CONTEXTUAL CORRELATES OF CHALLENGING BEHAVIOUR SHOWN BY CHILDREN AND YOUNG PEOPLE

by

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Thesis Overview

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology at the University of Birmingham. The thesis comprises of two volumes. All identifying information has been anonymised for confidentiality.

Volume One

This volume comprises three chapters. The first chapter is a quantitative systematic review of the literature reporting on maternal parental stress, child challenging behaviour and a psychological resilience construct. The second chapter is a multimethod research study which explores the reliability of a measure of emotional outbursts in the deaf population whilst investigating their emotional outburst profiles. The third chapter is a press release document, providing an overview of the systematic quantitative review and multimethod research study.

Volume Two

This volume comprises five clinical practice reports (CPRs). The first report presents the case of a 56-year-old female diagnosed with obsessive compulsive disorder, formulated from a cognitive behavioural and psychodynamic perspective. The second report presents a service evaluation of a new way of working within an adult community mental health team. The third report is a single-case experimental design, evaluating the effectiveness of a cognitive behavioural intervention with a 15-year-old female with social anxiety disorder. The fourth report presents a case study of a 54-year-old female with a learning disability presenting with behaviour which challenges, using cognitive analytic therapy. The final report presents an abstract of an oral presentation of the development of a staff well-being service during the Covid-19 pandemic.

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a) Volume One

i) Literature Review: What are the relationships between parental stress, child challenging behaviour and maternal psychological resilience? A systematic review of quantitative studies

ii) Empirical Research Paper: Profiling Emotional Outbursts in Deaf and Hard of Hearing Children and Young People

b) Appendices for Volume One

c) Volume Two

i) Clinical Practice Report 1: The Assessment and Formulation of ‘Sandra’ from a Psychodynamic and Cognitive Behavioural Perspective

ii) Clinical Practice Report 2: What is the impact of the new way of working within the Psychology Community Mental Health Team?

iii) Clinical Practice Report 3: A Single Case Experimental Design of a case study of 'Sophie', a client with Social Anxiety Disorder in a Child and Adolescent Community Mental Health Team

iv) Clinical Practice Report 4: A case study report of a cognitive analytic therapy intervention with 'Sharon', a client with relationship difficulties within a Community Learning Disability service.

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What are the relationships between parental stress, child challenging behaviour and maternal psychological resilience? A systematic review of quantitative studies

Abstract

Background

Mothers of children with neurodevelopmental disorders are at risk of experiencing stress, associated with the demands of parenting, an experience known as parental stress. Parental stress is known to impact on the way in which parents respond to the behaviour of their child, they perceive as challenging. Consequently, children can present with higher levels of challenging behaviour which in turn can increase the level of parental stress. Previous literature has examined coping strategies of mothers to manage their stress and efficacy of behavioural interventions. This review aims to deconstruct the term ‘psychological resilience’ into distinct constructs which can be examined for efficaciousness in reducing the negative impact of this transactional relationship.

Method

A systematic search of the literature was initially carried out on May 25th 2020, using PsycINFO, PubMed, Web of Science and ProQuest databases. 253 full texts were screened against exclusion criteria, resulting in the inclusion of 11 articles. Main inclusion criteria were studies which used self-reported measures of mothers’ parental stress, an aspect of psychological resilience and of child challenging behaviour. A quantitative review of the literature was carried out. Risk of bias was assessed using adapted quality frameworks. Five subgroups were created based on constructs of psychological resilience and specific measures or subscales allocated to them. Subgroups consisted of: Social support, active coping, cognitive framing, growth and avoidance. Relationship between parental stress and child challenging behaviour and the mean level of resilience data, for each subgroup, was synthesised into a visual graph.

Results

1521 participants were included in the overall review, most children were male and had a diagnosis of ASD; ages ranged from 2 to 18 years. Visual interpretation of the data, across studies, without considering subgroups, indicated an association between increased psychological resilience and a smaller relationship between challenging behaviour and parental stress. Of the various subgroups, social support and cognitive framing showed the most promise, with social support having the strongest association with a weaker relationship between parental stress and challenging behaviour. The results regarding active coping and growth were inconclusive. Increased avoidance appears to be associated with a stronger relationship between parental stress and challenging behaviour.

Discussion

These tentative associations across study populations could not be examined statistically and so must be considered with caution. They do however provide a foundation for considering future research in this area.

Parents of children with neurodevelopmental disabilities are at increased risk of experiencing parental stress compared to parents of typically developing children (Hsiao, 2017). Parental stress is a complex process which encompasses the link between tasks demands, parental psychological health, parent-child relationship, and the child's psychosocial adjustment. Parental stress is experienced as negative feelings, attributed directly to parenting demands (Deater-Deckard, 1998:2006). Parental stress is thought to arise from a mismatch between parental resource and the ability to respond and meet the demands of parenting (Abidin, 1990; Deater-Deckard, 1998; Williford et al., 2007). More consideration is now being applied to this specific stress response, given the negative implications it has in relation to both child behaviour (Silinikas et al., 2020) and family outcomes (Hsiao, 2017; Dennis et al., 2018).

Parent responses to the child can be negatively influenced by parental stress, due to an increase in irritation and a hypervigilance to perceived challenging behaviour (Kazdin & Whitley, 2003; Zablotsky et al., 2013). These responses often result in an increase in the child's perceived challenging behaviour, leading to maintenance and exacerbation of both child and parental distress (La Gasse et al., 2016). Despite a relatively small sample, Dennis et al. (2018) provided strong evidence showing that when higher levels of parenting stress are present, relational frustration is increased which, in turn, is related to an increase in challenging behaviour. To improve family outcomes, parental stress and its relationship with perceived challenging behaviour in children, alongside parenting variables which may mediate this relationship (Dennis et al., 2018), must be further understood (Hayes & Watson, 2013).

Challenging behaviour is commonly compartmentalised by two broad constructs of behaviour: externalising behaviour which encompasses hyperactivity, high impulsivity, aggression, tantrums and defiance and internalising behaviour which includes social withdrawal, anxiety, sadness, and fearfulness (Achenbach & Edelbrock, 1981; Werry & Quay, 1971; Woodman et al., 2014). Both types of behaviours can exacerbate parental stress, and parental stress can similarly exacerbate these behaviours, resulting in a transactional relationship between parental stress and challenging behaviour (LaGasse et al., 2016). Challenging behaviour, within this review, will refer to externalising behaviours as there is strong evidence that externalising behaviours shows robust power of predicting parental stress (Baker et al., 2003; Barroso et al., 2018; Crnic et al., 2005; Neece et al., 2012). Previously, Anthony et al., (2005) demonstrated, in a specific sample of two to six years olds within a parent intervention programme, that high levels of parenting stress correspond with high levels of externalising behaviour. Despite the limited generalisability of Anthony et al., (2005)'s research, recent literature supports the direct relationship between parental stress and a rise in externalising behaviour (Barroso et al., 2018; Mackler et al., 2015).

There is a high prevalence of challenging behaviour in children with developmental disabilities (Dennis et al., 2018). Currently, management of these behaviours is varied with both pharmacological and non-pharmacological interventions (Guinchat et al., 2020). The responsibility for management of these interventions often lies with the parents, arguably increasing the likelihood of stress on parents. Certainly, in a review of 17 qualitative research papers, parents of children with developmental disabilities reported chronic strain due to the demands of caregiving, particularly related to challenging behaviour (Griffith & Hastings, 2014). Despite evidence indicating that the demands of interventions contribute to stress in parents, it is unclear how successful behavioural interventions are. Tarver et al. (2019) conducted a systematic review and meta-analysis investigating the efficacy of behavioural interventions for challenging behaviour in children with Autistic Spectrum Disorder (ASD), and parental stress and efficacy. The impact of behavioural interventions on challenging behaviour appears unclear, which may be due to the weak rigour of the included studies and the relatively small sample included for review. Additionally, there was no effect on parental efficacy following interventions (Tarver et al., 2019). Given the complex and interactional relationship between parental stress and challenging behaviour, it may not be sufficient to focus solely on behavioural interventions.

Despite the abundance of literature highlighting the transactional relationship between parental stress and challenging behaviour, few interventions target parental stress (Dennis et al., 2018). Parents with high levels of parent stress, however, are found to be less likely to be able to implement behavioural interventions (Kazdin, 1995; Theule et al., 2018). To improve clinical outcomes, a recent review highlighted the need to understand parent variables and how these can influence treatment for families (Shalev et al., 2019). There is promising evidence to suggest psychological resilience can mediate the transactional relationship between stress and challenging behaviour (Guralnick, 2004; Migerode et al., 2012; Widyawati et al., 2021). Studying resilience within families of children with developmental disabilities allows researchers to identify various adaptive strategies that can support parents in overcoming stress (Gousse, 2010; Manicacci et al., 2019), however, studies investigating characteristics of parental resilience are scarce (Widyawaiti et al., 2021).

Scarcity of research in this area may be due to major discrepancies relating to conceptualisation of the term ‘resilience’ (Fletcher & Sarkar, 2013). Most definitions of resilience focus on positive adaptation to adversity (Fletcher & Sarkar, 2013). The term adversity – part of the core concept of resilience – is also contentious, however it has been defined by some researchers as any hardship or suffering which links to a difficulty, misfortune, or trauma (Jackson et al., 2007). Moreover, many adversities individuals encounter are not major disasters but daily struggles (Davis et al., 2009). In the present review, the term adversity relates to the experience of parenting a child with a developmental disorder, who presents with challenging behaviour. Psychological resilience, therefore, refers to a psychological construct which helps parents to adapt and overcome this adversity (Hayes & Watson, 2013; Vilaseca et al., 2020). To the best of our knowledge, no previous review has examined studies pertaining to all adaptive strategies that may constitute psychological resilience in this context.

The literature introduced above highlights the importance of understanding the role that all aspects of psychological resilience may play, in the complex relationship between parental stress and challenging behaviour, to optimise the family outcomes of a disabled child (Hsiao, 2017). Therefore, the goal of this systematic review was to focus specifically on research capable of furthering our understanding of the relationship between psychological resilience, parental stress, and the challenging behaviour of children with neurodevelopmental disorders. Given the limited number of papers reporting solely on fathers at abstract screening and considering the homogeneity of including papers which reflected both mothers and fathers, it was felt that focusing solely on mothers would increase the clinical effectiveness of the findings. Inclusion criteria, after abstract was altered to reflect this. We aimed to conduct a descriptive analysis to: (a) examine the relationship between parenting stress and child challenging behaviour to set the studies in this review against the wider backdrop of studies available in the literature; (b) examine the extent to which psychological resilience shows an impact on the relationship between challenging behaviour and parenting stress and (c) the impact of the different concepts of resilience.

Method

Selection of Studies and Inclusion Criteria

The full inclusion/exclusion criteria with justification are presented in Table 1. An initial search of the overall literature was conducted, prior to establishing exclusion and inclusion criteria. This allowed for a comprehensive view of current research within the field of parental stress, psychological resilience, and child challenging behaviour. The main criteria were for studies to have reported on the relationship between maternal parental stress and challenging behaviour of their child with a neurodevelopmental diagnosis and include a reported aspect of the mother's psychological resilience.

To increase clinical relevance, psychological resilience measures were restricted to concepts which could be taught (see Table 1, in which we also include a list of psychological resilience concepts derived from our search, which met this criterion). Vanderbilt-Adriance and Shaw (2009) theorised that resilience is a dynamic process, rather than an inherent characteristic, influenced by environmental factors. Recent research provides some evidence of self-reported change in personality characteristics through intervention (Stieger et al., 2020), however, most literature documents a steady personality trait development over time (Damian et al., 2018; Roberts & Walton, 2006) in contrast to something that can be learned or quickly changed.

Within the literature, evidence shows specific differences for coping and stress between genders, especially in the context of caring for children with disabilities (Vilaseca et al., 2020). Research often indicates that mothers' levels of stress are higher than fathers (Dabrowska & Pisula, 2010; Hastings, 2003; Herring et al., 2006), however, such findings are mixed (Ilias et al., 2018). Differences in types of coping have also been highlighted between genders (Al-Yagon, 2014; Hastings et al., 2005). Various studies suggest that avoidant coping strategies are more likely to be used with fathers of children with challenging behaviour, whilst Obeid and Daou (2015) found that this type of coping had a negative impact on mothers. There is tendency for mothers to have more involvement in acquiring and utilising support for their child (Benson, 2010; Vilaseca et al., 2020), therefore, here we focused on the parental stress and resilience of mothers in relation to child challenging behaviour.

Table 1

Inclusion criteria and justification

Inclusion criteria	Justification
Challenging behaviour of the offspring of the mother completing the report, which encompasses externalising behaviours such as aggression, tantrums, self-injurious behaviour etc.	This is to ensure that the studies reflect externalising behaviour, as although internalising behaviour can also be challenging, studies show that externalising behaviour has a higher correlation with parenting stress (Baker et al., 2003; Barroso et al., 2018; Crnic et al., 2005; Neece et al., 2012).
A self-report measure of at least one aspect of parental resilience where resilience is defined as a measurable psychological construct which may potentially protect against poor mental health outcomes. The aspects of potential resilience should refer to those which can be taught or trained. Include: • protective factors • adaptability • adjustment • coping • emotional adjustment • reframing • cognitive appraisal • personal resource • internal resource • problem solving • psychological flexibility • parenting efficacy • confidence	To collect clinical useful information to inform interventions focused on decreasing parental stress and challenging behaviour, only aspects of resilience that can be taught or trained were included. Personality traits, arguably, are less able to be changed.
Studies that report a measure of parental stress. Only the total score of parenting measures was included. Psychopathological symptoms, not related directly to	To examine parenting stress in relation to challenging behaviour and resilience it was important that studies were only included if a type of this was reported. If

Inclusion criteria	**Justification**
the child, such as anxiety measures were not included.	psychopathological symptoms were measured it would be unclear whether this was a result of the parent's own psychopathology. To correctly compare the data when studies used the Parental Stress Index (Abidin, 1995) , only the total score was used. Studies which only included an element of this measure were excluded.
Only cross-sectional studies were included or the primary data from longitudinal studies.	This is to investigate the relationships between the three variables without any confounding variables such as an intervention.
Participant focus	
Initially, the inclusion criteria encompassed parents of any age. The inclusion criteria were amended following abstract screening to mothers of any age.	Gender differences could not be accounted for in studies reporting on both parents, therefore, to increase heterogeneity this review focused on one gender. As mothers typically undertake more of the caretaking role there was a higher proportion of literature to review.
The term 'child' referred to offspring under the age 18. The child must have a diagnosis of a developmental disability.	Often adults with developmental disabilities can remain in the family home. To be able to generalise findings, it was important to establish the age range of the child.
Outcome data	
The studies are required to report either Means and Standard Deviations relating to resilience. Studies must report a correlational statistic related to stress and challenging behaviour.	To ensure that outcomes can be calculated into an effect size. To ensure a relationship has first been established between stress and challenging behaviour to be able to conduct an analysis on the role of resilience.
Type of article	
The following article types were excluded: meta-analysis/theoretical papers/ reviews/commentaries/ clinical guidance/non-outcome focused studies i.e. association studies/case studies/validation of psychometric scales/qualitative papers	These articles do not provide the outcome data needed for this review.
Peer-reviewed journal articles and theses and dissertations were included.	To increase the integrity of the overall review by including all possible sources whilst ensuring that those included contain accurate and reliable information.
Language	
Only journals that were written in English were	Obtaining non-English versions for translation was

Inclusion criteria	Justification
included.	beyond the scope of this review.
Outcome Data and study design (N<10, single-case designs, Case series)	
When the study does not present group data and only provides individual scores.	This is to ensure that an effect size can be calculated and increases methodological rigour of studies included.

