



CENTRE FOR AUTISM
MIDDLETOWN

Stress and Coping for Caregivers



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INTRODUCTION

This is the twenty-eighth Research Bulletin produced by Middletown Centre for Autism and it provides summaries of eleven articles spanning 2014–2018.

The Bulletin commences with an interview with Dr. Lenny Thornton.

Dr. Lenny Thornton MB ChB, FRCPsych is a consultant child and adolescent psychiatrist at the Cheshire Autism Diagnostic Service in the UK. He qualified in medicine from Glasgow University. His general psychiatry training and specialist child and adolescent psychiatry training were carried out in Manchester. Lenny has over 30 years' experience as a consultant child and adolescent psychiatrist and has held consultant posts in adolescent psychiatry, adolescent forensic psychiatry and general

child psychiatry. He was also clinical director for CAMHS and Learning Disability CAMHS in Cheshire. Since 1996, Lenny has worked as a clinician in the field of autism. He has set up and developed autism diagnostic services in the NHS and the independent sector. Lenny has lectured nationally and internationally on autism, related neurodevelopmental conditions and co-morbid mental health disorders. Lenny is also the parent of a son with Asperger's syndrome who lives independently and works as a freelance journalist.

Please note that the views represented in this document do not necessarily reflect the views of Middletown Centre for Autism. Reviewers have, where possible, used the original language of the article, which may differ from UK and Ireland usage and the usage of a range of terminologies for autism.

AN INTERVIEW WITH DOCTOR LENNY THORNTON

1. Is parental stress a common occurrence among parents of children with autism?

Yes, they are particularly at risk of becoming psychologically stressed and one study, for example, found that nearly 40% experience clinically significant levels of parenting stress. The parents of children with autism also report significantly higher levels of mental health problems (e.g. anxiety and depression) and lower levels of well-being than parents of children with other developmental conditions and parents of typical developing children.

2. Why do parents of children with autism experience parental stress?

This can be due to a combination of several factors including:

- The severity of the child's autism and associated symptoms and behaviours: these contribute to parental stress by challenging their parenting abilities. This is particularly the case for aggression, self-injury, hyperactivity, tantrums, sleep disturbances, repetitive behaviours (especially those related to cognitive rigidity) and disinhibited social behaviours; however, the child's impaired level of functioning (e.g. self-care abilities) and other difficulties (e.g. sensory hyper-reactivity, atypical eating routines, anxiety, depression and dyspraxia) can all contribute to parenting stress. In addition, they do not get to experience the typical emotional and social responses that other parents take for granted and which help fuel a relationship.
- Difficulty accessing and negotiating with multiple professional systems: the pressure of trying to access a range of supports and interventions for your child is particularly stressful for parents. This stress increases significantly if the professional supports are not available at all. As a parent you often have to take on several new roles (e.g. therapist, multi-agency coordinator, advocate, negotiator and diplomat) as well as being Mum or Dad and that is both effortful and stressful.
- Limited family and friendship supports: it is not uncommon for parents to have less than expected levels of support from their wider family and friendship groups. There may be practical reasons for this (e.g. geographical isolation from the extended family); however, parental stress is also associated with having impaired support networks. A lack of knowledge about autism by family and friends may result in them criticising the parents' apparent lack of parenting skills and their child's behaviour. The parents may respond by actively withdrawing their family from social contacts and activities to avoid negative reactions from others. Unfortunately, this leads to further social isolation.
- Parental maladaptive coping strategies: parents may attempt to avoid addressing their child's difficulties by minimising, rationalising or denying them. Although these strategies initially appear to work, in the long-term they are maladaptive. Parents may ultimately be left feeling disempowered, perceiving themselves as being ineffective, and feeling more stressed.

- Ongoing worries about their child and their future: every parent of a child with autism has these concerns and they contribute significantly to chronic parental stress. The worries about your child include their ability to: cope with school, obtain qualifications, form friendships and relationships, look after themselves, obtain employment and live both independently and happily. Perhaps the biggest parental concern is, 'Who will take care of my child when we are no longer around?'

3. How does parental stress impact upon the wider family circle?

Parental stress can often lead to the relationship with your partner and your children becoming strained. In addition, it can contribute adversely to your efficacy as a parent and general family functioning. This is particularly the case if the child with autism is exhibiting significant behavioural and/or functioning difficulties (e.g. unpredictable physical aggression, severe hyperactivity and poor sleep pattern) at home. These problems can disrupt or constrain your family's daily routine, restrict their outside social activities and lead to the family becoming socially isolated.

Not uncommonly, there can also be a significant negative change in family life post-diagnosis and beyond. Parents may now have to attend frequent clinic and therapy appointments, multi-professional meetings and school meetings, etc. and be directly involved in intensive interventions. As a result, they may have to arrange childcare provision and take time off work. All these demands occur while the parents are simultaneously trying to manage the practical

day-to-day tasks of running a household and maintain the well-being of family life.

To cope with these increased demands on their time and other personal resources, some parents either have to reduce their working hours or stop working altogether. This places an increased financial burden on the family. Family earnings of children with autism are less than those of families who have children with other health limitations and those with children without health problems.

The siblings of the child with autism can also become affected. Over time they may become inadvertently promoted by the parents to a pseudo-parental role within the family to provide 'more hands to the pump' to help with tasks that would under normal circumstances be carried out by the parents. I often see this in families where extended family members or a wider social support network are not available to the parents.

As a result of the parents' focus understandably being on the child with autism, some siblings may feel that their own needs are being ignored and this can lead to feelings of resentment. Siblings of children with autism also report high rates of mental health problems (e.g. depression) and there is a risk that in the midst of all the family pressures these may go unrecognised.

4. Does stress limit parents from accessing opportunities which may support their social and emotional well-being?

Yes, it can, and it is not unusual for parents to battle on in the face of quite significant mental (and physical) health problems. Parents are often unaware of the high levels of chronic stress under

which they are working and hence do not consider the need to seek support; however, some parents may ignore, minimise or normalise their own stress symptoms ('I'm fine', 'It's nothing', 'Everybody gets stressed') and be reluctant to seek help. A parent may feel that they will let their child down if they 'go under'. In addition to the guilt about becoming stressed, the parent may feel ashamed to admit that they are not coping and require help.

This stoical approach, however, is counterproductive. Parents with high levels of stress are less effective at implementing autism intervention strategies and depressed parents tend to use less effective coping skills. All of which leads to further stress.

If the parent also has a restricted social network, this reduces their chances of seeking emotional support and advice from family and friends, which further amplifies their level of stress.

5. What should educational professionals and parents do if they identify signs of parental stress?

For parents, my advice would be to seek help sooner rather than later. The longer the symptoms of stress continue the longer it will take for them to resolve. The specific supports available will vary from area to area and will depend on your specific needs but usually include general practitioners, community mental health services and counselling services. You should have the opportunity to discuss your difficulties and have them fully assessed to establish: the nature of your symptoms (e.g. anxiety and depression), the causes of your stress and what is the most appropriate intervention.

For educational professionals who identify a stressed parent, I think this is potentially trickier and very much depends on the quality of the

relationship you have with the parent. Don't forget, school is often a major source of stress for parents and as a result they may be reluctant to take advice from you about their emotional well-being! Despite this difficulty, however, it is important that you give the parent an opportunity to express their feelings. It is important to acknowledge that parenting a child with autism can be stressful. Check how the parent is coping and feeling (you may also feel it appropriate to mention that they appear stressed), ask about any personal emotional supports they currently receive, and tell them about the availability of local supports (e.g. counselling and mental health services) and how to access them. This is also an opportunity to address specific school-based causes of the parent's stress. Sometimes just being there and listening to how the parent is feeling is the most important thing you can do. You may very well be the first person who has done that, and it may trigger the parent to acknowledge their own difficulties and need for help.

6. In your opinion is parental stress related to child stress?

If we consider emotional and behavioural problems in the child with autism to be proxy markers for child stress, then there is robust evidence from a recent meta-analysis study for their association with both parental stress and parental mental health problems. From the same study there is some evidence for bidirectional predictive relationships between child emotional and behavioural problems and parent psychological distress over time; however, to understand this temporal relationship better more well-powered longitudinal research is required.

It should also be remembered that there will be other reasons for the development of parenting stress, parental mental health problems and children's psychological problems. It is unlikely to

be a simple linear causative relationship; other environmental and genetic factors will play a role. For example, parents of children with autism have increased rates of mental health problems both before and after the child's birth. In addition, it is possible that children's and adult's mental health problems exacerbate each other.

7. As a parent, did you find there were certain ages or stages of your child's development where you experienced more stress than parents who do not have a child with autism?

The short answer is yes! It begins even before you have a formal diagnosis for your child but as a parent you have concerns that there is something not quite right about their development.

I suppose if I were to simplify the subsequent stages, I would say that the most stressful times were the transition points: starting primary school, transferring to high school and living away from home to go to university. After university, the next major transition was leaving home to live independently on a permanent basis.

As a parent, you plan well in advance, teach as many new practical skills as you think your child will need and draw up many contingency plans; however, you cannot cover every eventuality and crises will happen – but you become adept at thinking on your feet and winging it!

In some respects, the earlier transitions and phases were easier to cope with as they had clear end points that you could work toward with your child. Living independently as an adult is an ongoing stressor both for them and for the parents; however, it is important that you continue to support and work with your adult-aged child to help them achieve the best possible quality of life.

8. In your experience, what strategies and supports can help strengthen parents' resilience against stress?

There are several practical strategies that parents can use to develop their resilience. These include: actively seeking information about autism and interventions (information is power!), actively seeking a wide network of supports both formal (e.g. parent advocacy) and informal (e.g. friends), accessing resources (e.g. child therapy services) and acquiring therapeutic skills (e.g. behavioural management techniques).

In particular, it is important to have practical advice and supports which ease your day-to-day stresses. Other parents of children with autism are often the best at providing practical advice (e.g. how to manage bathing/showering problems) and contacts for local autism-friendly 'people who do' (e.g. dentists and hairdressers).

Use your informal support network of family and friends (a.k.a babysitters) to take time off from parenting duties. This is important. You need space to recharge your batteries, talk with your partner, and, yes, ... plan ... but that includes organising the good bits too. In among all these pressures it is important that you also have a positive family life. Shared family activities, trips out and holidays should not be ignored – you are allowed to experience all the joys, hassles and arguments that so-called normal families have!

In addition to all these proactive help-seeking behaviours and supports, it is important to remain positive and optimistic. This is not easy but it will pay off! All these approaches will help you develop and maintain your sense of empowerment, problem-solving skills and self-efficacy ... and reduce your stress.

9. How can educators best support parents of children with autism?

Firstly, ensure that education staff are trained to have an understanding of autism (that's why we need the Middletown Centres of this world).

Secondly, communicate and listen! Get that right and the rest is easy (or easier!). It is essential that educators both talk with and listen to the parents and the child with autism.

Ensure that the parents have a named contact person within school with whom they can discuss their child. This person should have sufficient seniority, autism knowledge base, regular contact with the child to allow an informed discussion of the child's progress and have the authority to implement any subsequent actions that are required within the school.

