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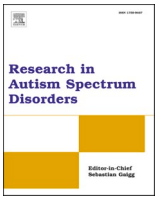

The impact of having an autisTic child on parental mental health and wellbeing in pakistan

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ABSTRACT

Background: Caring for a child with Autism Spectrum Disorder (ASD) poses significant challenges and parents are at increased risk of psychological distress and reduced wellbeing.
Methods: We investigated the impact of having an autistic child on the wellbeing of 103 parents in Pakistan. Data were collected using the Self-Reported Questionnaire (SRQ-20), Autism Parenting Stress Index (APSI) and the WHO's Quality of Life Brief Version.
Results: Parents reported reduced psychological health and worsened social relationships in comparison with population norms. The mean prevalence of APSI responses indicating frequent stress was 78 % overall; 91 % around core autism behaviours, 77 % around comorbid behaviours and 65 % around comorbid physical problems. SRQ-20 scores suggested that there were moderate mental distress levels in parents of children with ASD; 60 % of participants scored ≥ 8 indicating probable mental disorder. Parenting stress, including stress specific to comorbid behaviours, was modestly associated with (total) levels of (general) mental distress and with poorer physical and psychological health. Mothers reported significantly poorer psychological health and greater levels of mental distress than fathers, while quality of life markers concerning social relationships and environmental health were higher in parents of younger children with ASD.
Conclusions: Parents of children with ASD experience significant ASD-specific parental stress, psychological distress and decreased quality of life and wellbeing. These parents frequently present with reduced energy levels and depressive symptoms. This data provide a deeper understanding of the challenges faced by parents of children with ASD in Pakistan and provides a framework to guide further research and clinical practice.

1. Introduction

Autism Spectrum Disorder (ASD) is characterised by social communication deficits, restrictive interests and repetitive behaviour (American Psychiatric Association, 2013) and has a male-to-female ratio of 2.5–4.5 depending on the design and age of sample under study (Krakowski, 2022; Loomes, Hull, & Mandy, 2017; Posserud, Skretting Solberg, Engeland, Haavik, & Klungsøyr, 2021). The recent

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estimated global prevalence of children with ASD is 1:100 (Zeidan et al., 2022) and previously was quoted as 1:160 (Elsabbagh et al., 2012). Although ASD phenomenology is well documented and the prevalence of autism is increasing globally, authentic epidemiological data relating to ASD in Pakistan are scarce (Akhter, Ashraf, Ali, Rizwan, & Rehman, 2018; Ashraf et al., 2022). Nevertheless, a recent estimate from the Pakistan Autism Society indicated that about 350,000 children in Pakistan have ASD (Furrukh & Anjum, 2020).

Caring for a child with ASD poses significant challenges on a daily basis which can be overwhelming for parents and profoundly affect the well-being of the entire family (Giovagnoli et al., 2015). Poor quality of life (QoL) in parents of children with ASD, relative to those of typically developing children, has been widely reported (for reviews, see Dey, Castro, Haug, & Schaub, 2019; Vasilopoulou & Nisbet, 2016), including in countries with developing economies (Raju, Hepsibah, & Niharika, 2023). Parents of children with ASD frequently present with higher stress levels than other groups of parents (Bonis, 2016). Parental stress has been linked to severity of core ASD symptoms (Batool & Khurshid, 2015; Rivard, Terroux, Parent-Boursier, & Mercier, 2014) and mediates the relationship between ASD symptom severity and parental mental health (Shepherd, Landon, Goedeke, & Meads, 2021). Behavioural (e.g., oppositional-defiance disorder) and emotional (e.g., anxiety) comorbidities in children with ASD increase the risk of parents experiencing high stress and psychological distress (Enea & Rusu, 2020; Huang et al., 2014; Kurtz, Strohmeier, Becraft, & Chin, 2021; Salomone et al., 2018; Yorke et al., 2018) and are closely related to lower parental QoL (Vasilopoulou & Nisbet, 2016), poor parenting efficacy (Kurzrok, McBride, & Grossman, 2021) and negative parent-child relationships (Hickey, Hartley, & Papp, 2020). Both (co--morbid) sensory processing disabilities and sleep problems in children with ASD have also been uniquely associated with higher parental stress and poorer parental mental health (Enea & Rusu, 2020; Johnson et al., 2018; Martin, Papadopoulos, Chellew, Rinehart, & Sciberras, 2019).

Demographic and contextual factors can also impact parental stress levels and mental health, although the evidence is somewhat mixed. While it has been reported that parents of older children with ASD have lower QoL than parents of younger children with ASD (Dey et al., 2019), observed age effects are often modest or negligible (Shepherd et al., 2021; Vasilopoulou & Nisbet, 2016; Yorke et al., 2018). Mothers have reported significantly greater stress and lower QoL than fathers in a number of studies (Enea & Rusu, 2020; Vasilopoulou & Nisbet, 2016), and a recent review suggested that being a young mother or father of a child with ASD was associated with high stress levels (Enea & Rusu, 2020). But parental gender and/or age differences are not always observed (Salomone et al., 2018; Shepherd et al., 2021; Yorke et al., 2018). Nevertheless, having a child with ASD can complicate personal relationships and may result in higher divorce rates (Karst & Van Hecke, 2012) and can also limit parents' professional activity (Smith et al., 2010), resulting in financial pressures through a loss of family income (Montes & Halterman, 2008). Low household income and lack of social support have been closely linked with high stress, poor mental health and low QoL in parents of children with ASD (Enea & Rusu, 2020; Raju et al., 2023; Salomone et al., 2018; Vasilopoulou & Nisbet, 2016; Yorke et al., 2018). Parents often face stigmatization which can further impact on parental wellbeing and ability to cope (Gill & Liamputtong, 2011).