Search Strategy and Study Selection

A systematic search of the literature was initially carried out on May 25th, 2020 using PsycINFO, PubMed, Web of Science and ProQuest databases. Search terms were either free or combined by ‘OR’. The search was limited to peer review articles from 1967 to May 2020. The aim of the search was to obtain a comprehensive picture of the literature into psychological resilience, parental stress, and child challenging behaviour. The search terms that were used to identify these three constructs, which were then combined and are outlined in Table 2 below.

Table 2

Search strategy

Construct	Free Text Search Terms
Resilience	"psychological resilien*" or "protective factor*" or "Adaptability" or "Adjustment" or “Coping” or "Emotional adjustment" or "Adaptiv*" or “reframing” or “cognitive appraisal” or “personal resource*” or “internal resource” or “problem solving” or “psychological flexibility”
Stress	"parenting stress" or "parental stress" or "maternal stress" or "paternal stress" or "parent related stress" or "parenting hassles" or "caregiver stress" or "caregiver strain"
Child challenging behaviour	"Child behavio*" or "behavio* problems" or “Externalizing behavio*” , “externalising behavio*” aggress* OR “self injur*” OR “self-injur*” OR SIB OR destruct* OR tantrum* OR "temper outburst*” OR meltdown* OR blip* OR rage* O R “challenging behaviour*” OR “challenging behavior*” OR pica OR stereotypy OR noncompliance OR “inappropriate vocalization*” OR “inappropriate vocalisation*” OR screaming OR “off task behaviour” OR “off task behavior" OR yelling OR “inappropriate touching” OR pushing OR “not following

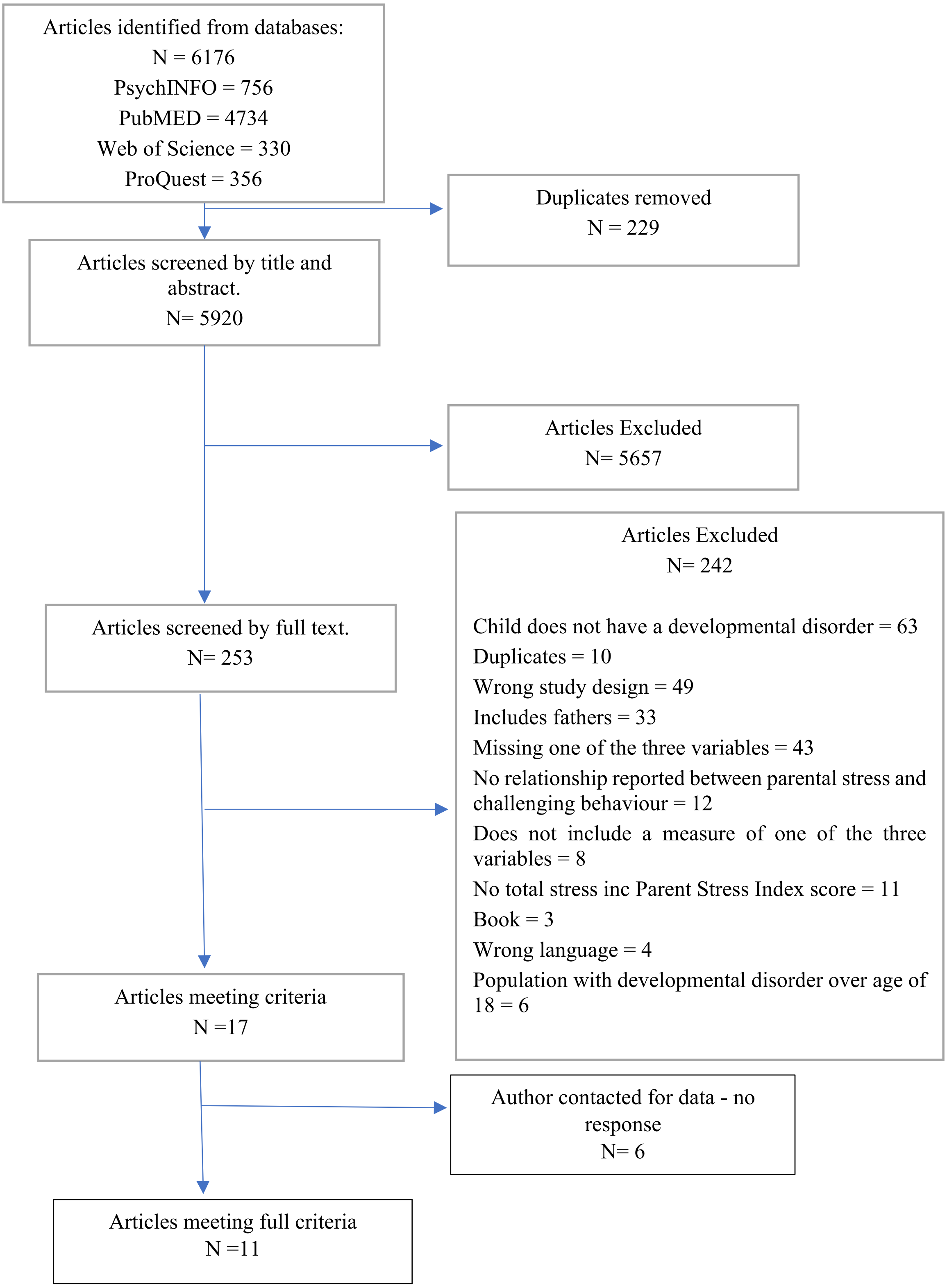
	directions” OR shouting OR arson OR regurgitation OR pinching OR scratching OR throwing OR biting

Study selection. The results of the systematic search are presented in Figure 1. The search yielded 6176 articles which reduced to 5918 once duplicates were removed. These articles were then screened by study title and abstract, using the exclusion criteria, by two reviewers. Both reviewers met to discuss any conflicts (N = 128) and agreed on which of these papers should be assessed at full screen (N = 51). At this stage, it was agreed, given the reasons reported in Table 1, that papers reporting on fathers would be excluded at the next full text screening stage. Full text screening took place (N = 253) with two reviewers. Again, the exclusion/inclusion criteria were used and reviewers met to discuss any conflicts (N = 25). If there were outstanding issues, it was planned that the authors of studies would be contacted, or a third research team member would be contacted.

The three most common reasons for exclusion were: Child not having a neurodevelopmental disability (N=63), wrong study design (N=49), missing one of the three variables, for example, challenging behaviour, parental stress, or resilience (N = 43) and including fathers (N = 33). 17 articles met the inclusion/exclusion criteria agreed by both reviewers. Due to data extraction issues, authors of 6 studies were contacted but did not respond; thus, the studies were excluded from the review. Overall, 11 articles were reviewed.

Figure 1.

Results of the systematic search and applied exclusion/inclusion criteria



Data Collection Process

A data extraction form was designed for the corresponding author to extract all the data. The reliability of selection processes was confirmed by employment of two screeners. Data extraction reliability was checked by a second researcher extracting data from a random sample of three included papers and cross checking with the initial data extraction. No conflicts arose during this process.

Information was extracted from each study on; (1) characteristics of study participants and young people (including age, country of residence, neurodevelopmental disorder and gender); (2) aim or hypothesis of the study; (3) study design; (4) outcome measures including subscales; (5) recruitment method; (6) quantitative data regarding relationship between parental stress and challenging behaviour, the mean and total score for resilience measures and the study sample size and (7) the overall findings of each study.

Risk of Bias within Individual Studies

Quality criteria were established to assess for risk of bias. The quality criteria were adapted from existing frameworks including: Downs & Black (1998), The Cochrane Collaboration Risk of Bias Tool (Higgins et al., 2011) and the Risk of Bias Assessment Tool for Nonrandomised Studies (RoBANS) (Kim et al., 2013). The framework assessed risk of bias in three domains: Selection Bias, Statistical Bias, and Reporting Bias (see Table 3). Reporting bias was separate for each measure to allow for further investigation of the three variables. Each domain was rated as either Low, Unclear or High risk. These ratings were compared with the blind rating of a second research team member, inter-rater reliability was substantial (77.4% blind agreement), conflicts were discussed, and final consensus agreed. If a final decision could not be reached, it was planned that a third research member would be contacted.

Table 3

Quality framework applied to assess risk of bias

Domain	**Details**	**Risk of Bias**
Selection bias	Have the selection method and characteristics of participants been described adequately?	High Risk – No description of the method by which, participants were selected, or characteristics of participants are not described. Stress and resilience have been spoken about in the recruitment. Unclear Risk – The characteristics of the study population are not clearly or fully reported. This includes age range, education years, socioeconomic status, ethnicity, where participants were recruited from (how). Not understood what has been explicitly reported prior to participation e.g. about stress Low Risk – Randomly selected sample from a big pool, or a whole population sample e.g. contacted everyone from a service. The characteristics of the study population are clearly described. Everyone has been invited on the study on child behaviour, not mentioning stress or resilience (more likely to respond if highly stressed so would skew results)
Statistical bias	Bias resulting from the (inappropriate) statistical treatment of the data.	High Risk – Inappropriate Pearson's Coefficient reported e.g. very small sample size (<30) Unclear Risk – A variation or alternative value is provided in place of a Pearson's Coefficient (This could be done on a small sample size) Low Risk – Pearson's Coefficient is reported for correlation
Reporting Bias	**Psychological resilience measure** **Child challenging behaviour measure** **Parental stress measure**	High Risk- Not reported any reliability or validity. Unclear Risk- Evidence of either reliability data or one type of validity data, not both.

Domain	Details	Risk of Bias
		Low Risk- Cronbach's Alpha value reported and at least one type of validity data presented in the paper or referred to as reported in previous research with relevant sample.

Summary Measures

To determine whether there was an association across studies between the mean level of resilience and the relationship between parental stress and child challenging behaviour, the effect size of the relationship was mean level of resilience which was a proportion of the total available resilience score. This method is in concordance with the advice reported by Vanderbilt-Adriance & Shaw (2009), who state that as resilience is such a broad construct encompassing many psychological concepts, it is important that studies do not report on overall resilience but define which type of resilience is being investigated and outcomes reported accordingly. A scatter plot inclusive of calculated 95% confidence intervals was constructed for the outcomes of the descriptive analysis of the quantitative data.

Planned Methods of Analysis

Given the heterogeneity of psychological resilience as a construct, resilience subgroups were defined based on descriptions of the measures, focusing on included items and subscales. The corresponding author identified commonalities and labelled them under a specific resilience measure. Resilience measures were then clustered together under a slightly broader subgroup. Subgroups needed to include more than one measure or subscale and reflect the various specific constructs encompassed within them, based on theoretical understanding of the constructs as defined by the literature. Subgroups were discussed and agreed by a second member of the research team, any conflicts were discussed and amended to determine agreed subgroups (Appendix E).

Meta-analysis was explored for the quantitative data, however within the small sample a diverse range of measures was used, measuring various types of resilience. It was therefore deemed inappropriate to run a meta-analysis, given the implications on the integrity and meaningfulness of the findings (Higgins et al., 2021). To aid visual interpretation of the association between type of resilience and strength of the relationship between child challenging behaviour and parental stress, the Pearson's R correlation coefficient and the standardised mean resilience scores were presented in a graph using excel.

Any studies which used beta-coefficient were approximated into Pearson coefficient using the transformation described by Lipsey and Wilson (2001) and Wilson (2016). Resilience measures were clustered into subgroups and resilience level of each subscale or measure was standardised by dividing the sum of mean values for each resilience measure belonging to a subgroup, by the sum of total scores for those resilience measures. Subscales/measures from the same study could not be clustered together in a subgroup, as the Pearson's value would be the same, therefore, the most valid and reliable measure was taken for the purpose of the review. For studies with more than one subscale reflecting a subgroup, a mean effect was calculated by calculating the mean of each subscale and dividing by the total number of subscales, as reported in Ekers et al. (2014) and justified by Van Tulder et al. (2003).

Results

Study Characteristics

Methods. The study characteristics of the eleven studies selected for the review are reported in Table 4. All studies were cross-sectional survey studies published in English. One study was a longitudinal study with only data at Time 1 represented within this review. Questionnaire completion took part either in person or via online surveys.

Aims/Hypotheses. Most studies aimed to examine the three variables (parental stress, child challenging behaviour and a resilience construct). The hypothesis or aims were mixed across studies, some focused on the impact of behaviour on stress whilst others looked at mediating variables. Only specific outcomes of the included studies were relevant to the review question, these are reported in Table 4 and the results.

Recruitment. Most recruitment took place from services specifically for families of children with autism or additional needs for example, health clinics, special educational settings. GPs, Schools, and support groups were also targeted. One study recruited across two states with no specific reference to the child having a diagnosis.

Participants. The included studies involved 1521 participants. The main inclusion criteria entailed mothers of children diagnosed with a neurodevelopmental disorder. Most children had a diagnosis of Autistic Spectrum Disorder (ASD); Other diagnosis included Down syndrome, Attentional Deficit Hyperactivity Disorder (ADHD), Cerebral palsy etc. The studies represent a multi-national population recruiting from Bangladesh (1), Taiwan (1), Spain (2), Australia (2), Malaysia (1), Canada (1), USA (2) and England (1). The age of the children of participants ranged from 2 to 18 years.

Measures. The full range of reliability and validity scores are reported in Appendix F. The studies reporting measures of psychological resilience had varied reliability, with internal consistency ranging from questionable (0.62; Norizan & Shamsuddin, 2010) to excellent (0.94; Wayment et al., 2019). Two studies referred to validity, although did not provide any measures (Connor & White, 2014; Plant & Saunders, 2007). One study (Moborak et al., 2000) did not report reliability or validity for the measure.

The reliability for measures of parental stress were consistently good to excellent, although one study (Ho, 2013) reported internal consistency of poor (.49) to excellent (.91). One study (Mobarak et al., 2000) did not report reliability or validity for the measure, although it was referred to in another study. Validity was referenced by three studies (Miranda et al., 2019; Pozo & Sarria, 2014; Zaidman-Zait et al., 2017).

The internal consistency in measures of child challenging behaviour ranged from acceptable (0.78; Wayment et al., 2019) to excellent (0.95; Zaidman-Zait et al., 2017). Pozo and Sarria (2014) reported their measure showed a significant correlation ($r = .55$, $p < .01$) with scores from the Behaviour Problems Inventory, a reliable and valid tool (Rojahn et al., 2001). One study (Mobarak et al., 2000) did not report reliability or validity for the measure, although it was referenced to in another study.