Work collaboratively with the parents and the child. Prewarn about and plan for any forthcoming changes and events in school, and in particular plan well in advance with the family for any major transitions (e.g. moving to high school). Written action plans should be provided for the family. Related to this, educators must know how to communicate with children using autism-friendly language, and any written information (e.g. behavioural targets) that is shared with the child must use language that is unambiguous and at the right level for them.

Ask the parents about the child's functioning at home and compare this with their school performance. This may help inform both school and parents on strategies that can be shared and implemented by both to ensure that parents and school are working in sync.

Give honest feedback on the child's progress; include positive achievements as well as

difficulties, be objective and avoid giving subjective opinions. Be honest and be realistic about what you can and cannot offer but also help the family identify what other resources may be available to support them and their child.

10. Are there any stress-management strategies that parents and professionals would benefit from incorporating into their everyday lives?

There are several stress-management approaches that are beneficial to everyone! In the ideal world we would use them all but even if you can only attempt one or two, they can help ease stress and improve your coping abilities.

Take control of your life! Prioritise the things you have to do, break big tasks into small, manageable bite-size pieces, set realistic time limits to complete the tasks and build in breaks.

Look after your physical health by (re)-establishing healthy routines: get enough sleep, eat as healthily as you can (there's nothing wrong with the occasional kebab and glass of wine – but do watch your alcohol intake!), increase your physical activity (you don't need to run 10K but just walking to the shops instead of taking the car is a start) and stop or cut down on smoking!

All of the above will help your mental health too, but also look at: building in time to relax (e.g. reading a book, listening to music or going on holiday), meeting with friends – don't lose contact with them (and try not to talk all the time about your kids – or even worse – their kids!), using relaxation techniques and mindfulness approaches (e.g. acceptance and breathing techniques) – they work! and keeping positive (yes, I know it's difficult but it does help).

11. Could greater autism awareness across the community and society diminish potential isolation and alleviate stress?

Yes, but we need to go beyond simply raising awareness. We need to educate the general public to increase their understanding of autism. Only then can we hope to reach the stage where society accepts those with autism, adapts to their needs and appreciates their strengths.

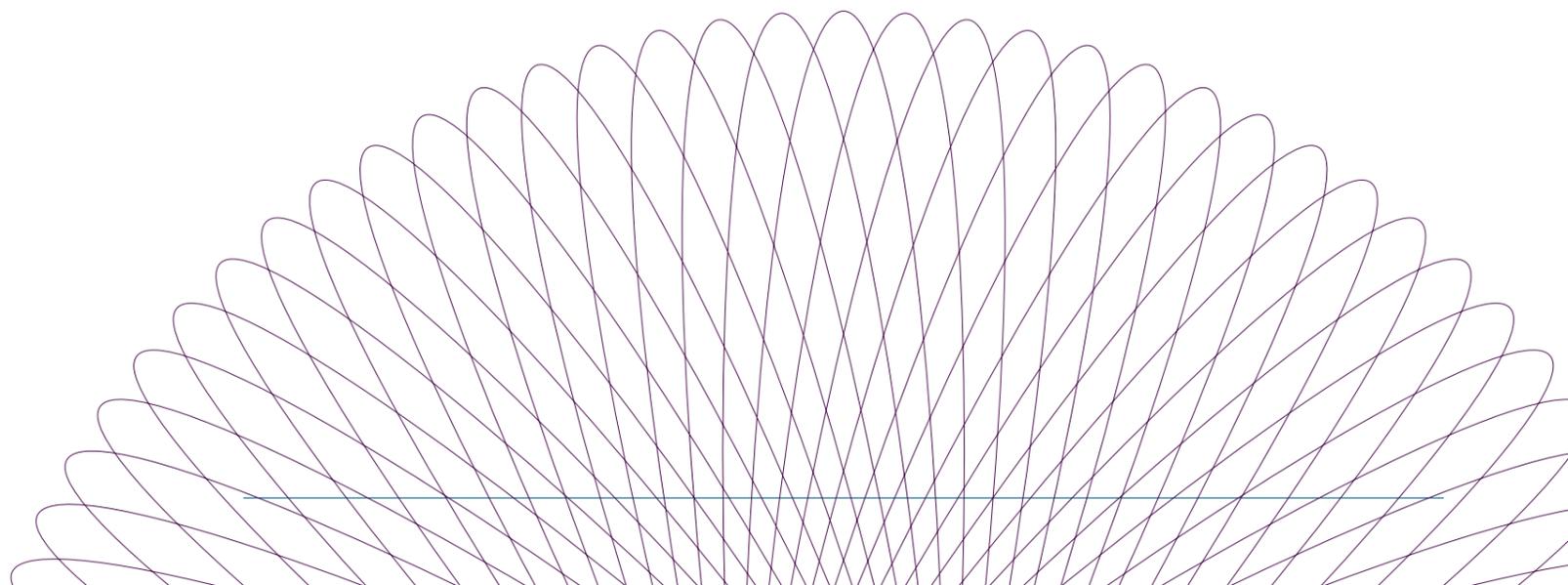
Autism is not an appendage but is part of the human condition. Children with autism have a right to be accepted for who they are and not what others want them to be. If we can develop autism-friendly environments where the child with autism is not stigmatised but accepted and valued, life becomes much less stressful and isolating for them and their whole family.

12. Can stress manifest physically and is this always recognised by the both the parent or medical professional?

Parents of children with autism often report psychological symptoms, physical complaints and low levels of health-related quality of life.

Parents under psychological stress can present with physical symptoms and signs. These can include: panic attacks, tiredness, disturbed sleep pattern, headaches, dizziness, nausea, changes in appetite and/or weight, indigestion, constipation and/or diarrhoea, muscular aches, chest pains and raised blood pressure. These physical manifestations of stress are not always recognised as being such by the parent, and it should be borne in mind that chronic stress can also have deleterious effects on physical health and parents may not be aware of this. This underlines the need for improved health education for parents.

Medical professionals should always be alert to the possibility that physical symptoms and signs may be due to psychological factors, and that physical ill health and mental health problems may co-occur. The possibility that one or both of these conditions is present requires careful assessment (including clinical history, physical examination, mental-state examination and relevant investigations) to clarify the diagnostic picture and the treatment approaches required.



PARENTING STRESS AND RESILIENCE IN PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER (ASD) IN SOUTHEAST ASIA: A SYSTEMATIC REVIEW

BACKGROUND

Psychological distress, stress and other health problems are frequently documented across studies exploring parents' experiences of raising a child with autism. Many studies identify that emotional and behavioural challenges correlate significantly with parental stress; however, the majority of these are focused in the Western world.

RESEARCH AIM

This paper systematically reviews twenty-eight peer-reviewed research papers examining the presence of parental stress and resilience in parents of children with autism in south-east Asia (SEA). The aim of this review is to identify specific sources of parental stress in order to reduce the dearth of information and ultimately to effectively inform support services for this cohort.

RESEARCH METHODS

The researchers carried out a systemic electronic search using a list of relevant search terms for autism and individually searching the SEA region and each country separately using both English and alternative names to ensure that no studies were missed. Articles were selected for review with respect to the following inclusion and exclusion criteria:

1. Studies relating to parental stress and resilience.
2. Studies that were autism specific with no other disabilities included.
3. Studies that were conducted in the SEA region.
4. Studies that were written in English and published in peer-reviewed journals.
5. Doctoral dissertations and master's theses were not included.

A total of twenty-eight articles met the above criteria. Two studies did not report the numbers of mothers or fathers in their studies but of the 1,639 participants identified, 1,288 were mothers and 253 were fathers.

Each study was read by four of the authors and three further researchers reviewed the analysis of findings agreed by the four authors.

RESEARCH FINDINGS

The authors report on studies investigating psychological well-being and distress in parents raising a child with autism in addition to several studies that examine parental stress directly. Research exploring themes of parent satisfaction, resilience, quality of life, family functioning and hopelessness are also included with a view to presenting a holistic understanding of how stress is perceived by this cohort.

The factors affecting parental stress are discussed across the following six categories:

Social support

Identified as support from immediate and extended family members, other families of children with autism, schools and other professionals. The spousal relationship was found to be a central form of social support across different cultures. By contrast, conflicting results are reported regarding extended family members, specifically in-laws.

Professional consultation is portrayed as a social support with parental stress linked to an increase in professional advice being sought in one study. Findings from another study also identify online support groups as a form of social support.

Severity of autism symptoms

Severity of autism was predominantly recognised as correlated to parental stress with mothers' perception of severity specifically identified in

two cross-cultural studies. Contrastingly, two further studies did not identify severity of autism symptoms as impacting on the stress levels or quality of life of parents.

Financial difficulty

Financial difficulty is reported as causal to parental stress across a number of studies with increases in financial income found to alleviate parental stress and psychological distress in two separate studies. Treatment costs specific to the child with autism are also identified as contributory to parental stress.

Parents' anxiety and worries toward their child's future

Concerns with regard to progression in education and adulthood are identified in qualitative studies where parents of children with autism engaged in interviews. Thoughts of this kind were perceived by the authors as promoting resilience.

Religious beliefs were similarly acknowledged as a coping strategy with engaging in religious traditions and in the religious community identified as a source of comfort.

Parents' perception and understanding toward autism and religious belief

These final two factors were reported as less impactful on parental stress than the previous four factors discussed.

Societal stigma is documented as impacting on parental stress with traditional or cultural beliefs of karma and curses reported as influential to parent stress even when parents did not hold those belief systems themselves; however, parents' perception and understanding toward autism also identified a range of coping strategies stemming from positive beliefs, emotional acceptance and understanding, cognitive reframing and adaptability.

IMPLICATIONS FOR PRACTICE (by the authors)

- More research is needed in this region, especially in respect to fathers' stress and in lower socio-economic regions.
- There is a need to increase economic and social support for disability and mental health across the SEA region.
- Social support for parents of children with autism needs to be of a high quality.

(by the author of this summary)

- For parents of children with autism, psychological welfare is of significant importance due to the range of factors that can cause stress.
- The identification of schools and other professionals as an important resource for parental social support expands the typical role of these persons to consider parents' emotional and mental health.
- There is a need for increased support to mediate the severity of autism symptoms, which is identified as correlated to parental stress in both SEA and Western regions.

Full Reference

Ilias, K., Cornish, K., Kummar, A.S., Park, M.S.A. and Golden, K.J., (2018). Parenting Stress and Resilience in Parents of Children with Autism Spectrum Disorder (ASD) in Southeast Asia: A Systematic Review. *Frontiers in Psychology*. 9(9), p.280.

