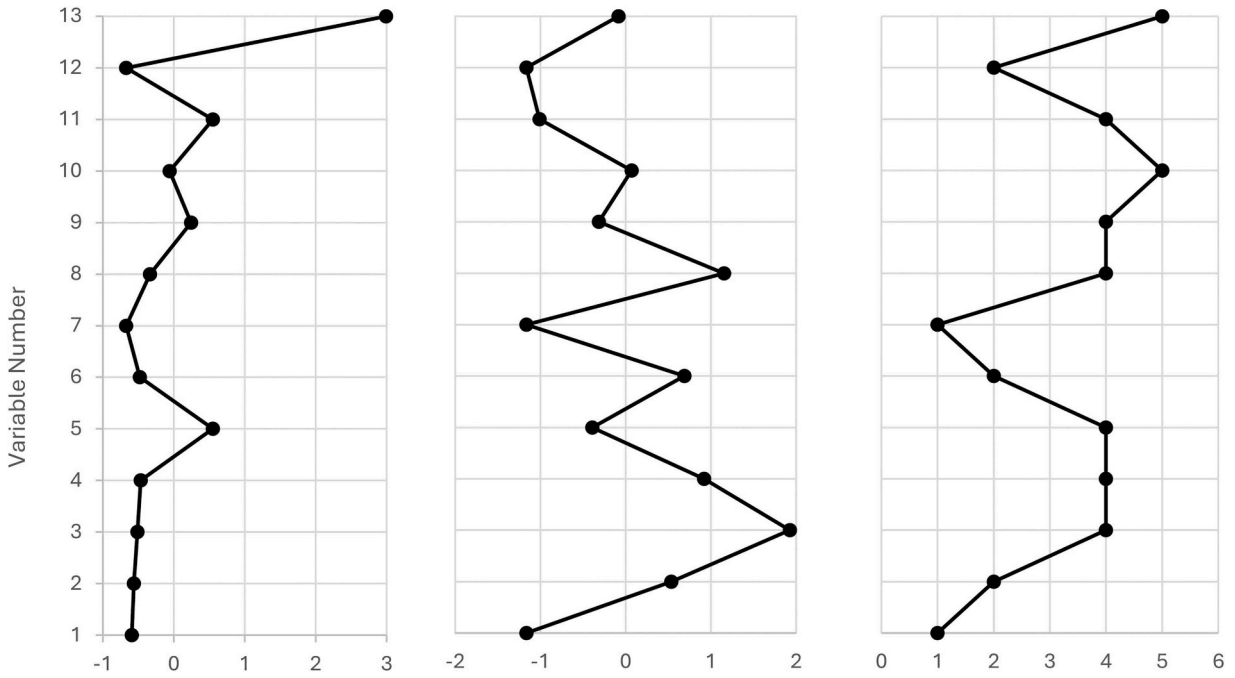

Fig. 4. Centrality Statistics of Bayesian Network with a blacklist, showing closeness (left), betweeness (middle) and degree (right) values. Note. Variable number 1 = Gender; 2 = Age; 3 = Child age; 4 = Age at diagnosis; 5 = AIM Restricted and Ritualised behaviour; 6 = AIM Communication and Language; 7 = AIM Socio-Emotional Reciprocity; 8 = AIM Odd Behaviour; 9 = PSS Total; 10 = SDQ Externalising Behaviour; 11 = SDQ Internalising Behaviour; 12 = SF−36 Physical Health Component Summary Score; 13 = SF−36 Mental Health Component Summary Score.

Table 4
Queries to Hybrid Bayesian Network presented in Fig. 3.

Variable 1	Median	Variable 2	Median	Probability
SF−36 PCS	< 59.8	AIM Restricted and Ritualised behaviour	> 28	.661
SF−36 PCS	< 59.8	SF−36 MCS	< 44	.765
SF−36 MCS	< 44	AIM Restricted and Ritualised behaviour	> 28	.592
SF−36 MCS	< 44	SDQ Internalising Behaviour	> 10	.607
SF−36 MCS	< 44	SDQ Externalising Behaviour	> 10	.663
SF−36 MCS	< 44	Parenting Stress Scale	> 46	.706

chronic stress, and parenting stress has been found higher when raising autistic children compared to non-autistic children (Barroso et al., 2018). Employing a gold standard measure of HRQOL, the SF-36, we noted that 38 % of participants reported low physical health and 70 % reported low psychological wellbeing. Further comparisons to the general population revealed that the participants reported significantly lower HRQOL, particularly in the areas mental health and social functioning. This finding is consistent with the weight of evidence in the literature indicating that parenting an autistic child is associated with lower parental HRQOL (Karst & Van Hecke, 2012), and in particular lower psychological QOL (Turnage & Conner, 2022).