Strategies aimed at the early detection and management of emotional behavioural problems in children with ASD can mitigate parental stress and improve mental health (Giovagnoli et al., 2015; Huang et al., 2014). A recent review of controlled trials of parent-focused interventions, which mostly included psychoeducation programmes, mindfulness, and acceptance and commitment therapy approaches (or a combination of these), indicated these interventions significantly reduce stress, psychological distress and depressive symptoms in parents (Li, Chien, Lam, Chen, & Ma, 2024). These approaches also can effectively reduce problematic and/or disruptive behaviours in children with ASD and improve parent-child relationships (Li et al., 2024; Postorino et al., 2017).

Generally, there is a lack of awareness and insufficient knowledge about ASD in Pakistan (Anwar, Tahir, Nusrat, Khan, & Khan, 2018). A recent study of the experiences of Pakistani mothers of children with ASD reported that 5 of 15 participants had not heard of the term "autism" before their child was diagnosed (Furrukh & Anjum, 2020). High levels of internalised subjective strain (e.g., perceived stress, feelings of worry, guilt and/or fatigue) are common in parents of ASD children in Pakistan, particularly mothers (Aftab, Pirani, Mansoor, & Nadeem, 2023). Further, approximately 40 % of children in Pakistan with ASD have sleep disorders (Baig, Mehdi, & Imtiaz Afzal, 2021), which internationally, have been associated with poorer parent mental health and higher parenting stress (Martin et al., 2019).

Cultural specificities concerning acceptance and understanding of ASD in Pakistan likely also play a role in parental stress and coping strategies. Disability in Pakistan is considered by some as a sign of punishment; families often hide individuals with disabilities in fearing of negative stigma associated with the disorder (Rathore, New, & Iftikhar, 2011). Studies suggest that parents who attribute their child's ASD to environmental factors (caused by something the child was exposed to after he/she was born) and/or experience emotional upset or confusion about ASD perceive the condition to be pervasive or burdensome (Haney, Houser, & Cullen, 2018). Such parental, familial and societal perceptions and stigmatization need to be considered when developing interventions as broader factors can influence the short- and long-term management of children with ASD (Raju et al., 2023). Therefore, a deeper understanding of the challenges faced by parents of children with ASD is needed to guide further research, intervention development, and clinical practice in Pakistan.

1.1. Aims

The primary objective of this study was to investigate parental distress and quality of life (QoL) in parents of children with ASD in Pakistan and their relationship with ASD-specific parental stress. The secondary objective of the study was to identify associations of parental socio-demographic factors (including gender, age and education level) and characteristics of ASD child(ren) with perceived distress and QoL. We hypothesized that parents would report high levels of parental stress and poor levels of psychological health and social relationships (relative to population norms), and that these would be more marked in parents of children with severe (core) ASD

symptoms and/or comorbid problems. More generally, the study intended to raise awareness of the specific difficulties faced by such parents in Pakistan and provide a benchmark on which to plan services aimed at reducing parental distress, improve their QoL and consequently help parents to meet the needs of their child and their family.

2. Methods

2.1. Setting and participants

This cross-sectional study of parents of children diagnosed with ASD over a two-year period (1.1.2019–31.1.2021) was conducted in the Department of Psychiatry and Behavioral Sciences at Faisalabad Medical University, Pakistan. Parents were recruited based on convenience sampling. The sample comprised parents attending the university hospital for evaluation and management of their child with ASD during the study period. All participants were Pakistani citizens, resident in the Punjab area, a parent caring for one or more children aged below 18 years with a confirmed diagnosis of ASD according to Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) criteria (American Psychiatric Association, 2013), and willing to participate. Participating parents who indicated an interest in receiving mental health support were offered access to stress management services.

2.2. Materials and procedure

For each participant, socio-demographic information, including level of education and marital and employment status, was requested. Data pertaining to their child or children with ASD, such as age of ASD diagnosis, severity level of ASD, and daily screen time, were also collected. Severity of ASD was determined by thorough assessment, behavioural observation and clinical evaluation on the basis of DSM-5 criteria, domains of the childhood autism rating scale (Schopler, Reichler, & Renner, 2010) and symptoms reported by the parents.

The World Health Organization's Self-Reported Questionnaire (SRQ-20) (Beusenberg, Orley, & Organization, 1994; Harding et al., 1980) was administered to measure levels of psychological distress in parents. The 20 items are scored in a binary manner (0 = 'no', symptom absent; 1 = 'yes', symptom present) and summed to yield a total score. A score above or equal to a widely used cut-off point of 8 indicates the existence of a probable mental disorder. Four factors have previously been suggested to describe different symptom groups in the SRQ-20: depressive thoughts, somatic symptoms, reduced energy, and depressive thoughts (Iacoponi & de Jesus Mari, 1989). The SRQ-20 has been used in community-based research in many low-resource settings as a screening tool for mental distress (Beusenberg et al., 1994) including urban Pakistani populations, with satisfactory observed sensitivity (80.0 %) and specificity (85.4 %) for detecting depression (Husain, Creed, & Tomenson, 2000) and acceptable internal consistency (Cronbach's alpha = 0.70) (Malik, Cheema, & Hussein, 2021).