CAREGIVER STRAIN AND SENSORY FEATURES IN CHILDREN WITH AUTISM SPECTRUM DISORDER AND OTHER DEVELOPMENTAL DISABILITIES

BACKGROUND

This paper uses the term ‘caregiver strain’ to describe the responsibilities, challenges and emotional outcomes of caring for a child with autism spectrum disorder (ASD) or other developmental disability (DD). The author references multiple studies which provide evidence that caregiver strain is more frequent in those with responsibility for a child with ASD than with other diagnoses. Other factors which can impact caregiver strain are also cited, including coping strategies, socio-economic conditions and level of support available. ‘Child factors’, such as adaptive and maladaptive behaviours, communication skills and cognitive level can also affect levels of caregiver strain.

Few studies have examined the impact of sensory differences on caregiver strain. Sensory differences encompass hyperresponsiveness to input (sensory sensitivities), hyporesponsiveness to input (absent or delayed response to stimuli) and unusual fascination with some sensory stimuli. Sensory differences are particularly associated with ASD, with authors noting that 69% of children with ASD have sensory differences compared to 38% of children with DD. These sensory differences can have an impact on caregiver strain as they affect family routines, such as mealtimes and bedtime, and more preparation is required for family activities.

RESEARCH AIMS

The aims of the study were:

- to examine if the CGSQ categories are relevant in measuring caregiver strain in the study’s sample of caregivers with a responsibility for children with ASD and DD.
- to examine if there is a difference in the objective, subjective internalised and subjective externalised strain between caregivers of children with ASD and caregivers of children with DD.
- to examine if these three categories of caregiver strain are affected by sensory hyperresponsiveness, hyporesponsiveness and sensory seeking in caregivers of children with ASD and DD (beyond the contributions of mother’s education, child cognitive status, and autism severity).

RESEARCH METHODS

Participants were recruited from a larger study taking place in North Carolina: ‘Sensory Experiences Project’. The sample consisted of 107 children and their caregivers. Seventy-one children had a confirmed diagnosis of ASD and 36 children had a DD, including genetic syndromes and developmental delays. Children were excluded from the DD group if they had a diagnosis of ASD or met the criteria for ASD. Children were also excluded from the study if they had a diagnosis associated with ASD (e.g. Fragile X syndrome, Tuberous Sclerosis), a visual or hearing impairment, a seizure disorder or cerebral palsy.

The following assessments and questionnaires were completed with all participants:

1. Sensory Experiences Questionnaire: Children were scored on the three factors of overresponsiveness, underresponsiveness and sensory seeking.

2. Caregiver Strain Questionnaire: This assessed three main factors of objective strain (e.g. missing work, financial strain), subjective internalised strain (e.g. feeling sad, worrying about the future) and subjective externalised strain (e.g. anger or resentment toward the child).
3. Mullen Scales of Early Learning: This was used as a cognitive measure for 51 of the child participants.
4. Stanford–Binet Intelligence Scales: This was used as a cognitive measure for 41 of the child participants.
5. Autism Diagnostic Observation Schedule: This was used to measure autism severity.

Information about maternal educational level was collected from the demographic information and was included in data analysis as some research has indicated that higher educational levels can be associated with increased caregiver strain.

RESEARCH FINDINGS

The key findings of the study were:

- Caregiver strain was higher in the group caring for children with ASD than in the group caring for children with DD.
- Subjective internalised strain was the most common type of caregiver strain in both groups of carers (ASD and DD), followed by objective strain.
- Subjective externalised strain was reported less frequently in both groups. This may be because caregivers of children with ASD and DD are less likely to feel anger or resentment toward their child or they are reluctant to report such feelings, or the questionnaire may not have identified the specific types of subjective externalised strain experienced by caregivers of children with ASD and DD.

- Sensory differences were associated with caregiver strain in the ASD group but were not significant contributors to strain in the DD group.
- Sensory hyperresponsiveness and hyporesponsiveness were most strongly correlated with objective strain in the ASD group, indicating that these sensory responses are most likely to have an impact on daily family life.
- Sensory hyperresponsiveness was a predictor of subjective internalised strain in the ASD group, meaning that sensory sensitivities in a child with ASD are likely to lead to caregivers experiencing feelings of sadness and worry.
- Higher levels of sensory-seeking behaviours in children with ASD were associated with decreased objective caregiver strain. The authors state that this may be because when a child is engaged in a favourite sensory activity, they are placing less immediate demand on carers.
- In the DD group, higher IQ levels in the child led to reduced objective caregiver strain, while a higher maternal educational level was associated with increased levels of objective strain. Similar findings were not found in the ASD group.
- It should be noted that some caregivers of children with DD experience high levels of caregiver strain, and, also, not all caregivers of children with ASD experience high levels of strain.

IMPLICATIONS FOR PRACTICE (by the authors and reviewer)

- Caregivers of children with ASD and DD are likely to need support to help them cope with subjective internalised strain as this can lead to increased levels of anxiety and depression.
- Caregivers of children with ASD and DD may benefit from practical support for issues such as loss of employment and financial difficulties.
- Caring for a child with ASD often has a significant impact on family life with disrupted routines, financial difficulties and a strain on personal relationships. Caregivers in this group therefore require greater levels of support for their mental health and advice and support for practical issues such as accessing financial assistance.
- Sensory sensitivities in children with ASD can often cause increased anxiety in their caregivers as these sensitivities can lead to extreme emotional responses in the child and will then impact daily outings (e.g. to shops and parks), daily activities (e.g. bathing, brushing teeth) and can disrupt sleep and diet. Caregivers of children with ASD and sensory sensitivities would therefore benefit from more information, advice and intervention to address these sensory concerns.
- Sensory hyporesponsiveness in a child with ASD can also disrupt family activities, and so advice and support would be useful to help the caregiver in engaging the child in daily activities and improving interaction.
- Interventions to address sensory differences in children with ASD may also have a positive impact on the caregiver as successful interventions could reduce caregiver strain.

- The authors suggest that as sensory-seeking behaviours seem to lead to reduced objective strain, interventions which reduce sensory-seeking behaviours may actually place greater strain on the caregiver. They acknowledge, however, that this requires further research.

Full Reference

Kirby, A.V., White, T.J. and Baranek, G.T., (2015). Caregiver Strain and Sensory Features in Children with Autism Spectrum Disorder and other Developmental Disabilities. *American Journal of Intellectual and Developmental Disability*. 120(1), p.32–45.

EFFECTIVENESS OF MINDFULNESS-BASED INTERVENTION ON PERCEIVED STRESS, ANXIETY, AND DEPRESSION AMONG PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

BACKGROUND

Research has shown that parents of children with autism spectrum disorder (ASD) frequently report higher levels of parental stress, anxiety and depression equating to poorer psychological well-being. Previous research supports the use of mindfulness-based interventions (MBIs) to help parents of children with autism manage their stress. MBIs have shown to help parental interaction, acceptance of diagnosis and can have positive effects on self-esteem. Despite these results, further studies are scarce.

RESEARCH AIM

The aim of the study is to examine the effectiveness of MBIs on perceived levels of stress, anxiety and depression for parents of children with autism in Jordan. In order to reduce the level of intensity and demand on parents, this study used a brief MBI with an emphasis on mindfulness parenting.

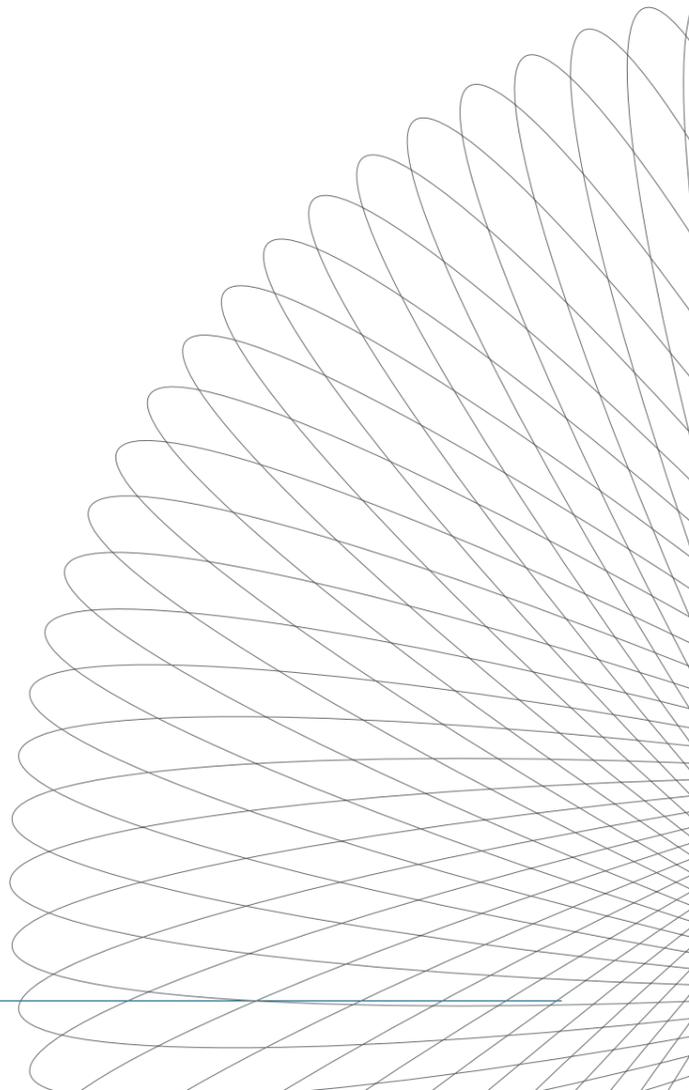
RESEARCH METHODS

This study used a pretest-posttest design with the inclusion of a comparison group. Researchers recruited parents of children with autism from ten autism centres, which considered DSM-5 criteria as standardised diagnostic criteria. Children were classified within levels of severity using DSM-5/Clinician-Rated Severity of Autism Spectrum and Social Communication Disorders Scale (DSM-5CRS-AS-SC-D)

Characteristics of parents: parents recruited in the study had at least one child with autism living at home, they were literate and Arabic-speaking, had access to a telephone or device to play audio resources and had no diagnoses of a psychiatric illness. 104 parents fully participated in the study; 70.2% were female, 98% were married and all had varied levels of education. 70% were not working or were retired, while 90.4% of the mothers were housewives. 52 parents were assigned to the intervention group and 52 were assigned to the comparison group.

Characteristics of children: 94.2% of parents had only one child with autism (parents who had more than one child with autism were instructed to provide data only about their youngest child). Data was provided for 81 boys and 23 girls with autism. Regarding level of severity within restricted interests and repetitive behaviours (RIRB), 42 children (40.4%) were classified as level 1 severity, 28 children (26.9%) were classified as level 2 severity and 34 children (32.7%) were classified under level 3 severity. Regarding level of severity in social communication, 65 children (63.5%) were classified under level 2 severity, and 39 children (36.5%) were classified under level 3 severity.

Measures included Depression, Anxiety and Stress Scale (DASS21) and the Mindful Attention Awareness Scale (MAAS). The programme was shortened to 5 weeks and delivery included various mediums such as in-person sessions (groups of 3–11), practising under CD directions, reading materials and telephonic sessions.



FINDINGS

This study had a response rate of 64.2%, which is considered relatively high, and an attrition rate of 13.3%, which is low compared to previous studies. The available statistics suggest a high parental compliance rate with the programme.