Comparatively, Ran et al. (2023) reported median PCS and MCS scores of 39.67 and 37.63 respectively, and classified 88.9 % of their Chinese sample as having low physical HRQOL, and 97 % as having low psychological wellbeing. The differences found between the current study and Ran et al.'s can be accounted for by their adoption of a 50 %, rather than a 44 %, cut-off, their use of an abbreviated version of the SF-36 (the SF-12), and potential differences in health delivery and support sources between China and New Zealand. Studying parents of autistic children in the United States, Johnson et al. (2011) reported PCS values of 49.10 and MCS values of 34.21, which were calculated using the same procedure used in the current study (Ware et al., 1994), and are in close agreement with both the current study and those for mothers partaking in a Japanese study (Yamada et al., 2012). In tune with the literature, the evidence from the current study indicates that parents of autistic children are vulnerable to lower wellbeing, and in turn could be providing their children with sub-optimal care as they struggle with the challenges of parenthood. Such transactional effects are cumulative, and parent-centred interventions have been advocated in some quarters to reduce parenting stress, improve the parent-child dyad, and increase the HRQOL of both (Musetti et al., 2024).

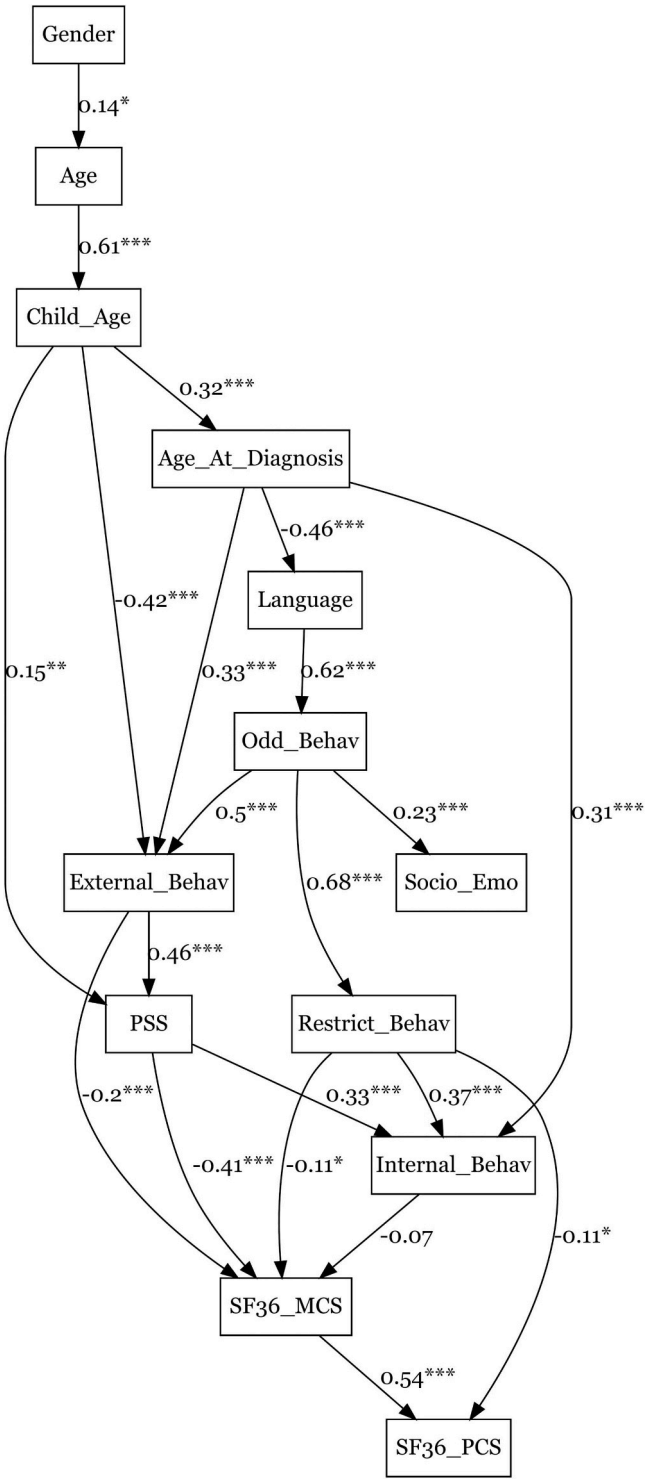

Fig. 5. Structural Equation Model of Hybrid Bayesian Network (re: Fig. 3). All coefficients from the structural equation model were standardised to facilitate interpretation.