Stress levels specific to parenting a child with ASD was assessed using the Autism Parenting Stress Index (APSI) (Silva & Schalock, 2012). This 13-item measure asks respondents to rate the level of stress related to various aspects of their child's health including ability to communicate, aggressive behaviours, and diet and sleep problems. Each item is scored on a 5-point Likert scale: 0 = 'Not stressful at all'; 1 = 'Sometimes creates stress'; 2 = 'Often creates stress'; 3 = 'Very stressful on a daily basis'; and 5 = 'So stressful sometimes we feel we can't cope'. The measure yields an overall parental stress scale and three subscales that measure stress levels specific to core autism symptoms, comorbid behaviours and comorbid physical issues, with higher scores on each indicative of greater levels of stress. The APSI has good psychometric properties (e.g., internal consistency (Cronbach's alpha) of overall scale = 0.83; four-month test-retest reliability = 0.88) (Silva & Schalock, 2012).

The World Health Organization's Quality of Life Brief Version (WHOQOL-BREF) (WHOQOL Group, 1998) was used to examine participants' quality of life (QoL). This self-reported questionnaire includes 24 items concerned with QoL across four domains: physical, psychological, social relationships and environmental. Items are rated on a 5-point Likert scale (low score of 1 to high score of 5) to determine a raw item score, which is transformed into a scaled score (0−100), with higher scores representing better QoL and a score of 50 indicative of QoL that is neither good nor poor (Skevington, Lotfy, & O'Connell, 2004; World Health Organization, 1996). The WHOQOL-BREF was designed with the intent to use across different cultures and has satisfactory psychometric properties across domains - internal consistency (Cronbach's alpha) of overall scale across country sites in international field trial (Skevington, Lotfy, & O'Connell, 2004): physical health = 0.55–0.88, psychological = 0.73–0.89, social relationships = 0.51–0.77 and environment = 0.65–0.87; 2–8 week test-retest reliability in original validation study (WHOQOL Group, 1998): physical health = 0.66, psychological = 0.72, social relationships = 0.76 and environment = 0.87.

For each participant, written informed consent was obtained after a complete debriefing of the purpose and procedure of the research in line with the ethical procedural requirements of the hospital site. Participants who were able to read and write completed self-administered scales as per standard while interview methods were used to elicit responses for patients who could not read and write. Ethical approval for the study was granted by the Academic Excellence Institute, Faisalabad (Reference number: 575). This study was registered with the Research and Development department at South West London and St George's Mental Health NHS Trust, London, United Kingdom.

2.3. Statistical analysis

Socio-demographic and ASD child(ren) data are presented as frequencies (%) while scale scores are presented using means (SD) with frequencies (%) provided to indicate the proportion of participants scoring above established cut-off points. Reliability (internal

consistency) of the questionnaire measures was calculated using a reliability coefficient (Cronbach's alpha). WHOQOL-BREF scores were formally compared with those observed in a recent (general) population-based study in Pakistan (Lodhi et al., 2019); comparisons were stratified by gender given female and male scores significantly differed on 3 of the 4 domains in the population-based study. Associations between different scale scores and between scale scores and socio-demographic/ASD child(ren)-related variables were analysed using Pearson product moment correlations and independent-group t-tests/analysis of variance (ANOVA), respectively. In the small number of analyses where continuous variables (in comparison groups) did not approximate a Gaussian distribution (according to skewness and kurtosis estimates - acceptable range between −1 and +1 and −1.5 and + 1.5, respectively (Hair, Anderson, Tatham, & Black, 1998)), bias corrected and accelerated bootstrapping using 2000 replications was employed. Where significant differences in group comparisons were observed, effect sizes (Cohen's *d*) were calculated; effect sizes were considered as small (d=0.2), medium (d=0.5), and large (d=0.8) based on benchmarks indicated by Cohen (1988). Statistical analyses were completed with SPSS (IBM, Version 26.0) with a criterion for statistical significance set at $p < 0.05$.

3. Results

Tables 1 and 2 respectively demonstrate the socio-demographic data of parents who participated in this study and relevant details of their child (or children) with ASD. Most participants were female, more than three-quarters were aged between 31 and 40 years and almost all were married. About a third were employed, although close to 60 % were educated at a tertiary level. Almost 80 % (78.6 %) of children with ASD of the parents in the study were aged (and received an ASD diagnosis at) less than 5 years and had ASD that was either mild or moderate in severity. Reported daily screen time of children with ASD varied widely across the sample, with more than a

Table 1
Sociodemographic data of parents of autistic children (n = 103). Values represent frequency (percentage).