Researchers conducted Analysis of Covariance (ANCOVA) to determine if there was a statistically significant difference between the intervention group and the comparison group. There was a significant effect on posttest levels of stress, depression and anxiety. All the mean scores were lower for parents in the intervention group compared to those in the comparison group, suggesting improved psychological well-being. There was also a significant difference on posttest levels of mindfulness scores; these were higher for parents in the intervention group, suggesting better outcomes (see Table 1 below).

IMPLICATIONS FOR PRACTICE (by the authors)

This study supports the finding that MBIs, including a 5-week shortened MBI, prove to be helpful for parents of children with autism. Parents within the intervention group scored significantly higher for psychological well-being and mindfulness.

- Limitations of previous studies using MBIs for parents of children with autism include high commitment levels which resulted in higher drop-out rates; whereas the shortened MBI programme utilised within this study appears to meet the needs of busy parents.
- This intervention programme focused on using mindfulness techniques. Those parents who received intervention reported higher mindfulness scores on post measures. These higher scores are associated with fewer physical and negative symptoms and increased positive consequences on psychological well-being. The researchers propose that professionals working with parents of children with autism should consider directed MBIs to manage parental stress.
- The researchers note that generalisation of the results may be limited due to their use of convenience sampling. This included choosing parents who were literate and whose children currently attend an autism centre.

Full Reference

Rayan, A. and Ahmad, M., (2017). Effectiveness of Mindfulness-Based Intervention on Perceived Stress, Anxiety, and Depression Among Parents of Children with Autism Spectrum Disorder. *Mindfulness*. 8(3), p.677–690.

Table 1: Mean differences in the dependent variables between pretest and posttest for the study groups

Group membership	t test (1st week vs 5th week)	Mean (1st week)	Mean (5th week)	t	Df	P value	Effect size (Cohen's d)
Intervention group	Stress	25.61	21.46	4.61	51	>0.001	0.64
	Anxiety	17.58	13.38	4.00	51	>0.001	0.55
	Depression	18.38	13.69	5.32	51	>0.001	0.74
	Total DASS	61.58	48.54	5.70	51	>0.001	0.79
Comparison group	Stress	26.85	26.31	1.29	51	0.20	0.18
	Anxiety	17.35	16.65	2.08	51	0.04	0.29
	Depression	19.92	19.31	1.58	51	0.12	0.15
	Total DASS	64.31	62.31	3.79	51	0.03	0.31

Df degree of freedom

A PRELIMINARY STUDY OF ACTIVATION, STRESS, AND SELF-MANAGEMENT OF PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

BACKGROUND

Autism Spectrum Disorder has a wide-ranging impact on the child and their family, and, as a result, children with autism tend to be higher users of services and often have need for multiple types of services. While little information is available on how parents of children with autism interact with the healthcare system, it has been found that these parents experience more stress and greater dissatisfaction with services. In order to provide better and more responsive services, attention is being focused on the role of activation and self-management in enabling parents to engage positively and successfully with the healthcare system. In this study self-management refers to a person's capacity to manage symptoms and consequences of a chronic condition. Activation is a related concept that includes facets of self-management and refers to possessing the information, knowledge, beliefs, motivation and skills to participate as a valuable team member. Research indicates that activation is linked to improved outcomes and that those with higher activation also have better self-management skills. For parents of children with autism, activation may be especially important given the difficulties associated with securing timely support that is of high quality and family focused. The measurement tool used in the study looks at four stages of activation: belief, confidence, action and persistence and assumes that activation progresses through these four stages.

The study utilised a model of outpatient multidisciplinary care which centred on collaborative parent-child service planning and decision-making. This model, named Therapeutic Programming Session (TPS), has three aims: to identify parent concerns, to help parents access

services based on their concerns and priorities, and to assist parents in navigating the service system. The TPS model uses a multidisciplinary approach that allows for recommendations to be prioritised according to the parent's main concerns and the team's observations.

RESEARCH AIMS

The aim of this preliminary study was to examine the relationships between parent activation and self-management, parent stress and satisfaction with services. The research questions posed were:

- What stage of activation do parents of children with autism report?
- What is the concurrent and predictive relationship between parent activation and self-management, stress, and satisfaction pre- and post-TPS?
- What is the relationship between changes in parent activation from pre- to post-TPS with indicators of parent stress and satisfaction at post-TPS?

RESEARCH METHODS

Thirty-six parents of children with autism receiving TPS participated in the study. The children, of which 89% were male, were aged between 2.3 and 15 years old. A modified version of the Parent Activation Measure for Developmental Disabilities (PAM-DD) was used along with a Self-management Assessment (SMA), the Parenting Stress Index-Short Form (PSI-SF) and an adapted satisfaction measure to test parental satisfaction with TPS. All measures were administered before the TPS and again within two weeks following the TPS except for the TPS satisfaction measure which was administered once following the TPS.

RESEARCH FINDINGS

The data from this study supports the theory that activation entails a developmental process. Consistent with previous research, this study found that activated parents reported less stress and felt better equipped to manage their child's needs across an array of high-frequency domains that are often difficult, such as behaviour, sleeping, eating and toileting. A positive relationship between activation and increased self-management was found highlighting the importance of activation interventions for families of children with autism given the chronic nature of concerns, the need for lifelong services and the stress related to procuring those services. Furthermore, the study found that the clinician was an important motivating factor in parent activation as activation increased the most in parents who were satisfied with their clinician. Additionally, in this study activation resulted in positive outcomes for the child in terms of improved self-management and for the parent in terms of reduced stress. This study of activation shows its potential as an aspect of quality of care for parents of children with developmental disabilities.

IMPLICATIONS FOR PRACTICE (by the authors)

- As the study was conducted with a small and limited sample, future research on activation would benefit from a larger sample of parents from differing populations including minority families.
- Future research should consider the impact of factors such as education, income, race and ethnicity on activation.
- A broader age range and other disabilities should be included in future studies.
- Further evaluation is required to ascertain whether typical clinical practices result in improved parent activation and in assessing the impact of parent activation on overall outcomes.
- Data should be gathered on the clinician's adherence to the TPS intervention model to provide information on consistency of delivery across therapists.
- Future research on parent activation has potential as an intervention but also as a means by which to measure service effectiveness.

Full Reference

Ruble, L., Murray, D., McGrew, J.H., Brevoort, K. and Wong, V.W., (2018). A Preliminary Study of Activation, Stress, and Self-Management of Parents of Children with Autism Spectrum Disorder. *Journal of Child and Family Studies*, 27(3), p.825–834.

PARENTAL STRESS AND ASD: RELATIONSHIP WITH AUTISM SYMPTOM SEVERITY, IQ, AND RESILIENCE

BACKGROUND

The authors identified that several studies of parents of children with autism document elevated stress levels. The theoretical concept of stress proposed by previous studies named in the paper considers stress to be an individual and subjective process that results from the interaction of an individual with his or her environment. Stress encompasses four parts: an external event (stressor), a cognitive appraisal of this event, coping mechanisms to reduce the noxiousness of this event, and the reaction of the event on the mind and body. When individuals deem an external event to have overwhelmed their resources, they engage in coping mechanisms to restore functioning. If the coping mechanisms cannot meet the demand, the outcome is stress.

Prior studies identified external events to be the severity of the autism symptoms, the child's behaviour problems and the child's level of intellectual ability, although the authors point out that the results from the intellectual ability studies were not conclusive. The authors cite a theoretical model that describes the relationship between the first two factors listed as bidirectional: the child's problematic behaviours lead to parenting stress, which in turn affects parenting behaviours, which then increases the child's problematic behaviours. In addition, factors related to parental characteristics are also associated with parental stress: personality factors (e.g. mental health, the partners' relationships and emotional problems that parents can suffer even before the child's birth) and external factors (e.g. economic conditions and perceived social support).

Resiliency was identified as being important when facing and dealing effectively with day-to-day life with an autistic child. The authors state that a recent review of the resilience literature on parents of autistic children concluded that those who possess indicators of resilience are better able to handle the challenge of raising an autistic child. These indicators are optimism and self-efficacy.

The authors felt this research was necessary as it went beyond published studies on the subject as they isolated the role of autism from intellectual functioning by comparing parents of children with and without autism matched on performance IQ.

RESEARCH AIMS

The aims of this study were

- 1) to evaluate parental stress in parents of children with autism and compare it with the stress in parents of children with typical development.
- 2) to study the relationship between parental stress, severity of autistic symptoms, verbal IQ and performance IQ.
- 3) to study the relationship between parental stress and resilience characteristics in parents of children with autism.

RESEARCH METHOD

This study took place in Valencia, Spain. The participants were recruited from a public school where autistic children attended TEACCH integrated classrooms beside their mainstream peers. As this study wanted to compare the perceived parental stress of parents of autistic children and typical development children, two groups were established: ASD group and Comparison group. Initially the ASD group consisted of 67 autistic children and the Comparison group consisted of 350 children. After criteria was applied (see Participants section of the paper) and information sought from families via a series of questionnaires and meetings with the school psychologist, the children were matched one-to-one on IQ performance, chronological age and gender. Two groups consisted of 84 families: 42 with an autistic child (ASD group: 38 boys and 4 girls) and 42 with a child with no diagnosis (Comparison group: 33 boys and 9 girls). Both groups had a mean age of around 80 months and a mean performance IQ (measured by the Raven test) around 100. Table 1 in the paper details the children's demographic information for both groups. Parent patriation was 80% mothers and 20% fathers.

RESEARCH FINDINGS

The authors found that perceived parental stress was significantly higher in the ASD group than in the Comparison group. This was in keeping with previous studies, although this study found the perceived parental stress in the ASD group to be at much higher levels than the norms reported in previous papers.

The authors found that the child's autism symptom severity contributed significantly to predicting parental stress related to the child's characteristics of distractibility and hyperactivity. Data collected by the authors revealed a significantly higher number of ADHD symptoms in the ASD group than in the Comparison group. The child's verbal IQ was a significant predictor of parental stress in both groups. The worse the child's linguistic skill, the more the parental stress was related to the child's characteristics. In the case of children with ASD, poor linguistic skills probably imply worse communication skills, which could be related to greater parental stress. Also, the lower a child's performance IQ is the greater parental stress is. This was due to the child's capacity to adapt to changes and transitions and to parent expectation. This finding was in contrast to the findings of similar previous studies.

The parents of the ASD group perceived themselves as moderately resilient to adversity. Two variables were identified as being significant: depression and competence. Parents who perceived themselves as resilient reported as having less depressive symptoms and being more competent in their role as parents. This result is in keeping with emerging research focusing on learning resiliency which finds indicators of resilience in families of autistic children to be optimism and self-efficacy, as these are predictors of a greater ability to cope with the challenge of raising an autistic child.

Despite the high stress levels parents experience, the parents of autistic children adapt to their children's needs with closeness. This coincides with previous research.