4.2. Demographic predictors of parenting stress and HRQOL

To further understand the factors that contribute to lower parental HRQOL in the ASD context, a Network Analysis was performed and a structural equation model generated. Considering first the demographic variables, neither parent or child gender were significant

nor direct predictors of parenting stress or HRQOL, though child age did mediate the relationship between parent age and parenting stress. More directly, child age correlated positively with parenting stress, replicating previous results (e.g., Tomanik et al., 2004), and supporting the predictions of the wear-and-tear hypothesis that as child age increases there is a corresponding increase in parental fatigue and burnout, and a decrease in help-seeking behaviour and use of supports (Shepherd et al., 2020). Unsupported by the current data is the coping hypothesis, which postulates that as the child ages, their parents learn strategies for dealing with challenging behaviours and become more adaptive, and by extension, experience less parenting stress. Overall, the current study downplays the importance of demographic variables on parenting stress and wellbeing, in opposition to current theory (e.g., McCubbin & Patterson, 1983; Belsky, 1984; Abidin, 1992).

Child age was linked to externalising behaviours, which in turn was strongly associated with parenting stress. Common externalising behaviours in the ASD context include verbal or physical aggression directed to other people, temper tantrums, destruction of objects, and defiance, which are reported to be more prevalent in autistic children compared to non-autistic children (Siu et al., 2019; Bauminger et al., 2010). The negative association between child age and externalising behaviours indicates that if the age of the child age is greater than five years, the frequency of externalising behaviours decrease (compared to younger than five years) in the current sample, possibly due to developmental factors and/or interventions. Thus while child age has a positive association with parenting stress, the decrease of externalising behaviours as the child ages indicates that the cause of parenting stress likely shifts to other factors, which are mediated by externalising behaviours.

The model indicated that children over the age of five are more likely to receive a formal diagnosis, while age of diagnosis was negatively associated with language ability, supporting previous findings that children with higher language function typically get diagnosed later than children with impaired language (e.g., Meads et al., 2022). This finding likely reflects distinct developmental trajectories of autism, and since the DSM-5-TR abandoned the Asperger's diagnosis other terms such as 'Profound Autism' and 'ASD – without intellectual or language impairment' or 'non-Profound Autism' (Lord et al., 2022) have emerged to fill the void left in the clinical lexicon. Hughes et al. (2023) argue that the distinction between Profound and non-Profound Autism has clinical significance, as those without language delay and with attenuated ASD symptoms may have different support needs and service requirements than those with Profound Autism. Interestingly, age at diagnosis is positively associated with externalising behaviours, potentially flagging a process whereby later diagnoses compound problem behaviours, as access to government or state provided interventions are often dependent upon a formal diagnosis. However, it cannot be discounted that the emergence of problem behaviours in non-Profound Autistic individual's acts as an impetus to seek a diagnosis, and further research is required.

For parenting stress, Huang et al. (2014) identified child externalising behaviours as a dominant predictor, a finding supported by the current study, which found PSI scores are dependent on externalising behaviours with higher levels of externalising behaviour being associated with higher levels of parenting stress. Externalising behaviour was also a mediating variable in the pathway between other variables and parenting stress. Performing a meta-analysis, Barroso et al. (2018) reported that, concordant with the current study, stress arising from parenting an autistic child was better predicted by externalising behaviours than internalising behaviours. Previous studies have indicated that language and communication impairment does not contribute significantly to parenting stress (Davis & Carter, 2008; Lecavalier et al., 2006; Tomanik et al., 2004), instead echoing the current findings that externalising behaviours are better predictors. Reference to the literature indicates that some controversy exists as to the relative contributions of child core autism symptoms and problem behaviours to parenting stress (e.g., Davis & Carter, 2008), with the current data supporting the notion that problem behaviours, considered a comorbid condition, can claim to be the dominant predictor.