Male/Female	23 (22.3) / 80 (77.7)
Age	
≤30 years	13 (12.6)
31-40 years	76 (73.8)
41-50 years	12 (11.7)
> 50 years	2 (1.9)
Marital status	
Married	93 (90.3)
Single	3 (2.9)
Separated	4 (3.9)
Divorced	2 (1.9)
Widowed	1 (1.0)
Location of residence	
Faisalabad	78 (76.5)
Other	24 (23.5)
Length of relationship	
≤10 years	74 (71.8)
11-20 years	26 (25.2)
21-30 years	2 (1.9)
> 30 years	1 (1.0)
Family system of care	
Nuclear	45 (43.7)
Joint	58 (56.3)
Employed	33 (32.4)
Spouse employed	73 (70.9)
Level of education	
Illiterate	4 (3.9)
Middle	10 (9.7)
Matric	9 (8.7)
Partial intermediate	4 (3.9)
Complete intermediate	16 (15.5)
College or university graduate	60 (58.3)
Number of children	
1-3	83 (80.6)
4-6	16 (15.5)
> 6	4 (3.9)
Multiple children with ASD	24 (23.3)

Note: For Location of residence, data was unavailable for one participant; For Employed, data was unavailable for one participant. With respect to Level of education, Matric is equivalent to General Certificate of Secondary Education (GCSE) in the United Kingdom (UK) and General Educational Development (GED) in the United States of America (USA) while intermediate is equivalent to Advanced level (A-level) qualifications in the UK and Advanced Placement (AP) in the USA.

Table 2
Data concerning the autistic children of participating parents (n = 103). Values represent frequency (percentage) unless otherwise stated.

Age of child with ASD	
< 6 years	81 (78.6)
6-12 years	22 (21.4)
Birth order of child with ASD	
1st-3rd	93 (90.3)
4th-6th	8 (7.8)
> 6th	2 (1.9)
Severity level of ASD	
Mild	33 (32.0)
Moderate	58 (56.3)
Severe	12 (11.7)
Suspected age of child when ASD emerged	
2-5 years	95 (93.2)
≥ 6 years	7 (6.8)
Age of child when ASD was diagnosed	
≤5 years	85 (82.5)
> 5 years	18 (17.5)
Daily screen time of autistic child	
Up to 1 h	39 (37.9)
2 h	22 (21.4)
3 h	12 (11.7)
More than 3 h	30 (29.1)
Other (comorbid) problem	42 (40.8)
Comorbid medical problem	19 (18.6)

Note: For Suspected age of child when ASD emerged, data were unavailable for one participant; For Comorbid medical problem, data were unavailable for one participant.

third indicating screen time of up to one hour only while about 30 % reported more than 3 h of screen time each day. More than 40 % of children with ASD had another problem (in addition to ASD) and one in five had a comorbid medical problem.

The mean values for QoL domains of parents of children with ASD are shown in Table 3. Scores suggested poor levels of psychological health and social relationships relative to population norms; both female and male scores were markedly lower than those in a recent (general) population-based study in Pakistan (Lodhi et al., 2019), reflecting medium or large sized effects depending on gender and specific domain. Conversely, survey participants' mean (SD) environmental health levels were higher than those observed in the general population study, particularly in participating males (d=0.70). Reliability (internal consistency) of each the four health domains (Physical α = 0.72, Psychological α = 0.71, Social relationships α = 0.54, Environmental α = 0.81) was consistent with those obtained across country sites in the international field trial (Skevington et al., 2004).

SRQ-20 scores suggested that, overall, there were moderate distress levels in parents of children with ASD (Table 4); almost 60 % (n = 61, 59.2 %) of participants scored 8 or more in total, which is the cut-off value most widely adopted to indicate a probable mental disorder. The majority of parents also expressed marked levels of stress specific to parenting a child (or children) with ASD on the APSI; almost 70 % (n = 71, 68.9 %) recorded total APSI scores ≥ 34, more than 1 SD higher than mean of the parents of children with autism in the APSI validation study (Silva & Schalock, 2012). The mean prevalence of stress responses across questionnaire items (determined

Table 3
Quality of life (QoL) in male and female parents of autistic children (n = 103) compared to values from the adult Pakistani general population.

	Mean (SD)	Response range	Norm mean (SD)	t	p	d
WHOQOL-BREF						
Physical health (0-100)	62.0 (13.7)	25-100				
Female	61.4 (13.2)	31-94	63.5 (14.7)	-1.24	0.216	-0.14
Male	64.0 (15.1)	25-100	66.4 (15.5)	-0.74	0.462	-0.15
Psychological health (0-100)	54.3 (14.7)	19-88				
Female	**52.5 (13.6)**	**19-81**	**66.0 (15.1)**	**-7.75**	**< 0.001**	**-0.90**
Male	**60.5 (17.0)**	**19-88**	**68.7 (14.7)**	**-2.64**	**0.009**	**-0.56**
Social relationships (0-100)	64.4 (15.2)	19-100				
Female	**64.7 (14.5)**	**19-100**	**71.3 (17.0)**	**-3.38**	**< 0.001**	**-0.39**
Male	**63.4 (17.6)**	**31-94**	**72.4 (15.8)**	**-2.70**	**0.007**	**-0.57**
Environmental health (0-100)	62.3 (14.4)	25-100				
Female	**61.2 (14.0)**	**25-100**	**54.8 (15.0)**	**3.69**	**< 0.001**	**0.43**
Male	**66.2 (15.3)**	**31-100**	**56.0 (14.5)**	**3.33**	**< 0.001**	**0.70**

Note: WHOQOL-BREF = World Health Organization's Quality of Life instrument (26-item version); Raw WHOQOL-BREF subscales scores were transformed into a linear scale of 0 to 100 (where 0 is the minimum satisfactory value and 100 is the maximum value); Norm mean values were extracted from those observed in a recent (general) population-based study in Pakistan (Lodhi et al., 2019). SD = standard deviation; d = Cohen's d. Significant associations are emboldened.