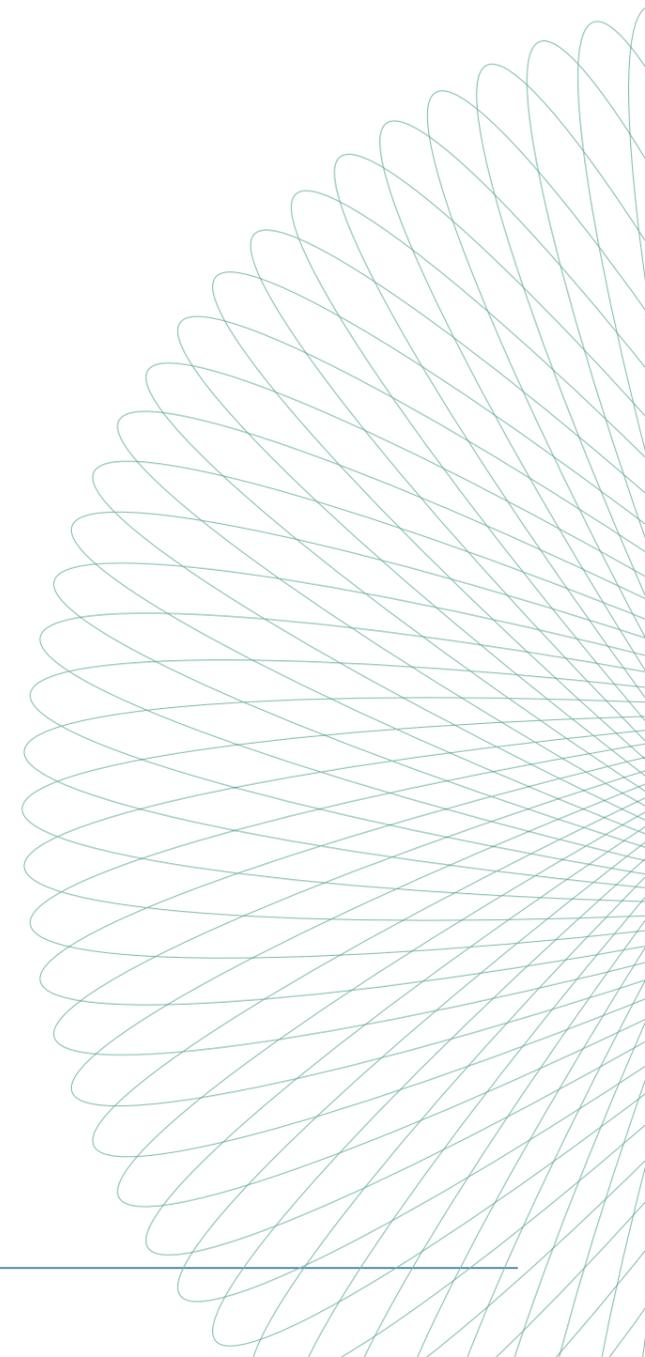
IMPLICATIONS FOR PRACTICE (by the authors)

The authors identify that parental stress is of great importance given its implications in the quality of life of the entire family and they make the following five recommendations for intervention:

1. Parents of autistic children need access to human, social, work, political resources etc. to allow them to deal effectively with stress, improve the family dynamics and functioning, and gain quality of life.
2. It is important that practitioners deliver interventions to prevent or mitigate the severity of the child's autism and related to distractibility and hyperactivity behaviours which often have a co-morbid presence in autism.
3. Speech therapy for autistic children should focus on pragmatic and functional aspects of language as well as other aspects of language necessary for reaching good linguistic competences e.g. morphological and syntactic aspects.
4. A basic goal of interventions, especially for autistic children with intellectual disabilities, should be to promote cognitive skills.
5. Two characteristics indicating resilience were identified: optimism and self-efficacy. Thus, it is important that interventions are designed to support and teach a family how to be resilient as this is beneficial to both the parents and the children.

Full Reference

Pastor-Cerezuela, G., Fernández-Andrés, M.I., Tárraga-Mínguez, R. and Navarro-Peña, J.M. (2016) Parental Stress and ASD: Relationship with Autism Symptom Severity, IQ, and Resilience. *Focus on Autism and Other Developmental Disabilities*. 31(4), p.300–311.



FOR FATHERS RAISING CHILDREN WITH AUTISM, DO COPING STRATEGIES MEDIATE OR MODERATE THE RELATIONSHIP BETWEEN PARENTING STRESS AND QUALITY OF LIFE?

BACKGROUND

It is a difficult time for parents when their child is diagnosed with autism. Many have more questions than answers and ultimately realise that they may face a difficult and lifelong pathway through the fields of education and health; however, the social, emotional, economic and personal impact are sometimes not appreciated or addressed, with research saying this is particularly pertinent for fathers.

It has only been relatively recently that the role of fathers and their involvement has been considered separately to the role of parents in relation to child development. Many men still perceive themselves as 'the protector' or 'the provider', financially and emotionally, of all family members and find difficulty understanding why they cannot prevent or protect their child experiencing pain, harm or distress. This dilemma may lead to higher levels of paternal stress and thus impact negatively on his quality of life, which in turn can affect the whole family's health and well-being.

RESEARCH AIMS

This study aims to examine the usefulness of eight specific coping strategies when examining the relationship between fathers of children with autism, their parental stress and thus quality of life. The eight strategies are:

1. Positive reappraisal – cognitively reframing an event as more positive.
2. Confrontive coping – determined efforts to change or amend the situation.
3. Planful problem-solving – deliberate problem-focused efforts to alter the situation coupled with an analytic approach to solving the problem.

4. Seeking social support – gathering information alongside tangible and emotional support.
5. Distancing – detaching from the situation while minimising the impact and significance.
6. Self-control.
7. Escape avoidance – wishful thinking and behavioural efforts to escape or avoid the situation.
8. Accepting responsibility.

RESEARCH METHODS

This study focused on the concepts of stress and the appropriate use of coping mechanisms with 101 fathers aged between 25 and 69 years. The children with autism, 85 boys and 16 girls, were between the ages of 2 and 13 years. Three measures were used to ascertain if, and when, fathers used the range of coping strategies:

1. The Parenting Stress Index-Short Form (PSI-SF) to assess total stress experienced.
2. The Revised Ways of Coping Checklist (WCC-R) to see the variety of coping strategies used.
3. The World Health Organization Quality of Life Assessment-BREF (WHOQOL-BREF) to assess personal perception of the individual's quality of life.

RESEARCH FINDINGS

Parents, in this instance fathers, find the process of raising a child with autism incredibly complex. The need to maintain and improve family life while being aware of all variables proves stressful. The combination of education, health, social, emotional and even financial considerations can impact on well-being, and at times fathers feel unprepared, overwhelmed and frequently impotent in managing these multifaceted factors.

Although the eight coping strategies were used at different times and in varied combinations by the fathers, none were found to be ultimately beneficial in alleviating the stress experienced or in the promotion of improved quality of life. Fathers who experienced greater levels and frequency of stressful situations tended to use less efficient and thus less effective coping strategies.

The authors felt that if they completed the study again, they would consider qualitative or longitudinal studies which may give greater insight into the strategies devised, used, amended and reimplemented through the journey of raising a child with autism. Health professionals, educators, counsellors and policymakers must understand the complex coping process of parenting stress to ensure that the appropriate paternal support services are available and in place when the need arises. Fathers of children with autism must find, learn or be taught effective ways of dealing with their stress and develop efficient coping strategies and differentiate such strategies depending on need at certain instances as this is a lifelong journey acting as their child's advocate.

IMPLICATIONS FOR PRACTICE (by the authors)

- Fathers need to be taught the range of validated coping strategies available to them, which they can implement when needed as this may elicit a more positive perspective ensuring that fathers do not become overwhelmed by the variety of issues to be considered.
- As life and life events are not solely based on one variable, many extraneous factors come together, the authors found that none of the aforementioned coping strategies were effective enough to deal with the diverse situation; therefore time and consideration

must be given to the breaking down of the situation, 'What will work well when and how do I manage to use it?'. Fathers need to be encouraged to express their thoughts and feelings when working with health or education professionals as it is only then that effective support can be offered.

- Fathers' personal characteristics, beliefs, motivation, goals and values must all be considered when formulating a supportive package of strategies and intervention. The recognition of these intrinsic qualities is vital if we are to support an improvement in quality of life.
- Social stigma still plays a role in the well-being of fathers of children with a complex learning need including autism. Fathers may report that they have asked for social support as a coping strategy; however, many are reluctant to discuss the quality and types of intervention they require or may use. This quality and form of intervention can directly impact on the overall improvement to quality of life. Societal understanding of autism and the needs of the family must be promoted.
- Fathers must address their reluctance to engage with the supportive mechanisms available, such as talking about their thoughts, experiences and hopes for the future, for them and their children.

Full Reference

Dardas, L. A. and Ahmad, M. M., (2015). For Fathers Raising Children with Autism, Do Coping Strategies Mediate or Moderate the Relationship between Parenting Stress and Quality of Life? *Research in Developmental Disabilities*. 36, p.620–629.

BEHAVIORAL AND EMOTIONAL PROFILE AND PARENTAL STRESS IN PRESCHOOL CHILDREN WITH AUTISM SPECTRUM DISORDER

BACKGROUND

Studies have previously found higher levels of stress among parents of children with autism spectrum disorder (ASD) compared to parents of typically developing children and children with other conditions including Down syndrome, intellectual disability, cerebral palsy and cystic fibrosis.

High levels of parental stress may have a negative impact on the effectiveness of early interventions for children with autism. Some studies have therefore attempted to identify which factors may influence the level of stress in these parents; however, so far there are mixed findings regarding the role of child factors such as autism symptom severity, behavioural problems, intellectual ability and level of adaptive functioning in terms of their impact on the stress levels of parents of young children with ASD.

It's also unclear how specific types of child behavioural difficulties (for example, attention problems, sleep issues, aggression or self-injurious behaviour) contribute individually to parental stress levels.

RESEARCH AIMS

This study aimed to examine and compare the levels of parental stress in parents of children with ASD and parents of typically developing children, as well as the types and severity of child behavioural problems present in both groups. The impact of factors including child behavioural and emotional problems, ASD symptom severity, intellectual ability and level of adaptive functioning on parental stress levels was also investigated.

RESEARCH METHODS

This study took place in Rome, Italy. One hundred and thirty preschool children with ASD and their parents participated in this study, as well as a group of 84 typically developing children and their parents. The mean age of the ASD group was 9.2 months, while the mean age of the typically developing group was 14.6 months. Children within the ASD group had been diagnosed with an autism spectrum disorder by an experienced clinician using DSM-5 criteria. Children in the typically developing group were matched with children in the ASD group according to age and gender.

The researchers collected several types of data from participants. For those in the ASD group, symptom severity was assessed using the Autism Diagnostic Observation Schedule (ADOS), which is a play-based observational measure. An assessment of cognitive abilities was also carried out within the ASD group, using the Griffiths Mental Developmental Scale, as well as an assessment of everyday adaptive functioning, using the Vineland Adaptive Behaviour Scale.