Table 4

Table of study characteristics, child demographics and outcomes

Authors/Date	Research Hypothesis/ Aims	Research instruments	Sample/Sampling methods	Child demographics	Outcome
Miranda et al., 2019	To determine whether there is a mediating role of coping strategies, behavioural difficulties and social support in the relationship between symptoms severity and parenting stress in mothers of children with ASD (autism spectrum disorder).	Resilience: (Brief COPE Carver, 1997; Spanish adaptation by Morán et al., 2010) Child Challenging Behaviour: (Strengths and Difficulties Questionnaire (SDQ); Goodman, 1997; adapted to the Spanish population by Rodríguez-Hernández et al. (2012) Parental Stress: Parenting Stress Index – Short Form (PSI-SF; Abidin, 1995; adapted to Spanish by Díaz-Herrero et al., 2010)	N=52 mothers recruited through public schools and support groups within the Vatican community in Spain. Questionnaires.	Diagnosis: ASD Gender: Male – 52 Female – 0 Age: Mean - 8.59 years SD – 1.83 years	Analysis revealed a significant positive correlation between parenting stress index and SDQ scores. There was also a significant negative correlation between parenting stress index and both engagement coping and social functional support. Both behavioural problems and engagement coping were significant predictors of parenting stress, confidant support was not. Mediation analysis highlighted a larger effect of engagement coping in the relationship between ASD symptoms and parenting stress than behavioural difficulties however both were significant.
Wayment et al., 2019	To empirically evaluate predictors of post traumatic growth (PTG)	Resilience: The Posttraumatic Growth Inventory (PTGI;	N=364 Mothers of children with Autism recruited from interactive	Diagnosis: ASD	Correlations revealed that PTG was significantly positively correlated with

	in mothers of children with Autism.	Tedeschi and Calhoun, 1996) Three questions on social support adapted from Lepore et al., (1996). The Quiet Ego Scale (QES; Wayment et al., 2015) Child Challenging Behaviour: Created by research team two-items on behaviour. Parental stress: ASD-related rumination was assessed with four items that were adapted from existing rumination scales	autism network (IAN) in Arizona. Online questionnaire.	Gender: Male - 289 Female - 75 Age: Mean – 11.63 years SD – 4.08 years	social support and quiet ego characteristics which represent a eudaimonic motivation. Child aggressive behaviour was significantly negatively associated with social support.
Halstead et al., 2018	To explore maternal resilience and whether it served as a compensatory (direct, positive impact on maternal well-being) or protective factor (moderate the association between child behavioural and emotional problems and maternal well-being).	Resilience: The Brief Resilience Coping Scale (Sinclair and Wallston, 2004) Child Challenging Behaviour: Strengths and Difficulties Questionnaire (SDQ: Goodman 1997, 1998) Parental Stress: a shortened seven-item version of the Parent and Family Problems scale from the Questionnaire on Resources and Stress-	N = 312 mothers recruited through multi-point recruitment methods e.g. GPs, Schools, Support groups within England. Online questionnaires	Diagnoses: ASD – 171 Various neurodevelopmental disorders – 93 Downs Syndrome - 48 Gender: Male – 227 Female – 85 Age: Range – 4 to 15 years	A significant correlation was found between both child behavioural/emotional problems and maternal resilience with maternal well-being outcomes. Further analysis yielded unclear interaction effects. Visual representation of the data indicated that higher levels of maternal resilience were associated with lower maternal stress when child behavioural and emotional levels were at low levels. This did not

		short Form (QRSF7: Griffith et al. 2011).			support the prediction that resilience would affect the maternal outcomes at high levels of child behavioural and emotional problems.
Zaidman-Zait et al., 2017	To determine whether parenting stress and mothers' personal (i.e. coping strategies) and social resources (both family and community-based) were associated, at the time of ASD diagnosis (T1), beyond child level variables.	Resilience: Ways of Coping Questionnaire (WoC; Folkman and Lazarus, 1988) Child Challenging Behaviour: Child Behaviour Checklist 1.5–5 (CBCL 1.5–5; Achenbach and Rescorla, 2000) Parental Stress: Parenting Stress Index: Short Form (PSI-SF; Abidin, 1995)	N=283 Mothers data from Pathways in ASD, a large Canadian longitudinal multisite study. Questionnaires.	Diagnosis: ASD Gender: Male – 237 Female – 46 Age: Mean - 38.9 Months SD – 8.6 months	Higher child externalising behaviour was associated with significantly higher levels of parenting stress after controlling for other child variables. However higher levels of use of social support and active engagement were significantly associated with less parental stress, and this association was significant, even taking into account that with child externalising behaviour.
Connor & White, 2014	It was hypothesized that, in mothers of children with and without ASD, increased levels of maternal mindfulness would significantly predict decreased levels of stress, above and beyond child behavioural problems.	Resilience: Mindful attention awareness scale (MAAS; Brown & Ryan, 2003) Child Challenging Behaviour: Aberrant behaviour checklist (ABC: Aman, Singh, Stewart, & Field, 1985)	N=67 Mothers were recruited through online sources and flyers across two American states. Questionnaires.	Diagnosis: ASD Male – 55 Female – 12 Age: Range - 4 to 17 years	For mothers of children with ASD, behavioural difficulties were significantly associated with increased maternal stress. Lower levels of maternal mindfulness were also significantly linked with higher levels of maternal stress.

	**Data from mothers of ASD group only used for this review.*	Parental Stress: Perceived stress scale (PSS; Cohen, Kamarck, & Mermelstein, 1983)			
Pozo & Sarria, 2014	To determine whether maternal stress levels can be predicted by child's behaviour problems, social support, and SOC 4.5 years later. To investigate movement or consistence in stress and predictive variables over time. **Longitudinal study data collected at Time 1 used for this review.*	Resilience: The Sense of Coherence Questionnaire (SOC; Antonovsky, 1987)/ The Support Checklist for Parents of the Handicapped Parental Stress: Parenting Stress Index – Short Form (PSI-SF; Abidin, 1995) Child Challenging Behaviour: Created by the research team	N = 21 mothers recruited from a convenience sampling within special educational needs schools in Spain.	Diagnoses: ASD - 18 Other - 3 Gender: Male – 17 Female – 4 Age: Mean -12.19 years SD = 7.19 years	The longitudinal results of the study highlighted the significant predictive value of initial sense of coherence and initial stress levels for stress levels 4.5 years later. Mothers with higher SOC to start reported lower levels of stress 4.5 years later. The longitudinal data indicates that child behaviour problems remain constant, and level of social support decreased.
Ho 2013	To investigate the association of child characteristics with maternal well-being. To investigate the moderating effects of support systems on child characteristics and maternal well-being.	Resilience: The Family Support Scale (FSS; Dunst, Jenkins, & Trivette, 1984) Child Challenging Behaviour: The Child Behaviour Checklist Tawainese Version Achenbach System of Empirically Based Assessment (Chen, Huang & Chao, 2009). Parental Stress:	N = 120 Tawainese mothers of children with developmental disabilities aged 3 to 5 years, recruited from occupational therapy services completed questionnaires.	Diagnoses: Developmental delay- 52 ASD - 19 ADHD - 8 Intellectual disability - 8 ADD - 6 Asperger syndrome/ high functioning autism - 5 Speech disorder/ auditory impairment - 5 Cerebral palsy - 5 Epilepsy - 4 Developmental coordination disorder - 4	Child behaviour problems were significantly associated with child-related parenting stress. After controlling for variables, informal support significantly moderated the effect of total problem behaviour on parenting stress. This was increased with clinically high behavioural problems and parents perceiving higher levels of informal

		Parenting Stress Index – Short Form (PSI-SF; Abidin, 1995)		Sensory integration dysfunction (sensory processing disorder) - 2 Behaviour disorder - 2 Hydrocephalus - 2 Chromosomal disorder - 1 Gender: Male – 88 Female – 32 Age: Mean – 54.1 Months SD – 10.3 Months	support. There was no significant effect found of formal support and child externalising behaviours and parenting stress.
Seymour et al., 2013	Child behaviour problems and use of maladaptive coping strategies would be associated, which would then be associated with higher levels of stress. That high levels of maternal fatigue and child behaviour problems would also be associated, with the increased use of maladaptive coping strategies and higher levels of stress being associated with that.	Resilience: The Brief COPE (Carver, 1997) Child Challenging Behaviour: The Brief Developmental Behaviour Checklist-P24 (DBC-P24; Taffe et al. 2007) Parental Stress: The depression, anxiety and stress scale-21 (DASS-21; Lovibond and Lovibond 1995): Stress subscale.	N=64 Mothers recruited from Autism Specific Organisations within Australia. Online questionnaire.	Diagnoses: ASD - 47 Asperger's disorder - 9 Pervasive developmental disorder NOS - 9 Gender: Male - 56 Female – 9 Age: Mean – 4 years SD - .95 years	Prior to the introduction of mediators, there was a moderate and significant direct relationship between child behaviour problems and maternal stress. Mediation analysis indicated that maternal fatigue mediated the relationship between the two variables, as the strength of relationship decreased and became non-significant. High levels of fatigue were significantly associated with the use of maladaptive coping. Maladaptive coping did not mediate the relationship between maternal stress and coping, but was

					associated with higher levels of maternal stress.
Norizan & Shamsuddin, 2010	The hypothesis was that child factors would be linked with parenting stress; and maternal factors (maternal characteristics and coping styles and psychological well-being) would moderate parenting stress.	Resilience: Measurement of coping style was adapted from COPE inventory which contain 15 sub-scales (Carver et al., 1989) Child Challenging Behaviour: Paediatric Symptom Checklist (PSC). Parental Stress: Parental Stress Scale (PSS). PSS was developed by Berry & Jones (1995).	N = 147 Mothers recruited during their health clinic within Malaysia. Questionnaires.	Diagnosis: Down syndrome Gender: Male – 73 Female – 74 Age: 2 – 12 years	There was a significant positive correlation between parenting stress and child's behaviour. There was a significant negative correlation between parenting stress and certain coping (acceptance, optimist and religious). Hierarchical regression analysis identified that maternal depression and lack of acceptance were significant predictors of parenting stress, rather than behavioural problems.
Plant and Saunders, 2007	To identify key factors affecting parent stress associated with care-giving tasks and integrate these into an intervention programme.	Resilience: Ways of Coping Questionnaire – Revised (Folkman & Lazarus 1988) Parental Stress: Created for the study - stress related to caregiving tasks Child challenging behaviour: One created for study and Developmental Behaviour Checklist (Einfeld & Tonge 1995)	N=105 Mothers of children receiving early intervention services within Queensland Australia, pre-school aged.	Diagnosis: Down syndrome – 25 Other chromosomal abnormality – 9 Cerebral palsy – 7 ASD – 25 Undiagnosed developmental delay - 25 Other - 14 Gender: Male -74 Female - 31 Age: 49.71 months (Mean)	Moderately significant positive relationships were revealed between parent stress levels and problem behaviour. Significant predictors of parent stress levels were difficult child behaviour during caregiving tasks, and variables relating to caregiving which indicated that parents who reported higher stress, reported caregiving tasks to be more difficult and associated with increased levels of child behaviour

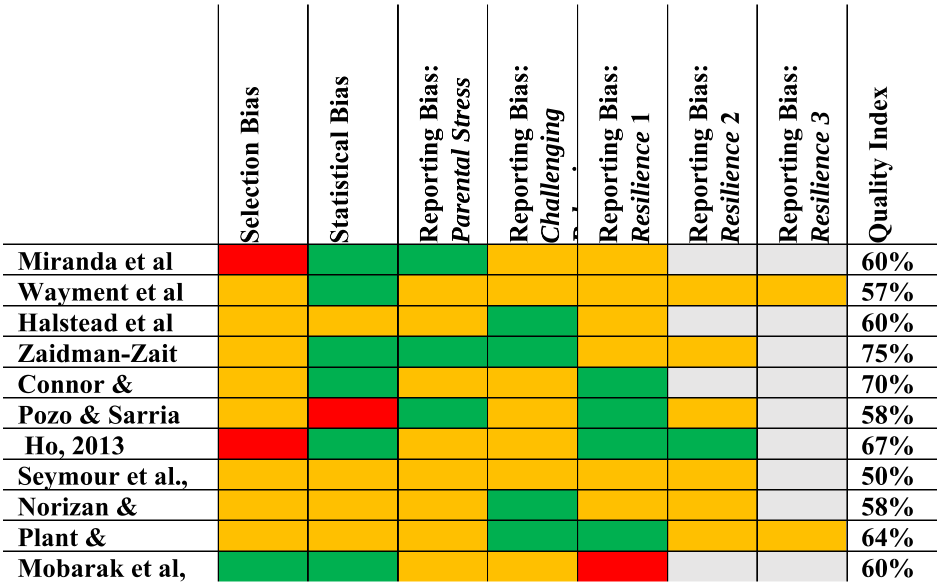
					problems. Negative cognitive appraisal of caregiving tasks showed a moderate significant positive relationship with level of parent stress, variables of difficulty during caregiving tasks and child behaviour during caregiving tasks. A significant but weak negative correlation was reported regarding low level of support and higher levels of parent stress.
Mobarak et al., 2000	To determine the degree of stress experienced by mothers of young children with Cerebral Palsy and investigate associated factors including child and family characteristics that reflect poverty.	Resilience: Family support scale. (Dunst et al.,1984). Child Challenging Behaviour: Behaviour Screening Questionnaire (Richman, Stevenson & Graham 1982) Parental Stress: 20-item self-report questionnaire 20 item yes/no Harding et al. (1980)	N = 91 Mothers were enrolled as they joined disability services for their child in Bangladesh. Questionnaires.	Diagnosis: Cerebral Palsy Gender: Male – 63 Female - 28 Age: Mean – 38.9 Months Range – 1 to 5 Years	Higher scores on the behaviour problems scale and child's age (older) were significantly associated with higher maternal stress. Level of support received by mothers did not have a significant association to maternal stress. Further analysis found that child's behaviour problem score was the main predictor of maternal stress.

Quality Assessment

Risk of bias scores were calculated by equating low to two points, medium to one point and high to zero points. The calculated value was transformed into a percentage to obtain the quality index score which represents the risk of bias across all domains (Figure 2). 100- 90% is excellent; 89-80% is good; 79-70% is acceptable; 69-60% is moderate; 59-50% is weak; 49% and below would be unacceptable. Assessment of quality is integral to reporting conclusions drawn from reviews to avoid any misguidance (Brown, 2010). Thus, results of the quality assessment are integrated throughout the reporting of results such that inferences can be drawn considering study quality.

Figure 2.

Summary of applied quality criteria.