Table 4
Quality of life (QoL) and perceived (di)stress in parents of autistic children ($n = 103$).

	Mean (SD)	Response range
Self-Reporting Questionnaire-20 (0-20)	8.3 (4.4)	0-20
Depressive/anxious (0-4)	1.7 (1.1)	0-4
Somatic symptoms (0-6)	2.3 (1.5)	0-6
Reduced vital energy (0-6)	2.9 (1.7)	0-6
Depressive thoughts (0-4)	1.4 (1.3)	0-4
Autism Parenting Stress Index (13-65)	39.7 (10.2)	19-61
Core autism symptoms (5-25)	17.7 (4.7)	8-25
Comorbid behaviours (4-20)	11.6 (4.5)	4-20
Comorbid physical issues (4-20)	10.4 (3.9)	4-20

Note: SD = standard deviation.

by the percentage of item responses at ''Often Creates Stress'' or higher) (Silva & Schalock, 2012) was 78.4 % (SD=15.8). At the factor level, the mean prevalence of stress responses was 90.5 % around core autism behaviours, 76.5 % around comorbid behaviours and 65.3 % around comorbid physical problems. Responses on both the SRQ-20 ($\alpha = 0.80$) and the APSI ($\alpha = 0.80$) showed satisfactory internal consistency.

Both physical and psychological health were reliably associated with ASD parental stress, although the magnitude of correlations was modest (Table 5). Stress levels specific to comorbid behaviours - rather than core autism symptoms - were significantly linked to reported physical and psychological health. However, parenting stress specific to core and comorbid symptoms of autism were significantly associated with (total) levels of mental distress, as measured by the SRQ-20, with the strongest associations between stress concerning core autism symptoms and reduced vital energy and between comorbid physical issues and reduced vital energy/ depressive thoughts.

Mothers experienced worsened psychological health (d=−0.56) and greater levels of mental distress than fathers (d=0.51; Table 6). Almost two-thirds of women ($n = 52$ or 65.0 %) scored above the SRQ-20 cutoff point compared with only 39.1 % (n = 9) of men ($p = 0.026$). Post-hoc comparisons of SRQ-20 subscale scores revealed significantly higher levels of depressive thought in women (Mean (M)= 1.6, SD= 1.3) compared with men (M=0.9, SD=1.0; $p = 0.015$, d=0.65). Quality of social relationships was significantly better in individuals with higher levels of education (versus educated up to matric, d=0.66; versus educated at intermediate level, d=0.31), but worse in those who were employed (relative to not employed; d=−0.46). The latter effect was driven largely by differences between women who were employed ($n = 19$, M=57.9, SD=16.4) and women who were not employed ($n = 60$, M=67.1, SD=13.2; $p = 0.015$, d=−0.57) rather than in men (Employed $n = 14$, M=63.0, SD=20.0; Not employed $n = 9$, M=64.0, SD=14.2; $p = 0.898$).

Across all QoL domains, parents of younger ASD child(ren) reported, on average, better health, although only social relationships (d=0.60) and environmental health (d=0.67) were significantly affected (Table 7). Parents of children with severe ASD reported numerically poorer health and higher stress but differences across severity groups were not significant (although there was a trend for differences on the APSI according to severity of ASD ($p = 0.078$). The number of children with ASD did not significantly impact on parental health or (dis)stress levels and there was no evidence to suggest daily screen time of the ASD child(ren) was significantly associated with outcomes. Parents of ASD children with a comorbid health problem reported poorer physical (d=−0.52) and psychological health (d=−0.66) than parents of ASD children without (Table 7). Further, autism-specific parental distress was significantly higher in those parents whose child had a comorbid medical problem compared with those who did not (d=0.60); post-hoc comparisons indicated elevated stress in comorbid behaviours (M=13.6, SD=4.7 versus M=11.1, SD= 4.4; $p = 0.027$, d=0.57) and comorbid physical issues (M=12.1, SD=4.7 versus M=10.1, SD= 3.7; $p = 0.043$, d=0.52) subscales.

Table 5
Relationship (Pearson r) of parenting stress specific to core and comorbid symptoms of autism with quality of life and perceived distress in parents of autistic children ($n = 103$).