4.3. Psychological HRQOL

In the current study HRQOL was operationalised using the SF-36, with analyses performed on the two summary scores calculated from the eight SF-36 subdomains: physical (PCS) and psychological (MCS) HRQOL. Turning first to the MCS, the analyses indicated a dependency with four other variables in the model: externalising behaviours, internalising behaviours, parenting stress, and the Restricted and Ritualised Behaviour subscale of the AIM. Thus, in opposition to the parenting stress measure, both child core ASD-related behaviours and problem behaviours are impacting parent psychological QOL, as reported elsewhere (Cappe et al., 2011). Reporting on a review of 15 studies involving 5565 participants, Turnage and Conner (2022) identified externalising behaviours (irritability, defiance, hyperactivity) as the dominant predictor of degraded parental HRQOL, while Shepherd et al. (2021) reported that parenting stress fully mediated the relationship between child ASD core symptoms and parent psychological wellbeing. The parent-rated internalising behaviours exhibited by the autistic children did not significantly influence parent HRQOL, a finding supported by Vernhet et al. (2022) with fathers, but not mothers. However, the general finding that the dominant predictor of the SF-36′s MCS scale is parenting stress (e.g., Lee et al., 2009) was replicated in the current study, indicating the importance of targeting parenting stress at the clinical level.

4.4. Physical HRQOL

Parents ratings of physical HRQOL, as measured by the SF-36′s PCS, was dependent upon the Restricted and Ritualised Behaviour subscale of the AIM and also the MCS. A review undertaken by Turnage and Conner (2022) reported that raising an autistic child was a strong predictor of degraded physical health, as have others (Bohadana et al., 2019; Parsons et al., 2020). Analysing a similar construct, Landon et al. (2018) observed a significant negative correlation between parents' satisfaction with life ratings and their child's ASD symptom severity, suggesting that HRQOL is impacted by the physical tasks associated with managing the behaviour of an autistic child. Johnson et al. (2011) report that autism-related caregiving tasks can become more physically demanding as a child advances in

age, with parents not only reporting greater childcare challenges, but also isolation and less participation in social and community events, and less involvement in their child's interventions. With reference to the latter, Ran et al. (2023) noted that formal social supports in the form of clinician-led interventions served to improve parent physical HRQOL, indicating a link between a reduction in child core symptoms and better parental physical HRQOL. However, it is not possible to conclude from the data whether the challenges presented by their child's ASD symptoms degrade parent physical HRQOL, or whether the deficit is due to reduced opportunities to engage in positive health behaviours.

Psychological HRQOL was the dominant predictor of physical HRQOL, however, as the current autism literature is bereft of structural models representing parent HRQOL, there are no studies with which we can compare this finding. More broadly, there is a known positive relationship between physical and psychological wellbeing, as captured in the adages "healthy body, healthy mind" and "mind over matter". Depression and anxiety, two conditions found to be over-represented in parents of autistic children (Shepherd et al., 2021), are associated with physical symptoms such as lethargy, sleep disturbance, musculoskeletal pain, and autonomic dysregulation. Physical HRQOL can be impacted by maladaptive coping strategies such as alcoholism and emotional eating (Wallace et al., 2021), which can act as potent mediators between parenting stress and wellbeing. Additionally, low parenting self-esteem can lead to inconsistent parenting and a degraded parent-child relationship, whereby parents become less emotionally available and less responsive to their child's needs. This in turn may exacerbate their child's emotional and behavioural problems, leaving parents overwhelmed by their caring responsibilities, and leading to burn out and lower physical HRQOL.

5. Strengths and limitations

A strength of the current study is that estimates of both child core ASD symptoms and problem behaviours were analysed simultaneously in the same model. Further strengths include a relatively larger sample size than is typically encountered in the autism literature, and the advantages associated with both Network Analyses and structural equation modelling. Limitations of the study include those typically associated with cross sectional designs, for example, constraints on causal inference. Secondly, as with most studies, the sample was acquired from a single country, and while that allows for cultural and health service delivery factors to be controlled for, it does limit generalisability. Additional limits placed on the generalisation of findings is the demographic characteristics of the sample, which was biased towards Caucasian females, and recruiting through national autism associations. The potential for both parents to respond to the survey should be acknowledged as a limitation, as this can lead to issues related to the dependency of observations.

Further, increasing the sample size to estimate the network would assist in approximating the true network structure for this population. Bayesian networks also do not allow cycles in the data, and other network approaches can be used in this instance. Despite this Bayesian networks are useful to obtain directed relationships for an SEM, and SEM's do not allow cycles like Bayesian networks. Furthermore, by discretising demographic variables we may have lost some information in these variables. Finally, the analysis utilised parent and not clinician ratings of both child characteristics and their own stress and HRQOL, which can be perceived either as a methodological strength or weakness. On the one hand, parents are in a better position to rate their child's functioning in everyday life (Sacrey et al., 2018; Miller et al., 2017), while on the other hand they lack the training and expertise of practitioners.