	Selection Bias	**Statistical Bias**	**Reporting Bias:** ***Parental Stress***	**Reporting Bias:** ***Challenging***	**Reporting Bias:** ***Resilience 1***	**Reporting Bias:** ***Resilience 2***	**Reporting Bias:** ***Resilience 3***	**Quality Index**
Miranda et al	🟥	🟩	🟩	🟧	🟧	⬜	⬜	**60%**
Wayment et al	🟧	🟩	🟧	🟧	🟧	🟧	🟧	**57%**
Halstead et al	🟧	🟧	🟧	🟩	🟧	⬜	⬜	**60%**
Zaidman-Zait	🟧	🟩	🟩	🟩	🟧	🟧	⬜	**75%**
Connor &	🟧	🟩	🟧	🟧	🟩	⬜	⬜	**70%**
Pozo & Sarria	🟧	🟥	🟩	🟧	🟩	🟧	⬜	**58%**
Ho, 2013	🟥	🟩	🟧	🟧	🟩	🟩	⬜	**67%**
Seymour et al.,	🟧	🟧	🟧	🟧	🟧	🟧	⬜	**50%**
Norizan &	🟧	🟧	🟧	🟩	🟧	🟧	⬜	**58%**
Plant &	🟧	🟧	🟧	🟩	🟩	🟧	🟧	**64%**
Mobarak et al,	🟩	🟩	🟧	🟧	🟥	⬜	⬜	**60%**

Note. Red indicates high risk of bias, amber marks an unclear risk of bias and green is a low risk of bias, grey indicates not applicable.

Selection bias. Overall, selection bias was unclear within the studies. Most of the studies did not explicitly state whether participants knew that the study was looking at resilience and stress before expressing an interest to participate. If studies state that they are interested in stress or resilience, the sample may be skewed e.g., individuals who are experiencing high levels of stress more likely to participate. Two studies were rated as low risk (Connor & White, 2014; Mobarek et al., 2000). Connor & White (2014)'s only inclusion criteria were mothers and recruitment were across two states. Moberak et al. (2000) invited all mothers accessing disability services for their child to participate. Miranda et al. (2019) was assessed as high risk as mothers were recruited from a small rural community support group and the participants were explicitly told the objectives of the study prior to participation.

Statistical bias. The statistical bias of the studies was rated as either unclear or low, with one study assessed as high risk (Pozzo & Sarria, 2014). At the exception of Pozzo and Sarria (2014) who reported a Pearson's correlation for a small sample size (N=21), all studies with unclear risk reported beta-coefficient rather than Pearson's. Beta-coefficient cannot be an accurate substitute for Pearson's correlation due to its covariate nature, that is, it reflects the influence of all predictor variables (Peterson & Brown, 2005). This cannot therefore be directly comparable to zero-order Pearson's coefficients as the results are tied to the idiosyncrasies of the reporting study.

Reporting bias: Parental stress. Many of the studies relied on outcome measures capturing stress that reported either validity or reliability, with just under half the studies reporting or referring to literature that refers to both. Many studies were rated unclear due only reporting either reliability or validity.

Reporting bias: Challenging behaviour. Many of the studies appeared to rely on outcome measures investigating challenging behaviour that reported either validity or reliability, with just under half the studies reporting or referring to literature that refers to both. Many studies were rated unclear due only reporting either reliability or validity.

Reporting bias: Psychological resilience. Each study reported either one, two or three measures of psychological resilience constructs; many studies reported two. One study (Moborak et al., 2000) used a social support measure (FSS; Dunst et al., 1984) assessed as high risk of reporting bias as neither reliability nor validity had been referenced. The FSS (Dunst et al., 1984) is reported in another study with acceptable reliability and therefore was not omitted from the review. Most studies were rated as unclear as they reported only validity or reliability, with only four studies reporting or referring to literature that refers to both.

Summary. Overall, the levels of bias across studies were unclear, with only four studies reporting a domain of high risk. Many studies reported at least one domain of low risk, except for one study (Seymour et al., 2013). High risk of bias appeared to be more present in the selection process and with the majority being unclear as there was a lack of clarity regarding how much information the participants were provided with prior to starting the study. Studies with medium to high risk of bias were included due to the low number of studies meeting the criteria. Therefore, results of this review should be interpreted in that light and it is hoped that future research will include higher quality research with a more generalisable population. However, the studies included represent the research literature as it stands currently.

Results of Individual Studies

The studies reflected within subgroups, and the individual mean and total scores have been calculated for each individual study which are presented in Table 5.

Table 5.

Table presenting mean score of resilience measure/subscale, total score and the calculated resilience level and assigned subgroup.

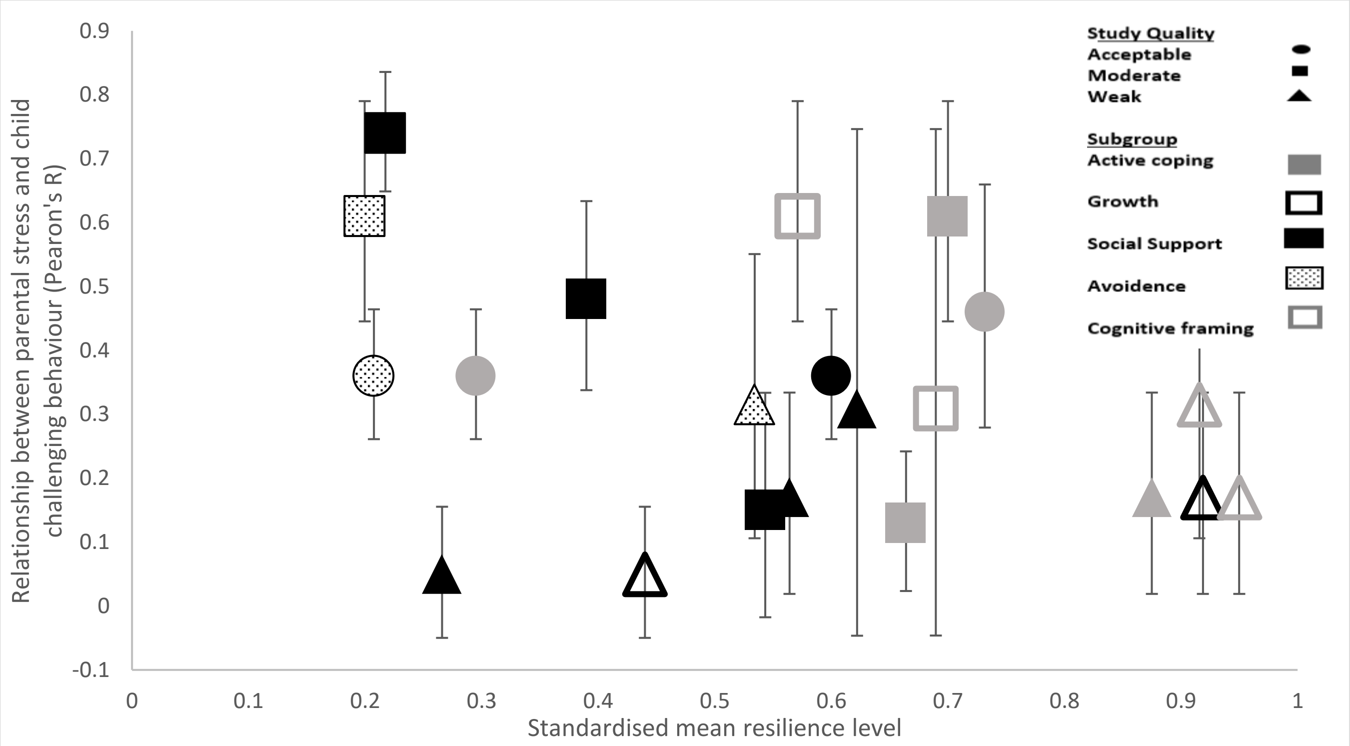
Study	Mean subscale/measure score	Total Score of subscale/measure	Proportion of available resilience score	Subgroup
Wayment et al., 2019	3.99	15	0.27	Social support
Zaidman-Zait et al., 2017	2.4	4	0.6	Social support
Norizan & Shamsuddin 2010	12.5	16	0.56	Social support
	11.1	16		
Mobarak et al., 2000	15.65	72	0.22	Social support
Plant & Sanders, 2007	28.77 24.23 12.49	56 56 56	0.39	Social support
Pozo & Sarria, 2014	57.23	92	0.62	Social support
Ho, 2013	29.34	54	0.54	Social support
Wayment et al., 2019	3.08	7	0.44	Growth
Norizan & Shamsuddin, 2010	14.7	16	0.92	Growth
Seymour et al., 2013	19.23	21	0.92	Cognitive framing
Norizan & Shamsuddin, 2010	15.2	16	0.95	Cognitive framing
Pozo & Sarria, 2014	38.62	56	0.69	Cognitive framing
Zaidman-Zait et al., (2017)	1.18	4	0.30	Active coping
Norizan & Shamsuddin, 2010	14.0	16	0.88	Active coping
Miranda et al., 2019	16.8	24	0.7	Active coping
Halstead et al., 2018	13.28	20	0.66	Active coping
Connor & White, 2014	54.88	75	0.73	Active coping
Seymour et al., 2013	20.83	39	0.53	Avoidance
Zaidman-Zait et al., 2017	.83	4	0.21	Avoidance
Miranda et al., 2019	7.78 1.21	24 18	0.20	Avoidance

Syntheses of Results

Visual presentation of the data can be observed in Figure 2. The types of resilience were sub-grouped, as reported in the methodology. As measures of these subgroups varied across studies and scales, we focused on describing the studies, the outcome of the extracted data and implications of this, in view of the question, rather than a meta-analysis.

Figure 3.

The strength of the relationship between parental stress and challenging behaviour and the mean score of resilience



Note. The Y axis shows the correlation between parental stress and challenging behaviour within the sample of participants of the specific study. The X axis reflects the standardised mean reported level of resilience for the corresponding study sample whereby 1 is high and 0 is low. Where multiple measures of resilience have been reported in the same study, the measure which is most validated is depicted. The shading of the shapes reflects the resilience type depicted (as categorised by the present author). The impact of the resilience type on the relationship is understood by its position on the graph in relation to the Y axis. All resilience types are included to allow for a comparable analysis. The shape reflects the quality of the study, which was included so that analysis could consider the study quality when drawing any conclusions. Quality of studies was determined using the quality index represented in Figure 2. The confidence interval shows the amount of deviation from the reported mean possible for the study sample.

Relationship Between Child Challenging Behaviour and parental stress

Across study data. Studies assessed as more moderate/acceptable quality show a stronger relationship between stress and challenging behaviour than studies assessed as weak quality, regardless of the level of resilience reported.

Within study data. Visual inspection of the data (Figure 3), without considering diversity of subgroups, indicates a possible association between increased psychological resilience and a smaller relationship between challenging behaviour and parental stress. All studies reported a relationship between parental stress and challenging behaviour, however the significance and strength of these relationship varied within studies. Most studies reported a moderate significant correlation coefficient (Connor & White, 2014, N=67, acceptable quality; Miranda et al., 2019, N=52, moderate quality; Plant & Saunders, 2007, N=105, moderate quality; Seymour et al., 2013, N=64, weak quality; Zaidman-Zait et al., 2017, N=283, acceptable quality;). One study found a significant, strong relationship (Moborak, 2000, N =91; moderate quality).

Both Halstead et al. (2018) and Norizan and Shamsuddin (2010) found significant, weak correlations. Halstead et al. (2018) results represented a relatively large sample size (N=312) and overall moderate quality. Norizan and Shamsuddin (2010) used a moderately sized sample (N=147), however the quality of the study was rated as weak due to the psychometric properties of the measures, the statistical reporting, and the selection.

Weak, non-significant relationships were reported by two studies (Ho, 2013, N = 210, moderate quality; Wayment et al., 2019, N=364, weak quality). Ho (2013) did report, however, a significant relationship between total problem behaviours and externalising behaviours and the child domain of the parent stress measure. Pozo and Sarria (2014) also reported a non-significant relationship, however this was moderate.

Resilience

Visual observation of Figure 3 indicates that as overall psychological resilience increases, the strength of the relationship between challenging behaviour and parental stress appears to decrease.

The Impact of Different Resilience Concepts and the Relationship between Parental Stress and Child Challenging Behaviour

Social support.

Across study data. Visual observation of the social support data indicates the emergence of a pattern where increased social support seems to be associated with relatively smaller relationships between parental stress and challenging behaviour. One study (Miranda et al., 2019) did not report the mean of social support; thus, could not be included on the graph. Sample size varied largely across the studies, ranging from 21 to 364. The study data was largely representative of children with ASD (N=4), however a range of neurodevelopmental disorders were included (Downs Syndrome, Cerebral Palsy, ADHD, Pervasive Developmental Delay). All recruitment took place using mothers receiving support from disability services. The measures used to investigate social support varied across the sample. Most studies used social support subscales of larger measures or created their own. Two studies utilised the Family Support Scale (Dunst et al., 1984). The overall quality of the social support measures is medium (N=5) with low risk of bias (N=1) and high risk of bias (N=1).

Within study data. Of the eight studies identified with data relating to social support, three reported findings consistent with social support being associated with lower levels of parental stress (Ho, 2013; Plant & Saunders, 2007; Zaidman-Zait et al., 2017). After controlling for levels of child externalising behaviour, there was still a relationship between increased social support and reduced maternal stress (Ho, 2013; Miranda et al., 2019; Zaidman-Zait et al., 2017). Two studies did not find a significant association between parental stress and social support (Mobarak et al., 2000; Norizan & Shamsuddin, 2010). One study (Wayment et al., 2019) did not report findings relevant to parental stress and social support but reported a positive association between social support and post traumatic growth, as well as a negative association between social support and child challenging behaviour.

Active coping.

Across study data. The variability observed around the strength of the relationship between maternal stress and child challenging behaviour across the studies did not appear to have an association with the level of resilience reported. Sample size varied moderately across studies, ranging from 52 to 312. Data was largely representative of children with ASD (N=4) but included some children with various neurodevelopmental disorders and down syndrome. Recruitment for this sample took place across states in America, schools, support groups, GPs, a health clinic and as part of a larger ASD study. The measures used to investigate active coping consisted of COPE and Ways of Coping, Brief Resilience Coping Scale measured as medium risk of bias. One study used Mindful attention awareness scale (MAAS; Brown & Ryan, 2003), assessed as low risk of bias.

Within study data. Of the five studies reporting on active coping, three reported findings consistent with higher active coping being associated with a weaker relationship between maternal stress and child challenging behaviour (Halstead et al., 2018; Miranda et al., 2019; Zaidman-Zait et al., 2017). Halstead et al. (2018) reported, however, that higher levels of active coping were only significantly linked with lower maternal stress when the child had low levels of emotional and behavioural problems. Connor and White (2014) report a significant association between high levels of maternal stress and lower levels of mindfulness. Norizan and Shamsuddin (2010) reported that active coping is one of the most utilised types of coping, however found no significant effect of this coping.

Growth.

Across study data. Visual observation of the results shows that whilst level of reported growth differs, the strength of the relationship between parental stress and child challenging behaviour remains similar. Sample size differed between studies from 147 to 364. The data is more representative of an ASD population (364) than of the downs syndrome population (147). Recruitment took place at a health clinic and an interactive autism network. The measures used to investigate growth were The Posttraumatic Growth Inventory (Tedeschi and Calhoun, 1996) and Optimist/Growth subscale of the COPE inventory (Carver et al., 1989). Both measures were assessed as a medium risk of bias.