	APSI Total	Core autism symptoms	Comorbid behaviours	Comorbid physical issues
WHOQOL-BREF				
Physical health	**-.30** * *	-.16	**-.29** * *	**-.25** *
Psychological health	**-.24** *	-.14	**-.28** * *	-.12
Social relationships	-.03	.06	-.06	-.07
Environmental health	-.12	-.04	-.17	-.08
Self-Reporting Questionnaire-20	**.27** * *	**.23** *	**.22** *	**.20** *
Depressive/anxious	.13	.13	.15	.01
Somatic symptoms	**.21** *	. 16	.19	.15
Reduced vital energy	**.25** *	**.21** *	.17	**.20** *
Depressive thoughts	**.22** *	.15	.17	**.22** *

Note: APSI = Autism Parenting Stress Index; WHOQOL-BREF = World Health Organization's quality of life instrument (26-item version); Significant associations are emboldened; *p < 0.05, * *p < 0.01.

Table 6
Quality of life (QoL) and perceived (di)stress in parents of autistic children according to sociodemographic characteristics ($n = 103$).

	WHOQOL-BREF				SRQ-20 Total	APSI Total
	Physical health	Psychological health	Social relationships	Environmental health		
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Gender						
Female ($n = 80$)	61.4 (13.2)	**52.5 (13.6)**	64.7 (14.5)	61.2 (14.0)	**8.8 (4.4)**	39.7 (10.7)
Male ($n = 23$)	64.0 (15.1)	**60.5 (17.0)***	63.4 (17.6)	66.2 (15.3)	**6.6 (4.0)***	39.7 (8.2)
Age						
≤ 30 years ($n = 13$)	59.6 (14.7)	50.6 (11.0)	64.9 (19.2)	61.2 (16.3)	9.6 (5.4)	44.6 (12.2)
31-40 years ($n = 76$)	62.3 (13.2)	54.7 (15.1)	64.2 (14.4)	62.7 (13.2)	8.3 (4.4)	39.1 (9.7)
> 40 years ($n = 14$)	62.6 (15.6)	55.4 (15.8)	64.8 (16.2)	61.2 (19.3)	7.5 (3.6)	38.5 (10.5)
Length of relationship						
≤ 10 years ($n = 74$)	62.8 (14.6)	55.6 (14.1)	65.0 (13.5)	63.9 (14.3)	7.8 (4.6)	39.3 (10.4)
> 10 years ($n = 29$)	60.1 (10.8)	51.0 (15.9)	62.8 (18.9)	58.2 (14.1)	9.6 (3.5)	40.9 (9.6)
Family system of care						
Nuclear ($n = 45$)	60.7 (13.4)	54.3 (13.4)	66.0 (13.9)	61.5 (14.0)	9.0 (3.7)	40.0 (10.4)
Joint ($n = 58$)	63.1 (13.9)	54.3 (15.8)	63.2 (16.1)	62.9 (14.7)	7.8 (4.8)	39.5 (10.1)
Employment status						
Employed ($n = 33$)	60.9 (12.9)	55.4 (16.6)	**60.1 (17.9)**	60.4 (16.4)	8.9 (4.5)	39.2 (8.4)
Not employed ($n = 69$)	62.6 (14.2)	54.1 (13.6)	**66.7 (13.3)***	63.6 (12.8)	8.0 (4.4)	40.2 (10.9)
Level of education						
Up to Matric ($n = 23$)	59.7 (14.7)	50.5 (16.1)	**58.4 (18.2)**	57.4 (17.1)	8.0 (3.5)	41.1 (10.3)
Partial/Complete intermediate ($n = 20$)	62.4 (13.2)	54.4 (16.3)	**62.2 (17.3)**	66.8 (17.2)	7.2 (3.8)	41.8 (10.7)
College/university graduate ($n = 60$)	62.8 (13.5)	55.8 (13.6)	**67.4 (12.4)***	62.7 (11.7)	8.8 (4.9)	38.5 (10.0)
Number of children						
1-3 ($n = 83$)	62.6 (14.1)	54.9 (14.4)	64.7 (14.5)	62.5 (14.6)	8.2 (4.6)	39.9 (10.1)
4 or more ($n = 20$)	59.5 (11.5)	52.0 (16.1)	63.2 (18.2)	61.4 (13.8)	8.8 (3.4)	39.1 (10.8)

Note: WHOQOL-BREF = World Health Organization's Quality of Life instrument (26-item version); SRQ-20 = Self-Reporting Questionnaire-20; APSI = Autism Parenting Stress Index. Group comparisons were administered using independent-group *t*-tests or one-way analysis of variance; *n* values across questionnaire subscales are slight variable due to a very small number of missing item response data. Significant differences are emboldened; *p < 0.05, * *p < 0.01.

4. Discussion

Several globally recognized instruments were used in this study to gather data about Pakistani parents' QoL, stress levels and mental health. Overall, the results are consistent with evidence that parental QoL, mental health and overall wellbeing is negatively impacted as a result of parenting a child with ASD (Bonis, 2016; Karst & Van Hecke, 2012; Vasilopoulou & Nisbet, 2016).