6. Conclusion and implications

In conclusion, this is the first study to embed the SF-36 into substantive multivariate models in the parenting stress and ASD context. These findings confirm previous reports that parents of an autistic child generally report lower HRQOL (Musetti et al., 2024), and support the notion that parent physical HRQOL is affected by both the severity of child ASD symptoms and externalising behaviours. These findings have a number of implications.

The first implication of this study is the lower HRQOL of the parent sample in comparison to national norms. Hitherto, the wellbeing of parents has not been a central consideration when formulating child interventions. However, the responsibility to deliver child interventions often falls on the parents themselves, and hence high levels of parenting stress and burnout can interfere with therapy goals (Osborne et al., 2008). Of concern, the higher levels of task stress and exhaustion typified by parents of an autistic child can result in parents needing therapy themselves (Rivard et al., 2014). Thus, as best practice, paediatric clinicians should carefully consider the health and function of not only the child but also promote positive outcomes for parents, as services focusing purely on child symptoms and behaviours may be less effective (Lainhart, 1999).

The second implication from the current study is that amplified parenting stress and attenuated HRQOL results from multiple interacting factors, though the contribution of demographic factors may be only limited in comparison to the child's core autistic behaviours and comorbid problem behaviours (Yorke et al., 2018). Important, however, is to avoid parent-or-child targeted interventions that focus on one factor (e.g., child core symptoms) at the cost of the other (e.g., conduct problems) unless the unlikely scenario that one-or-the-other is clearly absent holds. Indeed, as can be seen in the model, child core ASD symptoms and comorbid behaviours can interact and potentially exacerbate one-another, as can be seen with the significant relationship between the Restricted and Ritualised Behaviour subscale of the AIM and the SDQ's internalising behaviour scale. Thus biasing one type of child's behaviour over another could impact intervention efficacy.

The third implication of the research is to highlight the importance of transactional effects. In the current study child externalising behaviours were strong predictors of parenting stress, while parenting stress itself was a strong predictor of the child's internalising behaviours. Transactional effects arising for the reciprocal relationship between child behaviour and the parenting strategies they elicit have been documented in the ASD literature (Karst & Van Hecke, 2012). In discussing the dynamic interplay between an autistic

child's characteristics and parenting style, Lin et al. (2021) opined that while an autistic child's externalising behaviours can present parenting challenges, their mitigation lies in the coping strategies employed by the parents. Specifically, positive parent-child interactions serve to reduce both parenting stress and child frustration, and studies have demonstrated strong relationships between parenting stress and the frequency and impact of child externalising behaviours (e.g., Bauminger et al., 2010). Hence, parental factors should be considered important factors when designing interventions to nurture the development of autistic children, leading to greater intervention effectiveness and more positive outcomes for both parent and child.

Bayesian networks are powerful tools to model the complex interplay of symptoms of mental disorders (Parviainen & Kaski, 2017; Briganti et al., 2023). The Bayesian networks used in the current paper has provided important knowledge into the links between parent and child variables and how these impact parental HRQOL. However, the provision of additional variables that expand the model would afford further insights to be gained. For example, parent and child personality characteristics, including resilience, parent coping styles, and available formal and informal social supports could all be added to generate a more comprehensive model. While this study focused on parenting stress, future studies could also examine alternative sources of parental stress (e.g., work stress) and assess cumulative effects. Lastly, given the breadth and intensity of the stressors encountered when parenting an autistic child, it is important for both parent and child that knowledge continues to be accumulated in this area.

Compliance with ethical standards

Conflict of interest All the authors declare that they have no conflict of interest. Ethical approval Ethical approval for this study was obtained from the **< << Blinded for Review > >>** , and informed consent Informed consent was obtained from all individual participants included in the study.

CRediT authorship contribution statement

Khan Buchwald: Software, Methodology, Formal analysis, Data curation. **Richard J. Siegert:** Writing – review & editing, Project administration, Investigation, Formal analysis. **Matthieu Vignes:** Writing – review & editing, Writing – original draft, Supervision, Formal analysis. **Daniel Shepherd:** Methodology, Formal analysis, Data curation, Conceptualization.

Declaration of Competing Interest

None.

Data availability

Data will be made available on request.

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