Within study data. Of the two studies reporting on growth, only one reflects a significant negative association with maternal stress (Norizan & Shamsuddin, 2010). Neither study reports any significant findings which consider challenging behaviour. Wayment et al. (2019) reports that post traumatic growth is significantly positively correlated with use of social support and quiet ego characteristics.

Cognitive framing.

Across study level data. Visual observation of the data suggests that where cognitive framing level appears to be increasing, a weaker relationship is reported between maternal stress and challenging behaviour. The sample size was relatively low ranging from 21 to 147. The samples were largely representative of children with ASD, secondly down syndrome and some representation of children with other disorders such as developmental delay. Recruitment included mothers of children receiving educational and health services for neurodevelopmental disabilities. The measures used to investigate cognitive framing included The Sense of Coherence Questionnaire (SOC; Antonovsky, 1987), the problem focused subscale of The Brief Cope (Carver, 1997) and acceptance subscale from the COPE inventory (Carver et al., 1989). The SOC (Antovsky, 1987) was assessed as a low risk of bias measure, the other two measures were medium risk of bias. No definitive conclusions can be drawn from this data, but there is an indication that cognitive framing may explain some of the variance in the strength of the relationship between challenging behaviour and parental stress.

Within study level data. Of the four studies reporting on cognitive framing, only two reported data which supported an association with lower levels of parental stress (Norizan & Shamsuddin, 2010; Pozo & Sarria, 2014). Norizan and Shamsuddin, (2010) reported weak, significant negative relationship between aspects of cognitive framing (acceptance and optimism) and parental stress. Pozo and Sarria (2014) reported a significant predictive value of high SOC and lower levels of stress four and half years later.

Avoidance.

Across study level data. Visual observation of data indicates the emergence of a pattern whereby as avoidance increases, the strength of the relationship between maternal stress and challenging behaviour decreases. Sample size varied from 52 to 283. All studies presented data from children with ASD, although there was a small proportion (N=9) of children with pervasive developmental delay. Recruitment included mothers receiving support for autism or from special educational settings. The measures used to investigate avoidance included disengagement subscale from Brief COPE (Carver, 1997; Spanish adaptation by Morán et al., 2010), disengaged coping subscale from Ways of Coping

Questionnaire (WoC; Folkman and Lazarus, 1988) and the maladaptive coping subscale from The Brief Cope (Carver, 1997).

Within study level data. Of the three studies reporting on avoidance, only one reported significant findings relating to avoidance and the relationship between child behaviour and maternal stress (Seymour et al., 2013). Seymour et al. (2013) found although there was no mediation effect of maladaptive coping, it was associated with higher levels of maternal fatigue and maternal stress. Maternal fatigue was found to mediate the relationship between child behaviour and maternal stress. Whilst Miranda et al. (2019) and Zaidman-Zait et al. (2017) did not report any significant findings.

Discussion

Firstly, this review aimed to examine the relationship between maternal parental stress and child challenging behaviour in mothers from a subset of papers within the literature. Findings revealed a relationship between increased parental stress, and increased challenging behaviour displayed by children with a neurodevelopmental disorder. Secondly, it aimed to examine the extent to which psychological resilience may impact on this relationship. Findings indicate the strength of the relationship may be associated with the level of psychological resilience shown by the mother. In general, across studies, when a higher level of psychological resilience is reported (on average) by the sample, there seems to be a weaker relationship between maternal stress and child challenging behaviour. Lastly, the impact of the different concepts of resilience was investigated. The concept of resilience which appears to show the most stable association is social support. There also appeared to be an emerging similar pattern for cognitive framing. However, using avoidance appeared to be associated with a stronger relationship between maternal stress and challenging behaviour. The picture for other types of resilience was unclear. These tentative associations across study populations could not be examined statistically and so must be considered with caution. They do however, provide a foundation for considering future research in this area.

A positive relationship between the level of challenging behaviour and parental stress of mothers is demonstrated within studies, which supports the finding of previous reviews reporting on the link between parenting stress and challenging behaviour (Barroso et al., 2018; Yorke et al., 2018). The dominant finding was a significant, moderate, relationship between these two variables, however the sample size and quality of these studies is mixed. Conversely, Wayment et al. (2019) found no significant relationship between parental stress and challenging behaviour which was demonstrated in the largest sample size across all included studies. Variability of this finding may be impacted on by the type of measures used to collect data, as neither were standardised or recognisable measures. Furthermore, the measure of stress differed from other measures of stress as the focus of it was rumination related to the child's ASD. Stress is a significant predictor of rumination (Willis & Burnett, 2016; Valenas & Szentagotai-Tatar, 2015), therefore, higher levels of rumination regarding the ASD arguably are linked with higher levels of stress associated with parenting a child with ASD. Despite this justification for the consideration of this measure, the opposing results of this study indicate that rumination cannot accurately be compared with parental stress. Pozo and Sarria (2014) demonstrated a non-significant, weak relationship, however, the statistical reporting of this paper is questionable as Pearsons coefficient has been conducted on a sample size less than 25 (Bonnett & Wright, 2000).

The findings of this review, endorse the findings from a previous literature review of mothers of children with ASD, whereby social support was associated with lower levels of maternal stress (Boyd, 2002). Interestingly, Boyd (2002) found that the use of social support had a positive effect on the emotional response of the mother to the child's behaviour (Boyd, 2002). Arguably, if the mother responds in a more emotionally responsive way, the child's behaviour may decrease. Unfortunately, there were insufficient studies to conduct a statistical analysis on the mediating role of social support. It would be clinically useful to understand how social support acts as a mediator, and how this could be replicated or supported. Boyd (2002) found that mothers are more inclined to seek social support when they experience high levels of challenging behaviour from their child with ASD, however, due to the perceived stigma they may withdraw or be isolated. Certainly, the findings of Pozo and Sarria (2014) indicated that social support decreased over time. The findings of the current review support those previously, that social support appears to be beneficial, however if the likelihood of social support decreasing over time is considered, professionals need to think about how to promote this type of support for parents. Boyd (2002) found within the literature, that parent support groups are perceived as especially helpful. Certainly, social constructivist theory would understand this as being due to a mental alteration of beliefs due to having a new, shared experience (Davis et al., 2017).

The findings indicate that cognitive framing showed a tentative association with a weaker relationship between parental stress and challenging behaviour. Currently, most interventions around child challenging behaviour are behavioural in nature, of which, the effectiveness remains unclear (Wong et al., 2018). Behavioural interventions place emphasis on the role of parenting, which may not be the sole reason for parenting stress and poor child outcomes (Wong et al., 2018). A social-cognitive perspective would highlight the role of parental cognitions relating to parenting behaviour and stress (Johnston & Ohen, 2005). Recent empirical data found that cognitive reframing encourages a greater perceived competence in controlling child behaviour, and lower levels of parental stress (Berenguar et al., 2020). Certainly, meta-analyses have demonstrated beneficial impacts of Cognitive Behavioural Therapy on parenting stress and the attributions of child behaviour (Chronis et al., 2006; Singer et al., 2007). Nonetheless, whilst the use of cognitive reframing holds promise, it still places pressure on the parent which in turn has been shown to increase stress. Social support is something that can be offered to the family, whereas cognitive reframing may accentuate feelings of responsibility or blame on the parent and therefore this type of intervention should be treated with caution. Overall findings from Berenguar et al. (2020) found cognitive reframing alone did not hold enough power to mediate both child behaviour problems and parental stress, however the sample size was small. More investigation is needed to highlight the mediating role of cognitive framing, and how this can be used to promote positive outcomes within families. Cognitive behavioural intervention online have been shown to be efficacious (Barak et al., 2008) the use of these should be considered as they may increase accessibility and place less demand on parents.

There was some evidence that higher levels of avoidance may be associated with a stronger relationship between child challenging behaviour and parental stress. Understanding factors which increase stress levels is important, as more targeted interventions can be offered (Hayes & Watson, 2013). The use of avoidance has been shown to predict higher levels of stress and other mental health problems over a ten-year period (Holahan et al., 2005). Given what has been shown regarding the transactional relationship between parental stress and child challenging behaviour, increased levels of avoidance are likely to have a detrimental impact on whole family outcomes, and thus, it is important that avoidance use for parents is assessed, considered, and supported. This may be challenging as the term ‘avoidance’ is often associated with behaviours considered maladaptive, such as substance use, but psychological avoidance may encompass what may be seen as positive factors such as religion, exercise and so forth. Considering this, assessing the function of parental coping behaviour within a clinical setting, would appear to be advantageous.

As aforementioned, the concepts underpinning the term ‘resilience’ are broad. Previous literature on coping has been critiqued due to the complexity and variation in measurements of coping (Folkman & Moskowitz, 2004; Greenaway et al., 2015). Positively, this review aimed to break down aspects of resilience within measures, prior to comparing, which aided an understanding of any beneficial aspects of resilience which could be of practical benefit to families of children with developmental disabilities. Nonetheless, this review is unable to capture the confounding impact of different concepts of resilience, as Greenaway et al. (2015) referred to, this is a complex process and the way in which these processes interlink cannot be undermined. There is evidence that growth is associated with increased use of social support (Wayment et al., 2019) and parental stress has been shown to impact on ability to utilise coping strategies such as social support (Dennis et al., 2018; Hsiao, 2017, Seymour et al., 2017). These findings support those of Cooklin et al. (2011), who suggested increased fatigue in parents is associated with the use of maladaptive coping. Bonnano et al., (2015) emphasises the importance of reporting outcomes separately, however, also highlights the need to account for covariance which is a limitation of this review. Rather than providing conclusive evidence, this review allowed for indications of concepts of resilience which may be of interest, emphasizing the need for circumscribed research into that which has been highlighted.

Limitations and Future Research

Few studies report on the mediating impact of the construct of resilience, therefore, whilst the findings support the importance of the relationship between child behaviour and maternal stress and provide information on the impact of the type of resilience on the maternal stress, the impact on child behaviour remains unclear. This limitation is a reflection on the limited amount of mediation analysis reported within studies.

The outcomes of this review are restricted to mothers of children with developmental disabilities. There is a need for further investigation into father’s resilience and stress relationship with challenging behaviour; however, given the limited studies focussing on fathers specifically (Al-Yagon, 2014) a search may have elicited limited studies which were unlikely to be representative of the overall literature in this area. It must be noted that this review initially intended to include fathers, and by refining the criteria to include only mothers the number of papers drawn was decreased. Inclusion of fathers wielded data from mixed studies whereby data from the two genders could not disentangled. As there are gender differences, to draw conclusions from data which included both genders would be less clinically meaningful. It could be argued that due to limited number of fathers being studied, this study could have focused on fathers however given the small number of studies it was deemed beneficial for clinical impact, to review and draw conclusions from a larger dataset focused on mothers.

Additionally, the change in inclusion criteria during the study selection (after abstract screening) must be noted as a limitation. Given the initial focus on parents, search terms were not exclusive to mothers, thus there may be studies that were not included. Given the range of databases searched, it is hoped that most studies reflecting the search criteria as it finally stood is inclusive of most literature within this field.

Much of the literature regarding parental stress, resilience and challenging behaviour refers to children with either an ASD or ADHD diagnosis. Certainly, this review is reflective of a high proportion of children with ASD. Evidence indicates that children with down syndrome show less challenging behaviour than other developmental disorders (Crnic et al. 2004). Barroso et al., (2018) highlighted the need for differences in parenting stress to be investigated for the different groups of developmental disabilities.

The methodological rigour of the included studies is varied. Studies assessed as more moderate/acceptable quality did portray a stronger relationship between stress and challenging behaviour, regardless of the level of resilience reported. Within the present review, only two did not report a significant association and within Moberak et al. (2000)'s study there was an acknowledgment that the relatively low internal consistency of the scale utilised, alongside the generally low levels of helpful support received may have impacted on the findings.

Within studies, the level of significance was contrasting which should not discount what has been demonstrated but may reflect the way in which this type of research is conducted. Most studies did not make it clear whether participants were informed on the outcome of the study, furthermore most participants were already accessing some form of help due to the way in which recruitment was carried out. In addition, despite the large number of families experiencing parental stress and child challenging behaviour, many of the sample sizes were small. This indicates that there is a problem when recruiting for this type of study, which severely limits the conclusions which can be drawn. Further investigation is needed to understand what may encourage participation in studies such as those included, to allow for more rigorous and conclusive data.

Finally, the implications of the inclusion criteria should be considered. Given that only studies which included all three of the variables (parental stress, challenging behaviour, and psychological resilience) were included, the review reflects a small sub-sample of all papers which report on challenging behaviour and parental stress relationship and of those that report on a construct of psychological resilience and parental stress. This provides scope for future analysis or research into these variables but is not a complete review of all the literature within this large field.

Despite the limitations of this review, there are meaningful findings. Certainly, the need to provide support to mothers of children with neurological disabilities is fundamental to increasing life outcomes for both child and parent. NICE (2015) guidance highlights the need for care pathways to minimise transition between services and utilise integrated services. Despite this, the Care Quality Commission (CQC) report that families of disabled children feel that services are not effectively integrated and have negative experiences of support (CQC, 2017). Within the current National Health Services and Local Authorities, resources are stretched and there is often an increase in leaning on the parent to do the work to change the child's behaviour rather than providing much needed support to the parent. With much of the focus being reactive interventions, rather than long term sustainable input for the family. This review provides a rationale for providing family supportive interventions. Certainly, in other countries there are positive outcomes associated with holistic supportive approaches, in Sweden the whole family is provided with support, care and respite, highlighting the impact on both parents and siblings (Engwell & Hultman, 2020). More should be done to support the families of disabled children, with emphasis on support and building of long-term relationships from healthcare professionals to these families.

References

Abidin, R. R. (1990). The stresses of parenting [Special issue]. *Journal of Clinical Child Psychology, 19*, 297-400.

Abidin, R. R., & Abidin, R. R. (1990). *Parenting Stress Index (PSI).* Pediatric Psychology Press Charlottesville, VA.

Achenbach, T. M., & Edelbrock, C. S. (1981). Behavioral problems and competencies reported by parents of normal and disturbed children aged four through sixteen. *Monographs of the Society for Research in Child Development,* , 1-82.

Al-Yagon, M. (2014). Child–mother and child–father attachment security: links to internalizing adjustment among children with learning disabilities. *Child Psychiatry & Human Development, 45*(1), 119-131.

Anthony, L. G., Anthony, B. J., Glanville, D. N., Naiman, D. Q., Waanders, C., & Shaffer, S. (2005). The relationships between parenting stress, parenting behaviour and preschoolers' social competence and behaviour problems in the classroom. *Infant and Child Development: An International Journal of Research and Practice, 14*(2), 133-154.

Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research, 47*(4-5), 217-230.