This study suggests caring for a child with ASD in Pakistan has a significant negative impact on mental health and social relationships. The impact on parental psychological health is well documented in the international literature and these results add to this evidence base (Martin et al., 2019; Yorke et al., 2018). Self-rated psychological health on the WHOQOL-BREF was poorer than physical health, in line with findings from a recent study of parents of ASD children in India (Raju et al., 2023), and was the most affected domain. This signals that parental ability to enjoy life, feel they have a meaningful life and experience satisfaction with self are all specifically affected. A significant proportion of parents reported experiencing marked levels of stress, with 60 % scoring highly enough to indicate a probable mental health disorder. Psychological distress was more prevalent in mothers than fathers, drawing parallels with recent findings in an urban setting in Pakistan of higher levels of internalized subjective strain in female than male caregivers of children with ASD, the authors attributing this to feelings of worry, guilt, and fatigue which mothers experience while attempting to fulfil responsibility as part of their gender-role in Pakistani culture (Aftab et al., 2023).

Consistent with previous work internationally (Enea & Rusu, 2020), our data indicate that parents in Pakistan experience poorer physical and psychological health and higher levels of psychological distress when they experience parental stress. Stress levels around their child's core features of autism were significantly associated with reduced energy levels while elevated stress levels concerning their child's comorbid physical symptoms (e.g., bowel and dietary problems) was linked to poorer overall physical health, reduced

Table 7
Quality of life (QoL) and perceived (di)stress in parents of autistic children according to profile of their child/children ($n = 103$).

	WHOQOL-BREF				SRQ-20 Total	APSI Total
	Physical health	Psychological health	Social relationships	Environmental health		
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Age of child with ASD						
< 6 years ($n = 81$)	62.8 (14.5)	54.5 (15.1)	**66.3 (14.0)**	**64.3 (14.0)**	8.4 (4.5)	40.0 (10.3)
6-12 years ($n = 22$)	59.1 (9.4)	53.5 (13.3)	**57.5 (17.5)***	**55.0 (13.7)*** *	8.1 (4.0)	38.5 (9.9)
Severity level of ASD						
Mild ($n = 33$)	62.3 (13.7)	52.6 (13.7)	64.4 (14.6)	62.6 (14.4)	9.7 (4.6)	40.0 (10.2)
Moderate ($n = 58$)	62.1 (13.4)	55.6 (14.6)	65.1 (15.8)	63.4 (14.7)	7.8 (4.2)	38.3 (9.8)
Severe ($n = 12$)	61.1 (15.8)	52.6 (18.6)	61.0 (14.1)	55.8 (11.6)	7.5(4.2)	45.6 (10.6)
Screen time of autistic child						
1 h ($n = 39$)	64.4 (13.0)	58.5 (13.6)	67.1 (12.9)	65.6 (12.3)	7.8 (5.0)	40.9 (10.5)
2 h ($n = 22$)	62.3 (14.2)	51.0 (14.6)	61.1 (17.1)	57.5 (18.4)	8.6 (4.5)	37.8 (10.3)
3 + hours ($n = 42$)	59.7 (13.9)	52.2 (15.2)	63.5 (15.9)	61.7 (13.3)	8.6 (3.7)	39.7 (9.9)
Other (comorbid) problem						
Yes ($n = 42$)	63.3 (12.6)	53.5 (15.4)	61.5 (14.4)	61.2 (14.9)	7.8 (3.6)	38.6 (9.3)
No ($n = 61$)	61.2 (14.3)	54.9 (14.3)	66.4 (15.4)	63.0 (14.1)	8.6 (4.9)	40.5 (10.7)
Comorbid medical problem						
Yes ($n = 19$)	**56.3 (14.9)**	**46.5 (17.5)**	66.8 (16.1)	58.9 (17.8)	9.6 (4.3)	**44.7 (10.6)**
No ($n = 83$)	**63.3 (13.2)***	**56.0 (13.6)***	64.0 (15.0)	63.3 (13.3)	8.1 (4.4)	**38.7 (9.8)***
Multiple children with ASD						
Yes ($n = 24$)	62.9 (14.5)	56.9 (13.0)	60.2 (17.7)	60.3 (15.9)	7.2 (4.0)	36.7 (10.2)
No ($n = 79$)	61.8 (13.5)	53.5 (15.2)	65.7 (14.2)	62.9 (13.9)	8.6 (4.5)	40.6 (10.1)

Note: WHOQOL-BREF = World Health Organization's Quality of Life instrument (26-item version); SRQ-20 = Self-Reporting Questionnaire-20; APSI = Autism Parenting Stress Index. Group comparisons were administered using independent-group *t*-tests or one-way analysis of variance; *n* values across questionnaire subscales are slight variable due to a very small number of missing item response data. Significant differences are emboldened; *p < 0.05, * *p < 0.01.

energy levels and experiencing depressive thoughts. In contrast to expectations and previous studies (Batool & Khurshid, 2015; Enea & Rusu, 2020; Rivard et al., 2014; Salomone et al., 2018; Vasilopoulou & Nisbet, 2016), however, severity of child ASD symptoms or presence of comorbid (behavioural and/or emotional) problems in children was not directly associated with parental health or psychological distress levels. It is possible that the impact of ASD symptom severity and comorbid behavioural and/or emotional problems on parental mental health is, to some extent, mediated via perceived stress; as such, interventions and support services may be more effective by targeting parenting stress and the child-parent relationship rather than exclusively focussing on the child's symptom profile (Shepherd et al., 2021).