Children in both the ASD and typically developing groups were assessed for behavioural and emotional problems using the preschool version of the Child Behavior Checklist (CBCL). Parents of children in both groups completed a parental stress measure – the Parent Stress Index.

Analyses were then conducted to examine differences between the ASD and typically developing groups, and to establish whether parental stress levels could be predicted by child characteristics including emotional and behavioural problems, level of adaptive functioning and autism symptom severity.

RESEARCH FINDINGS

Differences between ASD and typically developing groups

The results showed that children in the ASD group displayed significantly greater levels of emotional and behavioural difficulties compared to children in the typically developing group. Parents of children in the ASD group also displayed significantly greater levels of parental stress than parents of children in the typically developing group.

Parental stress in ASD group

There was a significant correlation between levels of parental stress and emotional and behavioural problems among the ASD group: as the level of problems increased, so did the level of parental stress.

Autism symptom severity was not associated with the level of parental stress.

In terms of the specific behaviour issues that affected parental stress in the ASD group, the overall level of parental stress was positively correlated with all types of child behavioural and emotional problems measured by the CBCL (including emotionally reactive behaviour, anxious and depressed behaviour, withdrawn behaviour, attention problems and aggressive behaviour) with the exception of somatic complaints and sleep problems.

'Parental distress', a subscale of the Parent Stress Index which measures lack of perceived parental competence and depression symptoms, was positively correlated with emotionally reactive, attention and aggressive behaviour issues; while the 'difficult child' subscale, measuring characteristics of the child which affect how easy or difficult they are to manage, was correlated with all types of behaviour and emotional problems except sleep problems.

The Parent Stress Index subscale 'parent-child dysfunctional interaction' was associated with child adaptive functioning and child cognitive ability. Low levels of adaptive functioning and cognitive ability were linked to this specific form of parental stress involving difficulties with achieving successful parent-child interactions.

Further analyses revealed that among the ASD group the level of parental stress could be predicted by child behavioural and emotional problems, specifically emotional reactivity and attention problems.

Parental stress in typically developing group

Among the typically developing group there was also a strong positive correlation between levels of parental stress and child emotional and behavioural difficulties.

In terms of specific behavioural issues among the typically developing group, overall parental stress was associated with all types of child behavioural and emotional problems measured by the CBCL except sleep problems.

The 'parental distress' subscale was significantly related to aggressive behaviour and somatic problems; while the 'dysfunctional parent-child interaction' subscale was related to all types of behavioural and emotional problems except withdrawal problems and sleep problems.

In further analyses, overall parental stress among the typically developing group could be predicted specifically by child aggressive behaviour, withdrawal problems and somatic complaints.

IMPLICATIONS FOR PRACTICE (by the authors)

- Parents of preschool children with autism experience greater stress than parents of typically developing children.
- Parental stress levels appear to be associated with emotional and behavioural difficulties, but not autism symptom severity, among preschool children with ASD. This association has also been found in studies with older children, suggesting that child behaviour is a stable influence on parental stress across childhood.
- Although behavioural and emotional problems are also associated with parental stress levels among parents of typically developing children, the specific types of behaviours which predict parental stress differ between the two populations.
- As different types of behavioural or emotional difficulties appear to be related to different types of parental stress, these difficulties should be examined at an early stage among children with ASD in order to inform the development of parent and family support plans.
- Further research is needed to investigate whether the relationship between child emotional and behavioural problems and parental stress differs between mothers and fathers and whether this relationship changes across the lifespan.
- Factors which may protect parents of children with ASD from stress should be investigated and this knowledge should be used to inform early-intervention programmes aiming to prevent or reduce parental stress.

Full Reference

Giovagnoli, G., Postorino, V., Fatta, L. M., Sanges, V., De Peppo, L., Vassena, L., De Rose, P., Vicari, S. and Mazzone, L. (2015). Behavioral and Emotional Profile and Parental Stress in Preschool Children with Autism Spectrum Disorder. *Research in Developmental Disabilities*. 45–46, p.411–421.

PARENTAL STRESS, FAMILY QUALITY OF LIFE, AND FAMILY-TEACHER PARTNERSHIPS: FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDER

BACKGROUND

Research has identified that parents of children with autism report higher stress levels and lesser well-being than parents of typically developing children. Reducing parental stress and improving family quality of life (FQOL) are continuing concerns for families of children with autism.

Family-teacher partnerships have been identified as a way of supporting parents reduce their stress and improve their FQOL; however, the relationships between parental stress, FQOL and family-teacher partnerships need to be further examined.

RESEARCH AIMS

The purpose of this study was to determine the interrelations among parental stress, FQOL and family-teacher partnerships in families of children with autism..

RESEARCH METHODS

A convenience sample of parents who had school children with autism aged 3–21 were invited via email to participate in this study by using the databases of an autism centre located at a university, a state autism organisation, a regional autism organisation and a local autism service provider in the southern region of the United States. Those meeting inclusion criteria were asked to complete three questionnaires online:

- The Beach Centre Family Quality of Life Scale
- The Parental Stress Scale
- The Beach Centre Family-Professional Partnerships Scale (Family Version)

A total of 236 parents of children with autism voluntarily participated in this study. The majority of the participants were mothers (86.02%) and over half (50.85%) of the participants had achieved third-level education.

RESEARCH FINDINGS

This study investigated the relationships between:

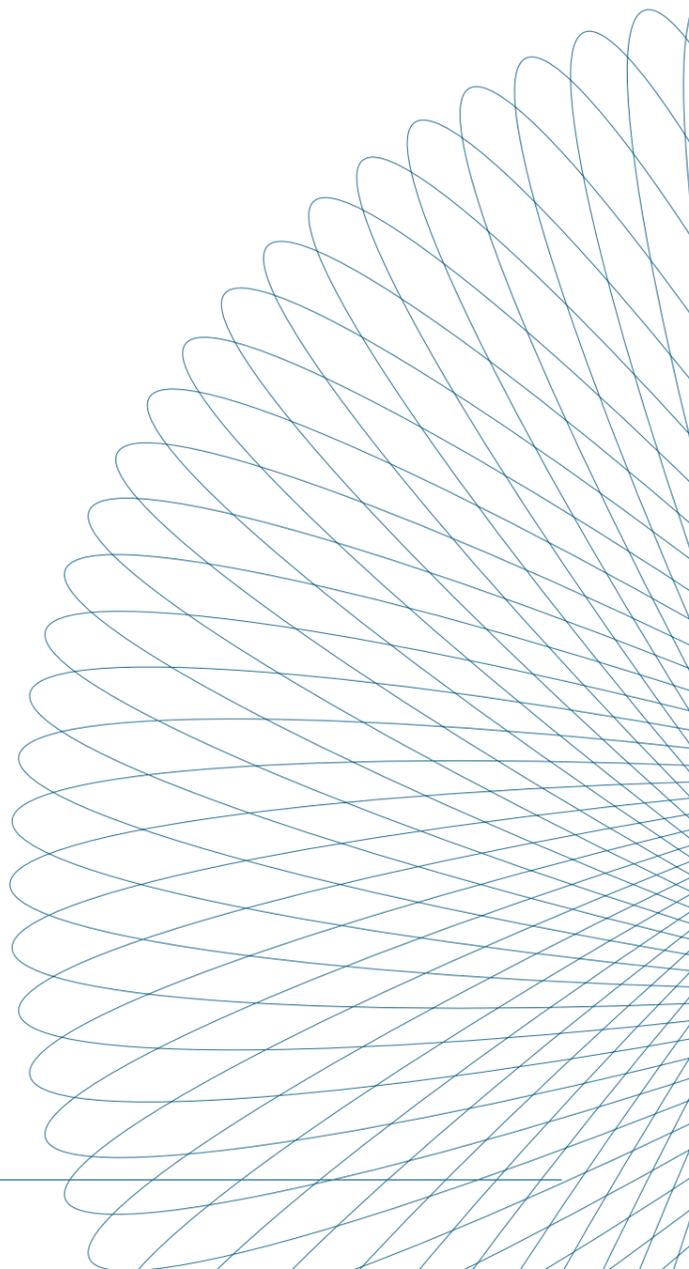
- Parental stress
- FQOL
- Family-teacher partnerships

Results showed that there was a relationship between parental stress and FQOL. When parents of children with autism perceived a higher level of parental stress, they reported a lower level of satisfaction with their FQOL. Reciprocally, when parents of children with autism perceived a lower level of satisfaction with their FQOL, they perceived a higher level of parental stress.

Parents with a lower level of FQOL may suffer problems such as poor family relations, lack of disability-related support or poor health conditions. All of these factors may be related to higher parental stress.

Family-teacher partnerships had a direct effect on FQOL. This study found that having strong family-teacher partnerships can contribute to increased FQOL; however, results suggest that family-teacher partnerships did not have a significantly direct effect on parental stress.

In summary, the findings indicate that both family-teacher partnerships and parental stress had direct effects on FQOL. This indicates that both family-teacher partnerships and parental stress may independently have an effect on FQOL for families of children with autism.



IMPLICATIONS FOR PRACTICE

Reducing parental stress could improve FQOL for families of children with autism and vice versa. Strong family–teacher partnerships could help parents of children with autism improve their FQOL and indirectly reduce their stress.

Family–teacher partnerships which value parents’ opinions about children’s needs and provide interventions such as skills to cope with behaviour problems could contribute to improving FQOL for families of children with autism.

Full Reference

Hsiao, YJ., Higgins, K., Pierce, T., Schaefer Whitby, P.J. and Tandy, R.D., (2017). Parental Stress, Family Quality of Life, and Family–Teacher Partnerships: Families of Children with Autism Spectrum Disorder. *Research in Developmental Disabilities*. 70 p.152–162.

RELATING STRESS OF MOTHERS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES TO FAMILY–SCHOOL PARTNERSHIPS

BACKGROUND

Mothers of children with disabilities experience increased levels of stress compared to mothers whose children do not have disabilities. Experiencing such high levels of stress can lead to a decline in physical and mental health, e.g. heightened levels of depression and also fatigue. To effectively address the levels of stress experienced by mothers of children with developmental disabilities it is important to understand the correlates of stress among mothers. To date, most research has focused on child characteristics in relation to maternal stress or aspects of family resources in relation to maternal stress. Few research studies exist concerning the effects of parent–school partnerships on parental stress.

RESEARCH AIMS

The primary goal of this research was to determine whether school characteristics were linked to different levels of maternal stress. To explore this goal the researchers aimed to examine which child, parent and parent–school characteristics correlated with maternal stress, and secondly to identify which parent–school partnerships would be most important.