Barak, A., Hen, L., Boniel-Nissim, M., & Shapira, N. (2008). A comprehensive review and a meta-analysis of the effectiveness of internet-based psychotherapeutic interventions. *Journal of Technology in Human Services, 26*(2-4), 109-160.

Barroso, N. E., Mendez, L., Graziano, P. A., & Bagner, D. M. (2018). Parenting stress through the lens of different clinical groups: A systematic review & meta-analysis. *Journal of Abnormal Child Psychology, 46*(3), 449-461.

Benson, P. R. (2010). Coping, distress, and well-being in mothers of children with autism. *Research in Autism Spectrum Disorders, 4*(2), 217-228.

Berenguer, C., Rosello, B., & Miranda, A. (2021). Mothers' stress and behavioral and emotional problems in children with ADHD. Mediation of coping strategies. *Scandinavian Journal of Psychology, 62*(2), 141-149.

Borenstein, M., Hedges, L. V., Higgins, J. P., & Rothstein, H. R. (2021). *Introduction to meta-analysis*. John Wiley & Sons.

Bonanno, G. A., Romero, S. A., & Klein, S. I. (2015). The temporal elements of psychological resilience: An integrative framework for the study of individuals, families, and communities. *Psychological Inquiry, 26*(2), 139-169.

Bonett, D. G., & Wright, T. A. (2000). Sample size requirements for estimating Pearson, Kendall and Spearman correlations. *Psychometrika, 65*(1), 23-28.

Bown, M. J., & Sutton, A. J. (2010). Quality control in systematic reviews and meta-analyses. *European Journal of Vascular and Endovascular Surgery, 40*(5), 669-677.

Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities, 17*(4), 208-215.

Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities, 17*(4), 208-215.

Care Quality Commission. (2017). Support for families with disabled children . Care Quality Commission.

Chronis, A. M., Gamble, S. A., Roberts, J. E., & Pelham Jr, W. E. (2006). Cognitive-behavioral depression treatment for mothers of children with attention-deficit/hyperactivity disorder. *Behavior Therapy, 37*(2), 143-158.

Conner, C. M., & White, S. W. (2014). Stress in mothers of children with autism: Trait mindfulness as a protective factor. *Research in Autism Spectrum Disorders, 8*(6), 617-624.

Cooklin, A. R., Canterford, L., Strazdins, L., & Nicholson, J. M. (2011). Employment conditions and maternal postpartum mental health: results from the Longitudinal Study of Australian Children. *Archives of Women's Mental Health, 14*(3), 217-225.

Crnic, K. A., Gaze, C., & Hoffman, C. (2005). Cumulative parenting stress across the preschool period: Relations to maternal parenting and child behaviour at age 5. *Infant and Child Development: An International Journal of Research and Practice, 14*(2), 117-132.

Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research, 54*(3), 266-280.

Damian, R. I., Spengler, M., Sutu, A., & Roberts, B. W. (2019). Sixteen going on sixty-six: A longitudinal study of personality stability and change across 50 years. *Journal of Personality and Social Psychology, 117*(3), 674.

Davis, M. L., Witcraft, S. M., Baird, S. O., & Smits, J. A. (2017). Learning Principles in CBT. *The Science of Cognitive Behavioral Therapy* (pp. 51-76). Elsevier.

Davis, M. C., Luecken, L., & Lemery-Chalfant, K. (2009). Resilience in common life: introduction to the special issue. *Journal of Personality,*

Deater-Deckard, K. (1998). Parenting stress and child adjustment: Some old hypotheses and new questions. *Clinical Psychology: Science and Practice, 5*(3), 314-332.

Deater-Deckard, K., Ivy, L., & Petrill, S. A. (2006). Maternal warmth moderates the link between physical punishment and child externalizing problems: A parent-offspring behavior genetic analysis. *Parenting: Science and Practice, 6*(1), 59-78.

Dennis, M. L., Neece, C. L., & Fenning, R. M. (2018). Investigating the influence of parenting stress on child behavior problems in children with developmental delay: The role of parent-child relational factors. *Advances in Neurodevelopmental Disorders, 2*(2), 129-141.

Downs, S. H., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology & Community Health, 52*(6), 377-384.

Engwall, K., & Hultman, L. (2020). Constructions of childhood: the assessment of respite care for children with disabilities in Sweden. *European Journal of Social Work,* , 1-12.

Ekers, D., Webster, L., Van Straten, A., Cuijpers, P., Richards, D., & Gilbody, S. (2014). Behavioural activation for depression; an update of meta-analysis of effectiveness and sub group analysis. *PloS One, 9*(6), e100100.

Fletcher, D., & Sarkar, M. (2013). Psychological resilience: A review and critique of definitions, concepts, and theory. *European Psychologist, 18*(1), 12.

Folkman, S., & Moskowitz, J. T. (2004). Coping: Pitfalls and promise. *Annu.Rev.Psychol., 55*, 745-774.

Goussé, V. (2010). Handicap grave et résilience: l'exemple de l'autisme. *Bulletin De Psychologie,* (6), 417-421.

Greenaway, K. H., Louis, W. R., Parker, S. L., Kalokerinos, E. K., Smith, J. R., & Terry, D. J. (2015). Measures of coping for psychological well-being. *Measures of personality and social psychological constructs* (pp. 322-351). Elsevier.

Griffith, G. M., & Hastings, R. P. (2014). 'He's hard work, but he's worth it'. The experience of caregivers of individuals with intellectual disabilities and challenging behaviour: A meta-synthesis of qualitative research. *Journal of Applied Research in Intellectual Disabilities, 27*(5), 401-419.

Guinchat, V., Cravero, C., Lefèvre-Utile, J., & Cohen, D. (2020). Multidisciplinary treatment plan for challenging behaviors in neurodevelopmental disorders. *Handbook of Clinical Neurology* (pp. 301-321). Elsevier.

Guralnick, M. J. (2004). Family investments in response to the developmental challenges of young children with disabilities. *Family Investments in Children's Potential: Resources and Parenting Behaviors that Promote Success,* , 119-137.

Halstead, E., Ekas, N., Hastings, R. P., & Griffith, G. M. (2018). Associations between resilience and the well-being of mothers of children with autism spectrum disorder and other developmental disabilities. *Journal of Autism and Developmental Disorders, 48*(4), 1108-1121.

Hastings, R. P. (2003). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research, 47*(4-5), 231-237.

Hastings, R. P., Kovshoff, H., Ward, N. J., Degli Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders, 35*(5), 635.

Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(3), 629-642.

Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: associations with parental mental health and family functioning. *Journal of Intellectual Disability Research, 50*(12), 874-882.

Higgins, J. P., Altman, D. G., Gøtzsche, P. C., Jüni, P., Moher, D., Oxman, A. D., Savović, J., Schulz, K. F., Weeks, L., & Sterne, J. A. (2011). The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. *Bmj, 343*

Ho, T. H. (2013). *Well-Being and Support Systems of Taiwanese Mothers of Young Children with Developmental Disabilities* (Doctoral dissertation, UC Riverside).

Holahan, C. J., Moos, R. H., Holahan, C. K., Brennan, P. L., & Schutte, K. K. (2005). Stress generation, avoidance coping, and depressive symptoms: a 10-year model. *Journal of Consulting and Clinical Psychology, 73*(4), 658.

Hsiao, Y. (2018). Parental stress in families of children with disabilities. *Intervention in School and Clinic, 53*(4), 201-205.

Ilias, K., Cornish, K., Kummar, A. S., Park, M. S., & 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*, 280.

Jackson, D., Firtko, A., & Edenborough, M. (2007). Personal resilience as a strategy for surviving and thriving in the face of workplace adversity: a literature review. *Journal of Advanced Nursing, 60*(1), 1-9.

Johnston, C., & Ohan, J. L. (2005). The importance of parental attributions in families of children with attention-deficit/hyperactivity and disruptive behavior disorders. *Clinical Child and Family Psychology Review, 8*(3), 167-182.

Lagasse, L. L., Conradt, E., Karalunas, S. L., Dansereau, L. M., Butner, J. E., Shankaran, S., Bada, H., Bauer, C. R., Whitaker, T. M., & Lester, B. M. (2016). Transactional relations between caregiving stress, executive functioning, and problem behavior from early childhood to early adolescence. *Development and Psychopathology, 28*(3), 743.

Kazdin, A. E. (1995). Child, parent and family dysfunction as predictors of outcome in cognitive-behavioral treatment of antisocial children. *Behaviour Research and Therapy, 33*(3), 271-281.

Kazdin, A. E., & Whitley, M. K. (2003). Treatment of parental stress to enhance therapeutic change among children referred for aggressive and antisocial behavior. *Journal of Consulting and Clinical Psychology, 71*(3), 504.

Kim, S. Y., Park, J. E., Lee, Y. J., Seo, H., Sheen, S., Hahn, S., Jang, B., & Son, H. (2013). Testing a tool for assessing the risk of bias for nonrandomized studies showed moderate reliability and promising validity. *Journal of Clinical Epidemiology, 66*(4), 408-414.

Lipsey, M. W., & Wilson, D. B. (2001). *Practical meta-analysis.* SAGE publications, Inc.

Mackler, J. S., Kelleher, R. T., Shanahan, L., Calkins, S. D., Keane, S. P., & O'Brien, M. (2015). Parenting stress, parental reactions, and externalizing behavior from ages 4 to 10. *Journal of Marriage and Family, 77*(2), 388-406.

Manicacci, M., Bouteyre, E., Despax, J., & Bréjard, V. (2019). Involvement of emotional intelligence in resilience and coping in mothers of autistic children. *Journal of Autism and Developmental Disorders, 49*(11), 4646-4657.

Migerode, F., Maes, B., Buysse, A., & Brondeel, R. (2012). Quality of life in adolescents with a disability and their parents: The mediating role of social support and resilience. *Journal of Developmental and Physical Disabilities, 24*(5), 487-503.

Miranda, A., Mira, A., Berenguer, C., Rosello, B., & Baixauli, I. (2019). Parenting stress in mothers of children with autism without intellectual disability. Mediation of behavioral problems and coping strategies. *Frontiers in Psychology, 10*, 464.

Mobarak, R., Khan, N. Z., Munir, S., Zaman, S. S., & McConachie, H. (2000). Predictors of stress in mothers of children with cerebral palsy in Bangladesh. *Journal of Pediatric Psychology, 25*(6), 427-433.

National Collaborating Centre for Mental Health, (UK. (2015). Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges.

Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behavior problems: A transactional relationship across time. *American Journal on Intellectual and Developmental Disabilities, 117*(1), 48-66.

Norizan, A., & Shamsuddin, K. (2010). Predictors of parenting stress among Malaysian mothers of children with Down syndrome. *Journal of Intellectual Disability Research, 54*(11), 992-1003.

Obeid, R., & Daou, N. (2015). The effects of coping style, social support, and behavioral problems on the well-being of mothers of children with autism spectrum disorders in Lebanon. *Research in Autism Spectrum Disorders, 10*, 59-70.

Peterson, R. A., & Brown, S. P. (2005). On the use of beta coefficients in meta-analysis. *Journal of Applied Psychology, 90*(1), 175.

Plant, K. M., & Sanders, M. R. (2007). Predictors of care-giver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disability Research, 51*(2), 109-124.

Pozo, P., & Sarriá, E. (2014). Prediction of stress in mothers of children with autism spectrum disorders. *Spanish Journal of Psychology, 17*(e6), 1-12.

Roberts, B. W., Walton, K. E., & Viechtbauer, W. (2006). Patterns of mean-level change in personality traits across the life course: a meta-analysis of longitudinal studies. *Psychological Bulletin, 132*(1), 1.

Rojahn, J., Matson, J. L., Lott, D., Esbensen, A. J., & Smalls, Y. (2001). The Behavior Problems Inventory: An instrument for the assessment of self-injury, stereotyped behavior, and aggression/destruction in individuals with developmental disabilities. *Journal of Autism and Developmental Disorders, 31*(6), 577-588.

Seymour, M., Wood, C., Giallo, R., & Jellett, R. (2013). Fatigue, stress and coping in mothers of children with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(7), 1547-1554.

Shalev, R. A., Lavine, C., & Di Martino, A. (2019). A systematic review of the role of parent characteristics in parent-mediated interventions for children with autism spectrum disorder. *Journal of Developmental and Physical Disabilities,* , 1-21.

Silinskas, G., Kiuru, N., Aunola, K., Metsäpelto, R., Lerkkanen, M., & Nurmi, J. (2020). Maternal affection moderates the associations between parenting stress and early adolescents' externalizing and internalizing behavior. *The Journal of Early Adolescence, 40*(2), 221-248.

Singer, G. H., Ethridge, B. L., & Aldana, S. I. (2007). Primary and secondary effects of parenting and stress management interventions for parents of children with developmental disabilities: A meta-analysis. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(4), 357-369.

Stieger, M., Flückiger, C., Rüegger, D., Kowatsch, T., Roberts, B. W., & Allemand, M. (2021). Changing personality traits with the help of a digital personality change intervention. *Proceedings of the National Academy of Sciences, 118*(8)

Tarver, J., Palmer, M., Webb, S., Scott, S., Slonims, V., Simonoff, E., & Charman, T. (2019). Child and parent outcomes following parent interventions for child emotional and behavioral problems in autism spectrum disorders: A systematic review and meta-analysis. *Autism, 23*(7), 1630-1644.

Theule, J., Cheung, K., & Aberdeen, K. (2018). Children's ADHD interventions and parenting stress: A meta-analysis. *Journal of Child and Family Studies, 27*(9), 2744-2756.

Valena, S. P., & Szentagotái-Tatar, A. (2015). The relationships between stress, negative affect, rumination and social anxiety. *Journal of Evidence-Based Psychotherapies, 15*(2), 179.

Van Tulder, M., Furlan, A., Bombardier, C., Bouter, L., & Editorial Board of the Cochrane Collaboration Back Review Group. (2003). Updated method guidelines for systematic reviews in the cochrane collaboration back review group. *Spine, 28*(12), 1290-1299.

Vanderbilt-Adriance, E., & Shaw, D. S. (2008). Conceptualizing and re-evaluating resilience across levels of risk, time, and domains of competence. *Clinical Child and Family Psychology Review, 11*(1-2), 30.

Vilaseca, R., Rivero, M., Ferrer, F., & Bersabé, R. M. (2020). Parenting behaviors of mothers and fathers of young children with intellectual disability evaluated in a natural context. *Plos One, 15*(10), e0240320.

Wayment, H. A., Al-Kire, R., & Brookshire, K. (2019). Challenged and changed: Quiet ego and posttraumatic growth in mothers raising children with autism spectrum disorder. *Autism, 23*(3), 607-618.

Werry, J. S., & Quay, H. C. (1971a). The prevalence of behavior symptoms in younger elementary school children. *American Journal of Orthopsychiatry, 41*(1), 136.

Werry, J. S., & Quay, H. C. (1971b). The prevalence of behavior symptoms in younger elementary school children. *American Journal of Orthopsychiatry, 41*(1), 136.