In addition to impacting on parental psychological health, social relationships are also adversely affected by having a child with ASD. Raising a child with ASD can be hugely challenging for parents affecting everyday family life and evidence suggests that parents can experience marital difficulties, lower satisfaction with their marriage and exhibit poorer adjustment (White, McMorris, Weiss, & Lunsky, 2012). The strain of having a child with ASD can lead to higher divorce rates in parents (Karst & Van Hecke, 2012), and this study highlights that overall satisfaction with personal relationships and sex life is negatively affected. The present study suggests that parents who have an older child with ASD (6–12 years) are more likely to experience a detrimental impact on their social relationships and environmental health. Lower QoL in parents of older mentally ill children relative to parents of younger children has previously been found in a meta-analysis (Dey et al., 2019). It is possible the strain of having a child with ASD becomes more apparent as the child gets older, and over time, parental ability to cope reduces and their social relationships suffer, particularly when their child's ASD symptoms persist and further problems develop (Dey et al., 2019; Karst & Van Hecke, 2012).

Parents who have children with ASD demonstrated increased QoL in the environmental health domain relative to population norms in Pakistan. Parents reported higher levels of comfort in their physical environment, financial situation, access to information and opportunity to access leisure activities. This contrasts with existing evidence suggesting that parents of children with ASD may have limited professional activity and therefore face financial pressures (Montes & Halterman, 2008; Smith et al., 2010). It is likely, at least in part, this reflects that most participants (60 %) were college/university graduates, and therefore, belong to a higher social class subset of Pakistani society who may be more financial stable. Further information regarding families' financial stability and background was not obtained so it is difficult to draw definitive conclusions based on the data alone.

Comorbid conditions, both behavioural and physical, are common in children with ASD (Klukowski, Wasilewska, & Lebensztejn, 2015; Mazurek & Sohl, 2016), and as evidenced here, compound parental stress, potentially posing additional burden and/or strain on parents. Parents' physical and psychological health was worse in those caring for a child with ASD who also had one or more comorbid problems. As previously noted, learning disabilities, sensory processing disorders and sleeping problems can pose additional challenges on caregiving and uniquely contribute to perceived stress and poor mental health (Enea & Rusu, 2020; Martin et al., 2019). A holistic multidisciplinary approach is required to ensure that comorbid difficulties of children with ASD are detected early so that they can be adequately managed. It can be difficult to determine whether the comorbidities are intrinsically linked to ASD and is challenging to disentangle in such children who often have a complex clinical presentation.

5. Strengths and limitations

To our knowledge, this is one of the few studies to date exploring parental stress and QoL in parents of children with ASD in Pakistan. As such, this information fills an important knowledge gap in the literature. This study used three different globally accepted instruments to collect data in a robust sample of more than 100 parents of children diagnosed with ASD over a period of one year, which adds to the reliability and validity of the results.

Nevertheless, there are some limitations. For example, this study did not consider whether children were prescribed any psychotropic medications. This information and parental perceptions of its impact is potentially important (Mumtaz, Fatima, & Saqulain, 2022). Also, the influence of socio-cultural stigma on parental stress, psychological distress and QoL of parents of children with ASD in Pakistan is likely to be important (Furrukh & Anjum, 2020). For example, in India, lack of knowledge and acceptance by the community can serve as obstacles to appropriate care and precipitate emotions of self-blame, guilt, and social humiliation in parents (Jain et al., 2019; Raju et al., 2023). The instruments used here did not explore the impact of cultural taboos on parents, however. Parents of children with diagnosed comorbid medical conditions reported greater stress levels than those of children without, but the specific comorbid conditions were not investigated. Further, children with ASD often have comorbid conditions and dual diagnoses; the extent to which these affect parental stress levels and QoL independently and/or interactively with ASD remains largely unexplored, and further studies specifically examining this would be beneficial. Low socioeconomic status may limit parents' ability to meet the demands of the family and (child and parent) access to health services (Raju et al., 2023; Vasilopoulou & Nisbet, 2016), and information concerning family income was also not collected here. Finally, the relatively small sample size of some groups in comparisons of parental stress and QoL according to characteristics of parents (e.g., men) and clinical aspects of their children (e.g., severe ASD, presence of a comorbid medical problem) underscores the need to exercise caution in interpreting and generalising observed results.

6. Implications for practice

In Pakistan, there is limited understanding of ASD in addition to socio-cultural stigmatization of the condition, which can increase caregiving-related stress in parents (Anwar et al., 2018). The potential impact on parents and families is generally underestimated (Aftab et al., 2023). This is reflected in a lack of peer-reviewed published material from Pakistan, which compromises awareness of the impact of caring for a child with ASD on parents, the specific drivers of poor mental health and psychological distress, and methods to help alleviate these (Ashraf et al., 2022). The present study demonstrates the significant psychological burden and strain placed on parents and provides a benchmark on which further studies and clinical practice can be guided. From this view, the results add to the limited literature in this area from Pakistan by providing detailed evidence of the specific nature of the impact that having a child with ASD has on parental mental health. More broadly, it reinforces recent calls for greater awareness and acceptance of ASD in Pakistani society and the need to implement caregiver screening and management services specifically targeting parental well-being in families with a child with ASD (Aftab et al., 2023; Furrukh & Anjum, 2020). Interventions set up to improve parental mental health and well-being are also likely to have a positive effect on the child with ASD.

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Data availability

Data will be made available on request.

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