RESEARCH METHODS

Nine hundred and sixty-five mothers of students with disabilities aged 24 to 67 years participated in the study. Children of these participants were predominantly male (69.5%) aged 3 to 22 years. The students displayed a range of disabilities including autism, developmental delays, Down syndrome, learning disabilities and intellectual disabilities. Participants were recruited initially through emails and flyers sent to local, state and national parent support groups, the Association of University Centres in Disabilities and a total of parent training and information centres

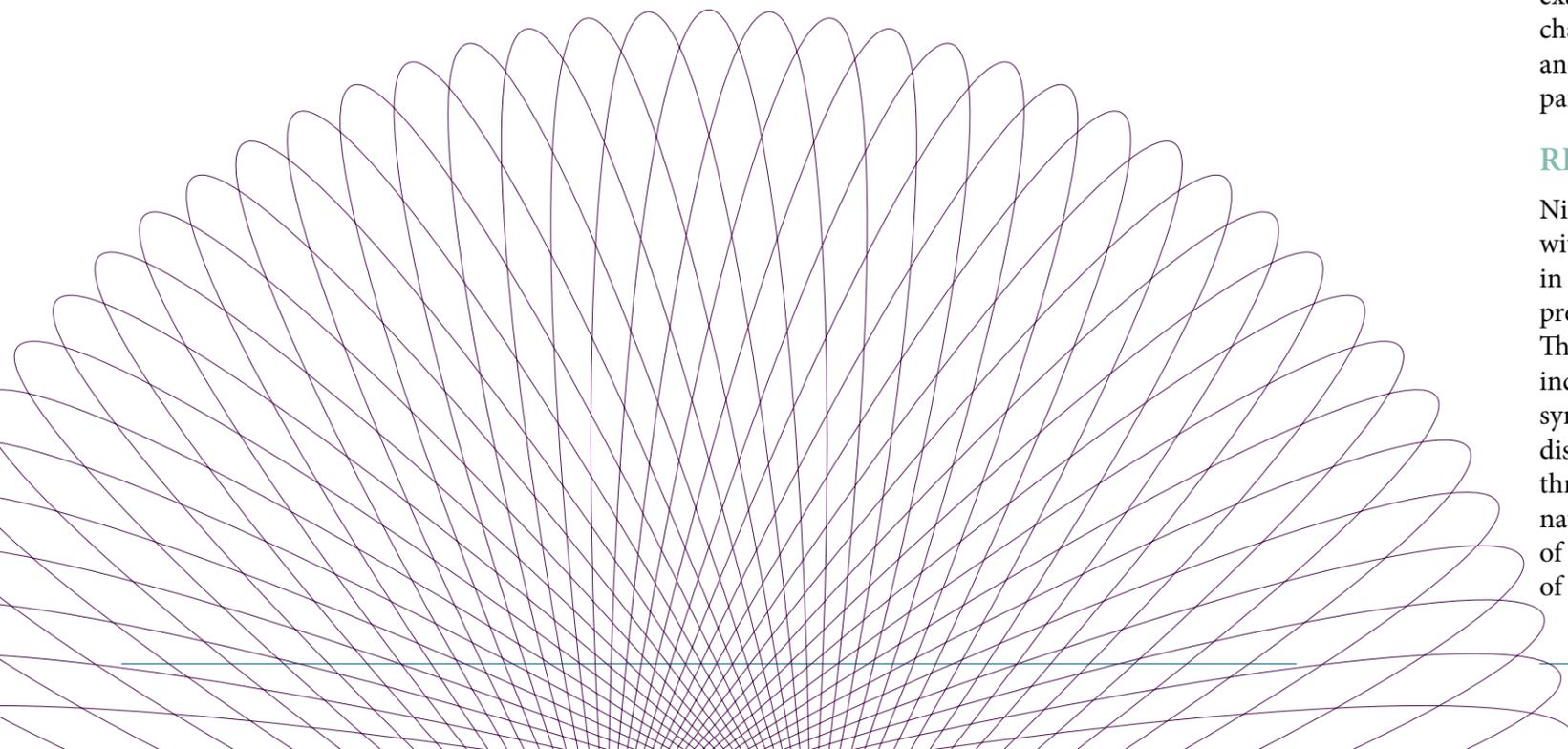
throughout the United States. Following this procedure emails were sent to 7,843 agencies, which included local parent support groups, non-profit disability agencies, including chapters of the Arcs schools and educational agencies, attorney, advocacy and legal agencies plus private service providers.

In collaboration with other disability researchers and community advocates a questionnaire, the parent–school collaboration survey, was developed and revised. The survey was piloted with 5 parents of students with disabilities, 10 professors, parents of individuals with disabilities, students and community advocates.

The parent–school collaboration survey took 20–25 minutes to complete via a secure link on a university website. Although most questionnaires were completed electronically, respondents could also complete and return paper versions.

RESEARCH FINDINGS

Results showed that mothers with lower stress levels reported better parent–school partnerships and low levels of parent advocacy. Lower maternal stress levels were also reported among those whose children had fewer behavioural difficulties, Down syndrome or who did not have autism. Stress was also reported by mothers who had rated themselves lower on neuroticism, were more extroverted, dependable and open to new experiences and who had not enacted procedural safeguards. Parental race was also significant as the findings from this study indicated that African Americans had significantly less stress than white mothers. When comparing white mothers to mothers of Asian, Hispanic or other minority backgrounds there were no significant differences recorded.



IMPLICATIONS FOR PRACTICE (by the author)

This study reinforces the importance of parent-school relationships. For children with and without disabilities the school system is the social service that both parents and children frequently engage with. The importance of family-school partnerships for outcomes which include the psychological health of mothers has implications for practice. The authors recommend that practitioners, particularly those in special education, should expand their focus to include the goals of the family-school partnerships. Cultivating stronger family relationships may contribute to better outcomes for students and act as a support in the improvement of the psychological health of their mothers. Having better supported parents enables them to help their children to achieve academically and socially.

These findings also give rise to the many areas which have not been explored in relation to parent-school connections and maternal stress; for example, future research should focus on exploring more closely the relationship between type of disability, family-school characteristics

and maternal stress. As this study highlighted that parents of children with autism experienced more stress levels, interventions may be needed to reduce maternal stress in these families. Another important issue for further exploration, as highlighted by the authors as a possible inaccuracy, includes the conceptualisation of stress as a maternal trait that remains constant over time. The authors query whether parents' stress increases immediately before an individual education plan (IEP) meeting as for many the jargon used in IEP meetings can be both intimidating and overwhelming. In a mother's anticipation of such meetings their stress levels may increase, therefore additional longitudinal studies examining parental stress over a period of time in relation to various aspects of parent-school relations should also be borne in mind and further explored.

Full Reference

Burke, M. and Hodapp, R., (2014). Relating Stress of Mothers of Children with Developmental Disabilities to Family-School Partnerships. *Intellectual and Developmental Disabilities*. 52(1), p.13-23.

THE NEED FOR AN ECOLOGICAL APPROACH TO PARENTAL STRESS IN AUTISM SPECTRUM DISORDERS: THE COMBINED ROLE OF INDIVIDUAL AND ENVIRONMENTAL FACTORS

BACKGROUND

Research indicates that parents of children with autism experience higher levels of stress than the parents of non-autistic children. This research aimed to determine what were the specific individual (demographic) factors and environmental (family) factors that contributed or alleviated the experience of parental stress.

RESEARCH AIMS

This study aimed to identify parental stress predictors in 115 parents of children with autism aged 3-10 years by considering individual and environmental factors.

RESEARCH METHODS

The researchers administered three broad self-report measures to the 115 parents in the sample. These measures were:

1. A parenting index that measured parental stress, levels of parental distress, parent-child relationships and parental self-efficacy.
2. A measure of individual parental factors, e.g. parental sex, age and employment status, and individual characteristics of the child, e.g. sex, age, autism diagnosis and communication abilities.
3. A measure of environmental characteristics, e.g. levels of home and community support, services that are available, accessibility and support of extended family.

These findings were then subject to a multiple regression analysis seeking to establish the relationships between and within the variables in order to determine the circumstances that might predict or alleviate parental stress.

RESEARCH FINDINGS

The researchers found that 70% of the sample (N=115) experienced high levels of stress and that

there was no significant difference between the stress experienced by mothers and fathers.

Overall environmental variables were found to be most related to the experience of parental stress. Parents who had less contact and support from extended family and had little or no support from the child's school or parents of children who were out of school all experienced higher levels of stress than those parents who had access to environmental supports.

IMPLICATIONS FOR PRACTICE (by the authors)

Studies into parental stress have focused on the characteristics of the child, e.g. difficult and unpredictable behaviours and communication difficulties. While child factors remain important, this research highlights the importance of exploring parental supports within the home, extended family and school. Those parents who experienced support from their community, family and child's school expressed lower levels of stress than parents who did not have access to supports, and this was irrespective of the child's diagnosis and experience with autism.

Service planners should be mindful of capacity building within schools, families and communities when planning supports for parents of autistic children.

Full Reference

Derguy, C., M'Bailara, K., Michel, G., Roux, S. and Bouvard, M., (2016). The Need for an Ecological Approach to Parental Stress in Autism Spectrum Disorders: The Combined Role of Individual and Environmental Factors. *Journal of Autism and Developmental Disorders*. 46(6), p.1895-1905.

THE ROLE OF CHILD PROBLEM BEHAVIORS IN AUTISM SPECTRUM SYMPTOMS AND PARENTING STRESS: A PRIMARY SCHOOL-BASED STUDY

BACKGROUND

Parents of children with autism spectrum disorder (ASD) are reported to experience higher levels of stress than those of typically developing (TD) children. Previous research has demonstrated that externalising problem behaviours such as disruptive and conduct problems consistently correlated with parenting stress over time. In contrast, internalising behaviours, such as emotional behaviours, were a weak predictor of parenting stress. Further research has noted that only externalising problem behaviours, parental coping abilities and social resources predicted parent stress at the time of diagnosis among preschoolers with ASD rather than the severity of the diagnosis itself.

RESEARCH AIMS

While child problem behaviours were found to be a major source of parenting stress in parents of children with ASD, the role of ASD symptoms, problem behaviours and prosocial behaviours in contributing to parental stress has been rarely investigated. While stressful experiences are reported by parents during the diagnostic process, it is not yet known whether the diagnosis of ASD itself increases parenting stress. The current study aims to (1) compare child behavioural characteristics and parenting stress between two groups; (2) examine the relationships between ASD symptoms, child problem behaviours and prosocial behaviours, and parenting stress in the two groups; (3) examine the role of an ASD diagnosis in parenting stress in a combined sample of both groups; and (4) to test the mediating effects of child problem and prosocial behaviours on the association between ASD symptoms and parenting stress.

RESEARCH METHODS

A primary-school based case-control study was conducted to evaluate the test accuracy of the Cantonese version of the Childhood Autism Spectrum Test (CAST). In the school-based survey, measures were added which assessed child problem and prosocial behaviours and parenting stress. These were examined for relationships among parents of children with ASD and TD children aged 6–11 in Hong Kong.

The case-control design allowed the researchers to examine the role of ASD symptoms in the relationship between child externalising and internalising behaviours and parenting stress. These were measured between two groups of parents of children with ASD and TD children, some of whom experienced ASD symptoms but were not formally diagnosed. By using a continuous variable of ASD symptoms, it enabled the researchers to examine the labelling effect of the ASD diagnosis.