Widyawati, Y., Scholte, R., Kleemans, T., & Otten, R. (2021). Positive parenting and its mediating role in the relationship between parental resilience and quality of life in children with developmental disabilities in Java Island, Indonesia. *Research in Developmental Disabilities, 112*, 103911.

Willis, K. D., & Burnett Jr, H. J. (2016). The Power of Stress: Perceived Stress and Its Relationship with Rumination, Self-Concept Clarity, and Resilience. *North American Journal of Psychology, 18*(3).

Williford, A. P., Calkins, S. D., & Keane, S. P. (2007). Predicting change in parenting stress across early childhood: Child and maternal factors. *Journal of Abnormal Child Psychology, 35*(2), 251-263.

Wilson, D. B. (2016). Formulas Used by the" Practical Meta-Analysis Effect Size Calculator. *Practical Meta-Analysis.*

Wong, D. F., Ng, T. K., Ip, P. S., Chung, M. L., & Choi, J. (2018). Evaluating the Effectiveness of a Group CBT for Parents of ADHD Children. *Journal of Child and Family Studies, 27*(1), 227-239.

Woodman, A. C. (2014). Trajectories of stress among parents of children with disabilities: A dyadic analysis. *Family Relations, 63*(1), 39-54.

Yorke, I., White, P., Weston, A., Rafla, M., Charman, T., & Simonoff, E. (2018). The association between emotional and behavioral problems in children with autism spectrum disorder and psychological distress in their parents: a systematic review and meta-analysis. *Journal of Autism and Developmental Disorders, 48*(10), 3393-3415.

Zablotsky, B., Bradshaw, C. P., & Stuart, E. A. (2013). The association between mental health, stress, and coping supports in mothers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*(6), 1380-1393.

Zaidman-Zait, A., Mirenda, P., Duku, E., Vaillancourt, T., Smith, I. M., Szatmari, P., Bryson, S., Fombonne, E., Volden, J., & Waddell, C. (2017). Impact of personal and social resources on parenting stress in mothers of children with autism spectrum disorder. *Autism, 21*(2), 155-166.

Profiling Emotional Outbursts in Deaf and Hard of Hearing Children and Young People

Abstract

Background

There is a high prevalence of emotional outbursts experienced by children who are deaf. Despite this, there is limited research into the development and characteristics of the outbursts. 90% of deaf children are born to hearing parents. Deafness may impact on emotional regulatory systems, both through neurological impact but also due to the communication differences between the caregiver and the child. Whilst there is a reasonable proportion of neurological disorders within the deaf population, there is evidence to suggest that emotional outbursts are transdiagnostic and thus, should not be attributed to a disorder. Investigation of the mechanisms underpinning emotional outbursts is vital for efficacious and individualised interventions. To understand emotional outbursts, it is important that a measure is used which enables a holistic understanding of the outburst including the triggers, antecedents, and characteristics which until recently, could only be collected through interviews. An emotional outburst measure has been created encompassing these aspects, and this study aims to explore the reliability of it when used within a deaf population.

Method

A cross-sectional, comparative study design was utilised. Online questionnaires (EOQ and SCQ) were provided to caregivers of deaf children aged between 6 and 25 years. Caregivers were asked to volunteer to complete the EOQ again two weeks later. Data from this study was compared with data from the larger study (Chung et al., 2020), after selecting a comparison group of non-deaf young people with as closely matched demographics as possible. Reliability was investigated for two responses that were provided again, two weeks later. Comparison of the deaf (N=8) and non-deaf (N=8) group responses relating to behavioural characteristics (using both open-ended answers and behavioural item responses) and outburst intensity features of both most and least severe emotional outbursts. Comparison between the groups was also conducted looking at factor scores relating to contextual pathways of outbursts.

Results

The measure demonstrated fair inter-rater reliability and moderate test-retest reliability. Verbal expression was the most common behavioural characteristic expressed amongst both groups. Escape behaviours were a more salient characteristic of the least severe outburst for deaf children. Non-deaf children were more likely to not respond to things around them and engage in food related behaviours for the most severe outbursts. Deaf children were more likely to react to perceived cognitive demand and physiological states whilst non-deaf children were more triggered by sensory stimulus.

Discussion

Differences between the emotional outbursts could be indicative of the mechanisms of the outbursts. Deaf children appear to experience emotional outbursts as an expression of emotional distress, leading to dysregulation. The reasons for this are tentatively considered with the wider literature. Non-deaf children appear to experience outbursts in response to sensory stimulus, which results in a more dissociative state.

Thirty-four million children around the world are diagnosed with deafness or hard of hearing (World Health organization, [WHO], 2021). 'Deafness' is the result of profound hearing loss whereby the main method of communication is sign language; 'hard of hearing' encompasses hearing loss ranging from mild to severe (WHO, 2021). As well as being born with deafness or hearing loss, individuals can acquire it later in life, nonetheless ninety-five percent of deaf and hard of hearing children are born to homes where spoken language is the only method of communication (Hall et al., 2019; Mitchell & Karchmer, 2004). Whilst there is a distinguishable difference across types and cultures of deafness, for the purpose of this study the term 'deaf' will encompass the range of hearing loss from mild to profound.

Thirty to fifty percent of deaf children experience behavioural problems which come under the term 'emotional outburst' (Mitchell & Quittner, 1996; van Eldik et al., 2004:2005; Vostanis et al., 1997). Chung et al., (2020) define an emotional outburst as

> "a highly emotional, explosive episode, which is characterised by the presence of a pattern of challenging behaviour that varies across individuals and across time but can be immediately identified by caregivers. Within the literature, emotional outbursts are often referred to as "temper outbursts" or "tantrums", but other terms that are used synonymously include "meltdowns" and "rages"."

Several behaviourally defined psychiatric diagnosis include emotional outbursts as one of the diagnostic criteria, including Disruptive Mood Dysregulation Disorder (DMDD), Intermittent Explosive Disorder (IED) and Oppositional Defiant Disorder (ODD). Furthermore, emotional outbursts are highly prevalent in several neurodevelopmental disorders, including Autistic Spectrum Disorder (ASD; Dominick et al., 2007), Attention Deficit Hyperactivity Disorder (ADHD; Godovich et al., 2017) and Intellectual Disabilities (ID; Eaton et al., 2021). Commonly, emotional outbursts are referred to as 'temper tantrums' (NHS, 2019). Despite the high prevalence of emotional outbursts displayed by deaf children, there is limited research into the development and characteristics of emotional outbursts within this population (Theunissen et al., 2014; VanOrmer et al., 2019). To offer support and intervention, it is important to first understand emotional outbursts in deaf children.

The development of emotional regulatory systems may be influenced by the discrepancy between communication styles within families of deaf children. Emotional regulation is known to be, in part, dependant on the parent-child relationship and thus, difficulty within the parent-child communication, can impact on the child's ability to emotionally regulate (Quittner et al., 2010). 90 to 95% of deaf children are born into hearing families (Ching et al., 2018, Hall et al.,2019; Mitchell & Karchmer, 2004). Dependant on the level of sign language fluency the parent and family have, there is a possibility of miscommunication between the child and their family (Barker et al., 2009; Roberts & Hindley, 1999). This can lead to frustration and misattunement, factors expected to play a role in emotional outbursts. Certainly, many investigations highlight better cognitive and emotional development in deaf children who are born to deaf parents than deaf children of hearing parents (Bailly et al., 2003). Whilst the mismatch between parent-child communication is likely to be a key factor in emotional outbursts, it may not be the only explanation.

Being unable to acquire verbal language can affect emotional regulation within deaf children (Calderon & Greenberg, 2003). The lack of early auditory stimulation and language acquisition seems to impact neurocognitive processing domains, related to auditory and visual working memory, inhibition, and attention. This deficiency can impact cognitive and emotional control, planning and organisation (Fellinger et al., 2012) all of which are related to emotional regulation. Indeed, Boerrigter et al. (2019) found that children who had poorer speech perception and receptive vocabulary showed the highest levels of behavioural problems. These aspects of cognitive development also hinder a child's ability to interact and understand people, cultures and social rules (Calderon & Greenberg, 2003; Moeller, 2007; Vaccari & Marschark, 1997). Feelings related to social difference and isolation can impact on the child's psychosocial development.

In some deaf children, the struggle to establish an early language can give rise to difficulties when developing key skills needed for relationships, such as empathy and social problem-solving skills (Wong et al., 2017). Reiffe (2012) found that children who were deaf were more aggressive and confrontational in their responses to problems whilst their hearing peers would adapt their communication/ problem solving dependent on the situation. A review and meta-analysis of 48 papers investigating emotional and behavioural disorders in hearing impaired children reported that they are at greatest emotional risk due to peer relational difficulties (Stevenson et al., 2015). Comparatively, children who have cochlear implants acquire better language skills and consequently have better psychosocial outcomes (Wong et al., 2017). Finding it difficult or being unable to easily communicate needs or desires, or to understand the parental and societal rules could be a reason for clinically elevated levels of behavioural difficulties (Barker et al., 2009).

30 to 40 percent of deaf children have additional diagnoses of neurodevelopmental disorders (Fortnum et al., 2002; VanOrmer et al., 2019). The presence of behavioural and

emotional problems within neurodevelopmental disorders is high (Miller et al., 2018). Recent research by Chung et al., (2020) provides evidence to suggest the aetiology of emotional outbursts can be clustered into contextual pathways reflective of the triggers, antecedents, and consequences of emotional outbursts. In addition, these contextual pathways have been found to be transdiagnostic. Whilst emotional outbursts are common across neurodevelopmental disorders, Chung et al. (2020) proposes that emotional outbursts must be considered in the context of other factors. It would, therefore, be too simplistic to refine the cause of emotional outbursts in deaf children, with neurodevelopmental disorders, by the disorder. Rather, neurodevelopmental disorders must be considered alongside biopsychosocial factors, associated with deafness. As Bigler et al. (2018) found in a systematic review of 36 studies investigating behavioural problems in deaf and hard of hearing children, there is an abundance of literature reporting on behavioural problems, but no clear understandings of the mechanisms underpinning them.

To date, most research investigating emotional outbursts relies on interviews to gather information regarding the characteristics of emotional outbursts (e.g. frequency, duration, and behaviours displayed during an outburst). This information is important in informing the development of intervention strategies for emotional outbursts. However, interviews are resource intensive (Alshenqeeti, 2014) and therefore severely limit the sample size from which data can be collected. Despite the limitations, researchers often choose to conduct interviews over the use of existing questionnaires, as they provide the researcher an opportunity to discover information that is often hard to capture using questionnaire methodology (Blaxter, 2010).

The use of questionnaires measuring behavioural problems in deaf children is common within the literature (Theunissen et al., 2014; Sakiet al., 2019), there is however a scarcity of literature exploring typology or characteristics of behavioural problems (Theunissen et al.,

2014) including emotional outbursts. Indeed, VanOrmer et al. (2019) recommended that more research is conducted within this population. Common measures include the Child Behaviour Checklist (Achenbach, 1991; Archenbach & Rescorla, 2000), the Vineland Behaviour Adaptive Scales (Sparrow et al, 1984) and the Strengths and Difficulties Questionnaire (Goodman, 1997). Current measures, such as those above, lack validation within the deaf population (Bigler et al., 2018) and do not examine emotional outbursts specifically. The Emotional Outburst Questionnaire (EOQ; Chung et al., 2020) has recently been constructed to examine emotional outbursts transdiagnostically, however this measure has not been examined or validated in a deaf sample. To facilitate research within the field of emotional outbursts within deaf children, it is important that an appropriate measure is validated for use.

Therefore, the aims of this research were twofold: A) to conduct a preliminary analysis of responses by up to two caregivers of deaf children to the emotional outburst questionnaire to explore the validity of the measure in a deaf sample. B) To investigate the development, communication and function of emotional outbursts, relevant to deafness through comparison of characteristics, contextual factors, and temporal features between deaf and non-deaf children. Given the small sample, only reliability, as one critical aspect of validity could be explored.

Method

Design

A cross sectional comparative design was employed for this study. Data obtained for the present study, was combined with a sample from data previously obtained from a larger study of emotional outbursts (Chung et al., 2020). Recruitment methodology between studies was analogous, however the present study recruited exclusively caregivers of children with deafness. Participants were provided with a demographic questionnaire (Appendix C), a measure of social communication and a measure of emotional outbursts (EOQ; Appendix B) at Time 1. Participants were asked to volunteer themselves or a second caregiver to complete the EOQ again two weeks after initial completion (Time 2).

Recruitment

Participants were recruited to complete an online survey through a multi-point recruitment method. The principal investigator liaised with mental health professionals from the National Deaf Children and Adolescent Mental Health Service, whose focus is to provide a mental health service for deaf children, young people and their families within the UK. Support groups within the UK and English-speaking international countries, for the parents and carers of children and young people who are deaf, were also approached. Special Educational Needs schools within the UK were sent social media adverts and contacted via email to arrange meetings. Following all correspondence, online links to the questionnaire and information sheets were sent out. Online recruitment via social media (Twitter and Facebook) was also on-going throughout the recruitment period. 15 parents responded to the survey, of these, eight responses were fully completed. Two participants completed the EOQ at Time 2.

Matching comparison group

Following the recruitment of caregivers of deaf children, the demographic data was entered into R 4.0.2 (R Core Team, 2021) alongside the data from the larger study (N=268). A programme was created by a member of the research team which facilitated the comparison of the two datasets so that each individual dataset from the present sample, could be compared with the larger sample. Variable(s) were selected by the principal investigator and the programme refined the existing dataset to those matching the individual deaf data group on the selected variable(s). This enabled each individual dataset within the deaf sample to have a comparison individual dataset from the larger study, as closely matched as possible in terms of age, gender, neurodevelopmental disorders, and mental health diagnosis. Although this matching process was conducted practically via individual matching, the aim was to achieve group level matching between the deaf group and non-deaf group for comparative analysis. See Table 1 for groups.

Table 1

Demographics of deaf (bold) and the comparison non deaf group

Participant ID	Age	Gender	Learning Disability	Learning Difficulty	ASD	ADHD	Anxiety	Depression	Level of deafness	Other Diagnosis
4	**17.75**	**Male**	**Yes**	**No**	**Yes**	**Yes**	**Yes**	**No**	**Profound**	**No**
39	17.83	Male	Yes	No	Yes	Yes	Yes	No		Sensory processing disorder
5	**17.58**	**Male**	**Yes**	**No**	**Yes**	**Yes**	**Yes**	**No**	**Profound**	**Charge Syndrome**
316	17.33	Male	No	No	Yes	No	Yes	No		emotional and behavioural difficulties
6	**9.08**	**Female**	**No**	**No**	**No**	**No**	**No**	**No**	**Profound**	**No**
364	9.42	Female	No	No	No	No	No	No		Diagnosed SPD
7	**8.75**	**Male**	**No**	**Yes**	**No**	**Yes**	**Yes**	**No**	**Profound**	**No**
20	8	Male	No	No	No	No	No	No		No
8	**6.33**	**Male**	**No**	**No**	**No**	**No**	**No**	**No**	**Severe**	**No**
61	6.58	Male	No	No	No	No	No	No		No
10	**10.5**	**Female**	**Yes**	**Yes**	**Yes**	**No**	**Yes**	**Yes**	**Profound**	**No**
32	10.33	Female	No	No	No	No	Yes	No		Yes
11	**7.5**	**Female**	**Yes**	**No**	**No**	**Yes**	**No**	**No**	**Mild**	**Suspected FASD**
539	8.16	Female	Yes	No	No	No	No	No		CdLS
13	**8.08**	**Other**	**Yes**	**No**	**No**	**No**	**No**	**No**	**Mild**	**No**
383	16.83	Other	Yes	No	Yes	No	Yes	No		No

Note: Deaf are represented by bolden text

Participants

Once the comparison group had been identified, the overall sample consisted of 16 participants: eight caregivers of deaf young people and eight caregivers of non-deaf young people. Inclusion criteria was the child of the participant was aged from 6 to 25 years, and experienced emotional outbursts with a frequency equal to or greater than, one per month.