Participants for the study were recruited via an ASD screening tool which was distributed to parents of children attending five mainstream primary schools and two ASD special education schools. The final sample of analysis used for the study included 177 children with ASD and 554 TD children.

The CAST was completed by parents and assessed the severity of autism spectrum symptoms. The Strengths and Difficulties Questionnaire (SDQ) was used to assess externalising and internalising problem behaviours and prosocial behaviours. Finally, the Parenting Distress subscale of the Parenting Stress Index-Form (PSI-SF) measured the level of stress a parent perceived as a direct cause of personal factors relating to parenting.

RESEARCH FINDINGS

A total of 731 parents, including 177 children with ASD and 554 TD children, completed the survey of which 77% were female. Ninety-three per cent of the children referred to in the study with ASD and 85% of TD children were male.

The following nine key variables were measured:

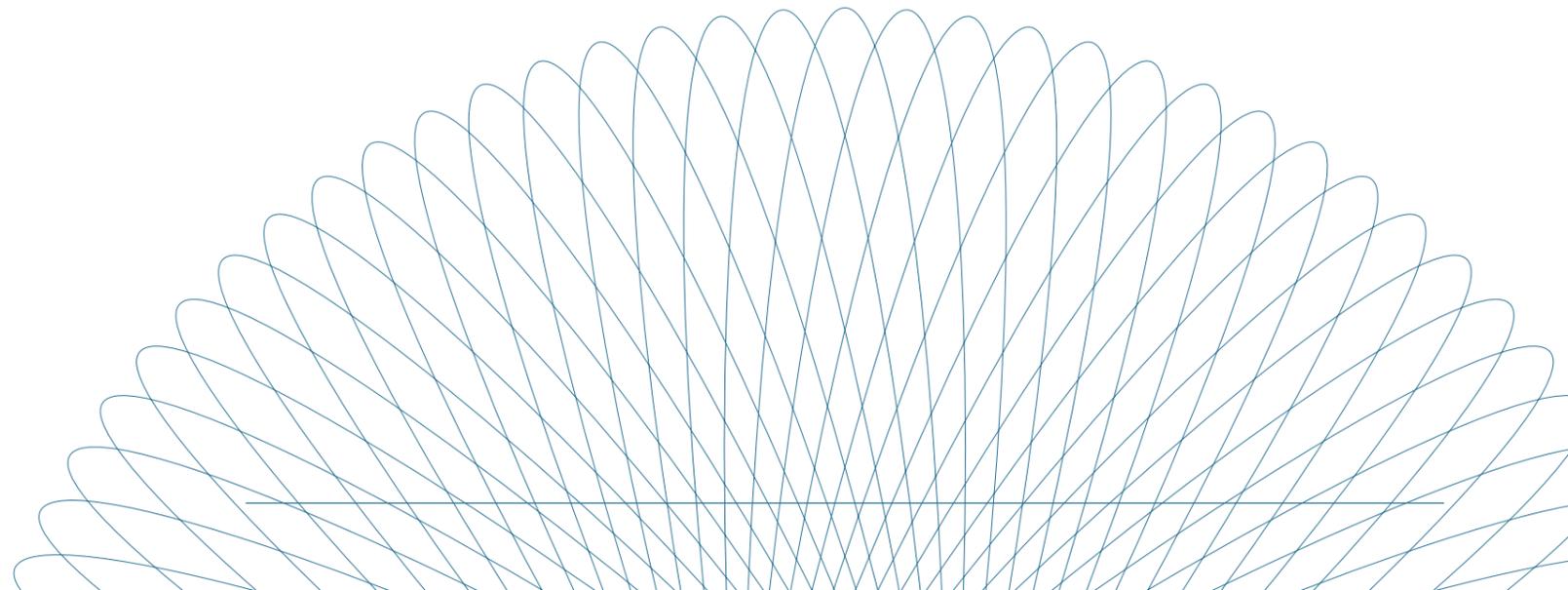
1. Parenting stress
2. CAST
3. Externalising behaviours
4. Conduct behaviours
5. Hyperactivity
6. Internalising behaviours
7. Emotional problems
8. Peer problems
9. Prosocial behaviours

Compared to parents of TD children, parents of children with ASD reported significantly higher scores of parenting stress, CAST, externalising and internalising behaviours and lower scores in prosocial behaviour.

For parents of children with ASD, externalising problem behaviours and prosocial behaviours of children were significant indicators of parenting stress. Parenting stress was positively associated with externalising behaviours and negatively associated with prosocial behaviours. Single parenting and severity of autism symptoms were also positively associated with parenting stress; however, these results were not significant when all variables were examined as a whole.

For parents of TD children, internalising and externalising behaviours were found to be significant indicators of parenting stress. Parenting stress was further positively associated with single parenting and household income. The severity of autism symptoms in TD children displaying characteristics of ASD was positively associated with parenting stress; however, these results were not significant when all variables were examined as a whole.

Considering the whole sample, the diagnosis of ASD alone did not account for parenting stress significantly; however, externalising behaviours, internalising behaviours and prosocial behaviours were significant.



IMPLICATIONS FOR PRACTICE (by the authors)

- The importance of sharing caregiver roles is emphasised for stress management in parents.
- Interventions for children with ASD that target externalising behaviours could be effective in improving the child and parent outcomes in comparison to clinical symptom-oriented interventions.
- Early intervention in parenting stress is crucial to increase family resilience.
- Parental needs and cognitive and behaviour skills to cope with child problem behaviours should be assessed at the time of ASD diagnosis.
- Parental interventions should include parental management of daily-life activities, linking with support groups, parental training specific to ASD and positive cognitive interventions to support parental adjustment to parenting a child with ASD from a positive perspective.

Full Reference

Siu, Q.K.Y., Yi, H., Chan, R.C.H., Chio, F.H.N., Chan, D.F.Y. and Mak, W.W.S., (2018). The Role of Child Problem Behaviors in Autism Spectrum Symptoms and Parenting Stress: A Primary School-Based Study: *Journal of Autism and Developmental Disorders*, p.1-14. [Viewed 4 February 2019]. Available from: doi.org/10.1007/s10803-018-3791-7

CONCLUSION

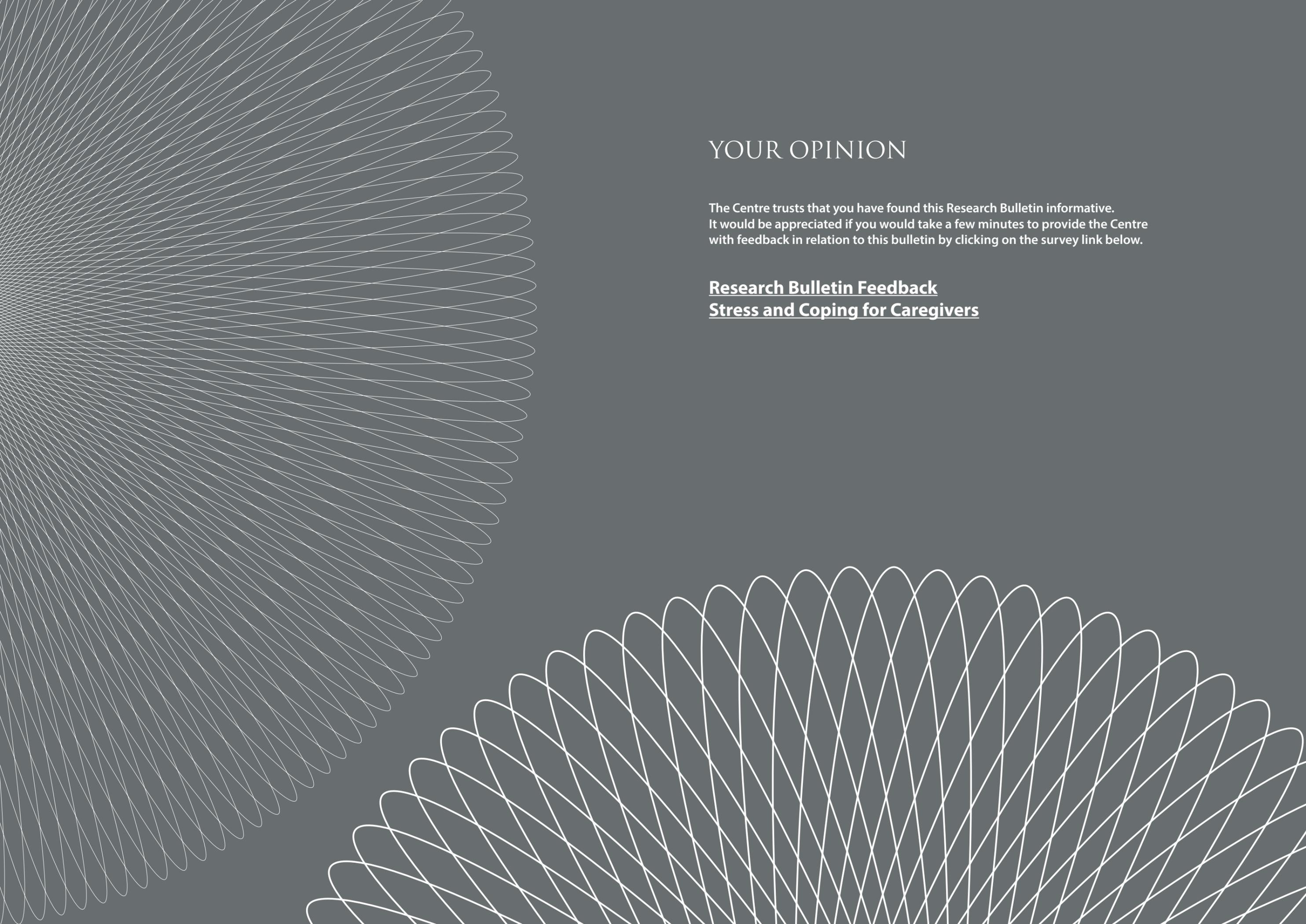
This Bulletin provides summaries of eleven research articles. The articles address a range of issues related to the experience of stress in parents of children with autism and the factors that exacerbate and alleviate stress.

Parental support is a key issue and this refers to practical and emotional supports; for example, financial issues can place a strain on parents as can issues related to accessing suitable supports and interventions for their children. Community and extended family support are also important; those parents who experienced higher levels of support within their families and communities reported lower levels of stress.

Professionals and agencies providing parental supports should bear the following in mind:

- Practical supports, e.g. transportation to appointments.
- Emotional supports, e.g. stress and coping.
- Training and information for parents and extended family and awareness for communities and employers.
- Access to support for young adults, e.g. support with life skills.

Support for parents is not a one-off occurrence around the time of diagnosis and assessment but rather an ongoing process that is dynamic with the development of the child and family.



YOUR OPINION

The Centre trusts that you have found this Research Bulletin informative. It would be appreciated if you would take a few minutes to provide the Centre with feedback in relation to this bulletin by clicking on the survey link below.

Research Bulletin Feedback
Stress and Coping for Caregivers



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