Most children were male (50%; N=8), 37.5%, were females (N=6) and 12.5% identified as other (N=2). Ages of children ranged from 6 to 17 years with a mean age of 11.26 years (SD = 4.76). Of the sixteen individuals, 68.75% (N=11) had co-morbid neurodevelopmental disorders diagnosed by psychiatrists, general practitioners, and clinical psychologists. 68.75% (N=11) of individuals had a special educational needs plan in place. 50% (N=8) of the young people attended mainstream educational settings, 43.75% (N=7) attended special educational unit and 6.25% (N=1) was unemployed/out of education. Diagnoses of deafness (N=8) were from audiologists within the children's hospitals. Level of deafness ranged from severe (N=1), profound (N=5) and mild (N=2). Communication between the deaf sample and their family was either verbal (N=6) or sign language (N=2). All caregivers (N=8) of deaf individuals were hearing. Full demographic details are presented in Table 1.

Ethical approval

Ethical approval was obtained from the South Birmingham NHS Research Ethics Committee (the Health Research Authority (HRA) (Appendix A) and by the Research and Development Teams from the participating NHS Trust.

To support any potential distress caused, contact numbers and information for supportive charities were provided to participants throughout the process. Participants were informed that they could stop and come back to it at any time.

Measures

The Social Communication Questionnaire (SCQ; Rutter et al., 2003). The SCQ (Rutter et al., 2003) is an instrument for screening for autism in individuals over the age of four with a mental age over two years. SCQ is a 40-item parent questionnaire containing yes/no items. Caregivers are provided with either the lifetime version or the current version, depending on whether the child was in their care from the age of four to five years. The lifetime version focuses on behaviour throughout development, the current version focuses on behaviour within the last three months. Chesnut et al. (2016) conducted a meta-analysis of 17 studies (N = 3315) to investigate whether this tool was psychometrically sufficient in screening for Autistic Spectrum Disorder (ASD) by looking at the area under the curve (AUC). Findings indicated perfect diagnostic validity for children at or over four years (AUC = 0.922, N = 1640; Chesnut et al., 2016; Hanley & McNeil, 1982). The measure contains three subscales: Reciprocal social interaction, language and communication and stereotyped patterns of behaviour. Discriminative validity has been reported for children aged between 9.8 to 14.5 years (Chandler et al., 2007). Rutter et al. (2003) report good internal consistency across age and developmental ability and good convergent validity with the ADI-R (Chung et al., 2020). The initial aim to explore validity of the measure required the use of the SCQ, due to the necessary restriction to examination of the reliability aspect of validity because of limited sample size, the SCQ data was not included in the current analysis.

Demographic questionnaire. Caregivers were asked to provide information relating to the child or young person whom they were reporting on. Information on the child or young person's characteristics (i.e., age, gender, diagnoses, medication, deafness severity, communication preference, education and IQ) was obtained. Other relevant information (.i.e., whether the caregiver was deaf, previous support/ resources accessed) was also collected.

Emotional Outburst Questionnaire (EOQ; Chung et al., 2020). The EOQ is a 133-item parent report questionnaire, aiming to measure various characteristics of emotional outbursts in children and young people aged 6 to 25 years. The questionnaire is made up of three sections: Sections 1 and 2 explore characteristics of the most and least severe outbursts over the past month, including behavioral composition, frequency, duration, intensity, and recovery duration of outbursts. Open-ended questions are used to explore what the caregivers find the most distinguishing about the most and least severe outbursts, whilst behavioural item questions are used to understand how often certain behaviours are present. Section 3 investigates common characteristics of outbursts, encompassing setting events and antecedents related to outbursts, behaviors following outbursts, and the effective caregiver management strategies. Whilst the psychometric properties of the measure are still under investigation, it was derived from pre-existing measures which were associated, in general, with reasonable reliability (Chung et al., 2020). Furthermore, moderate test-retest reliability, and interrater reliability of items within Section 3 has been demonstrated (Chung et al., 2020).

Procedure

All participants completed the questionnaire online using Qualtrics (Qualtrics, 2021). Prior to the questionnaire, a written information sheet was presented on the webpage, which detailed the aims and purpose of the study along with information around anonymity and withdrawal. Age-appropriate information sheets were provided to share with the child or young person, should the participant feel that they would understand. Participants were asked to only consent and continue provided, they felt the child or young person understood the study or it was within their best interest. Participants were also asked if they would provide an email address so that the EOQ could be sent out and completed a second time (2 weeks post initial completion).

Ethical considerations

All participants gave consent to participate. All collected data was anonymised, including demographic information. Those who completed a second questionnaire were asked to provide their email address. This was stored in a separate database from the participant responses. Stored email addresses were deleted after two weeks. Participants were instructed to create a unique identifier code which was then used to link their second response with the initial response.

Data analysis

Inter-rater Reliability of Measure. Kappa coefficients have been calculated for inter-rater reliability between the time one and time two responses, using IBM SPSS Statistics for Windows (Version 27). Inter-rater reliability is the degree to which two distinct informants give responses about the same child, which are consistent with each other. The data set is representative of two participants reporting on the same child. The outcomes are interpreted using the guidelines specified by Landis and Koch (1977), where strength of the kappa coefficients is interpreted in the following manner: 0.01-0.20 slight; 0.21-0.40 fair; 0.41-0.60 moderate; 0.61-0.80 substantial; 0.81-1.00 almost perfect.

Intra-reliability of Measure. Pearsons correlation coefficient is an accepted measure of test-retest reliability. Test-retest reliability or 'intra-rater reliability' measures the degree to which responses are consistent over time (assuming no real change has occurred). Cohen's (1988) interpretation of effect size is used so a coefficient of .50 and above is considered large, .30 is moderate and .10 is small. A large correlation indicates evidence of good test-retest reliability (Collins, 2007). IBM SPSS statistics for Windows (Version 27) was used to calculate the intra-reliability of the measure when responses were provided by the same participant at two different time points, regarding the same child.

Factor scores. Chung et al. (2020) previously conducted an exploratory factor analysis on the 55 items pertaining to the antecedents and setting events of outbursts in a transdiagnostic sample of (N = 268) young people who experience at least one emotional outburst per month. Based on the factor analysis, items were condensed into factors which reflect the type of items within them. Interpretation and internal consistency scores can be found in Table 2. The mean difference in factor scores for both the deaf and non-deaf group were analysed through a Mann-Whitney U test, using IBM SPSS Statistics for Windows (Version 27).

Table 2

Definition of factors

Factor	**Definition**	**Cronbach's Alpha (Chung et al., 2020)**
Sensory	Items relating to sensory hypersensitivity.	α = 0.83
Cognitive demand	Items reflecting antecedents which increase cognitive demands on the individual.	α = 0.79
Threat to self	Items encompassing antecedents reflecting a perceived threat to the concept of self.	α = 0.84
Cross settings	Items pertaining to various settings and people whereby the individual was more likely to experience an outburst.	α = 0.78
Safety	Items containing settings and people linked to safety.	α = 0.68
States	Items consisting of physiological states such as hunger, thirst, and tiredness.	α = 0.68

Content analysis. Content analysis, based on the method by Erlingsson and Brysiewicz (2017), of the open-ended questions relating to the least severe and most severe outbursts was conducted. To analyse the content, firstly answers are described as a 'meaning unit' for example: 'Sudden eruption, physically aggressive, shouting, can last for a couple of hours'. Meaning unit is simplified into a 'condensed meaning unit' which encompasses the focus words of the answer: 'Unexpected, physical aggression, shouting, long duration'. Next, 'codes' are established based on different parts of the 'condensed meaning unit', for example 'codes' would be: 'Unpredictable, aggression, verbal, long' and are then described under a 'category' which reflects multiple 'codes' that come up. Categories here would be: 'Unpredictable, physical aggression to others, verbal aggression, long duration'. Categories are then linked to a less specific but more inclusive 'theme' based on the categories which come up across all the answers. For example, the theme *'Verbal expression'* encompassed categories such as 'verbal frustration' and 'verbal aggression' which were made up from identified codes including 'verbal', 'verbal threats', these reflected condensed meanings such as 'shouting', 'threating', 'screaming', 'growling'. 13 themes were identified within each of the least and most severe outbursts. The exhaustive list of themes and definitions can be found in Appendix D. Themes and definitions were cross checked by a second member of the research team. The established themes were subsequently counted to support a numerical comparison.

Descriptive analysis. A descriptive analysis was conducted for the outburst intensity features of the questionnaire. To enable this, the items pertaining to outburst intensity features of the most and least severe outbursts were coded as presented in Table 3. The codes were transformed into standardised mean scores to allow for descriptive comparison between groups. A descriptive comparison was then related back to the categorical meaning of the mean score to provide a meaningful interpretation and comparison of these features between the deaf and non-deaf group, relating to least and most severe outbursts. Descriptive analysis was conducted for the quantitative data pertaining to behavioural characteristics questionnaire items. To facilitate the comparative analysis for most and least severe outbursts, responses for behavioural characteristics items were counted. The median was calculated, the numerical interpretation for this can be seen in Table 4. Within the least severe outbursts, only six caregivers provided responses for the behavioural items and therefore, the six matched data sets were used for comparison.

Table 3

Coded responses for outburst intensity items

Temporal feature	Code
Frequency	Never (0) 2-3 times a month (1) Once a week (2) 2 – 3 times a week (3) Once a day (4) More than once a day (5)
Duration	Fewer than 5 minutes (0) 5-15 minutes (1) 15-30 minutes (2) 30 minutes to 1 hour (3) 1-2 hours (4) 2 hours to a day (5)
Intensity	1 = Not angry or upset at all 2 3 4 5 6

	7= As angry or upset as I have ever seen him
Eye contact	More than baseline (1) Same as baseline (2) Less than baseline (3)
Recovery	Fewer than 5 minutes (0) 5-15 minutes (1) 15-30 minutes (2) 30 minutes to 1 hour (3) 1-2 hours (4) 2 hours to a day (5)

Table 4

Quantitative transformation of responses for the calculation of the median

Response	**Never/rarely** **(0-2 times out of 10 outbursts)**	**Sometimes** **(3-7 times out of 10 outbursts)**	**Often/always** **(8-10 times out of 10 outbursts)**
Number reflecting response	1	2	3

Results

Inter-rater Reliability of Measure

Kappa coefficients between two raters (N=2) regarding the same child indicated fair reliability (κ=0.44, p=<.001).

Intra-rater Reliability of the Measure.

Intra-rater coefficient at a two-week interval was moderate (r=.60, p=<.001) for the same participant (N=1).

Most severe outbursts

Content analysis of open-ended responses between the deaf and non-deaf group.

The table of themes and contributing definitions can be found in Appendix D. Content analysis of themes between groups for most severe outbursts is presented in Table 5. Across both groups verbal expression was the most highlighted behaviour for the most severe outbursts, followed by aggression to others and objects. Escape behaviours were reported slightly more in the deaf sample; however, these were referenced in both groups. The deaf group had no reported self-injurious behaviour in most severe, whilst it was referred to more frequently in the non-deaf group. The caregivers of both groups experienced these outbursts as long in duration. Behaviour's indicative of emotion were the second most reported behaviour within the most severe outbursts for the non-deaf group, whilst only two caregivers reported this for the deaf group. Increased motor activity and complete loss of control was also commonly reported in the non-deaf group whilst only one incidence of loss of control was reported in the deaf group, and this was followed by remorse which was not reported within the non-deaf group. The non-deaf group had a report of the outbursts being high frequency which was not referred to within the deaf sample. One person within the deaf sample was reported to be soothed by their caregiver.

Table 5

Between groups comparison of themes within most severe outbursts

Comparison of themes	
No difference	Verbal expression (6:6)

	Aggression to objects (3:3) Long (2:2)
Highest in deaf group	Unexpected outburst (2:0) Aggression to others (5:4) Escape behaviours (2:1) Soothed by caregiver (1:0) Followed by remorse in (1:0)
Highest in non-deaf group	Self-injurious behaviour (0:4) Increased motor activity in non-deaf (0:3) Behaviours indicative of emotion (2:5) Complete loss of control (1:3) Caregiver label emotions (1:2) High frequency (0:1)

Note: Numbers represent amount of times themes appear (deaf:nondeaf).

Descriptive analysis of responses to behavioural items pertaining to the most severe outbursts. Across the most severe outbursts there were ten out of 22 responses where the median was the same between both groups. There were 12 responses where a different median was reported. See Table 6. Behavioural indicators of emotion, mild verbal aggression and avoidance were most frequent features of the most severe outbursts across both groups (Deaf M =3, Non-Deaf M=3). Extreme verbal aggression, extreme self-injurious behaviours, defecation or urination, contextually inappropriate sexual behaviours and making themselves sick were the least common features of severe outbursts across both groups (Deaf M =1, Non-Deaf M =1). Mild physical aggression towards others and increased physiological arousal were displayed sometimes across both groups (Deaf M =2, Non-deaf M =2). The biggest differences reported were food related behaviours (Non-deaf Group M=3; Deaf M =1) and not reacting to things going on around them (Non-Deaf Group M=3; Deaf group

M=1). Aggression to objects was present across both groups, however it has been reported more commonly as a behaviour for the deaf group, specifically extreme aggression which was rarely present for the non-deaf group (Mild aggression: Deaf M=3; Non-deaf M=2; Extreme aggression Deaf=2; Non-deaf M=1).

Table 6

Descriptive analysis of the response of most severe

	Median score (1=never/rarely; 2=sometimes; 3=always/often)		**Never/rarely** **(0-2 times out of 10 outbursts)**		**Sometimes** **(3-7 times out of 10 outbursts)**		**Often/always** **(8-10 times out of 10 outbursts)**	
	Deaf	Non-Deaf	Deaf	Non-Deaf	Deaf	Non-Deaf	Deaf	Non-Deaf
Non-speech vocalisations	3	2	3 (37.5%)	1 (12.5%)	0	4 (50%)	5 (62.5%)	3 (37.5%)
Mild aggression towards property	3	2	2 (25%)	0	1 (12.5%)	5 (62.5%)	5 (62.5%)	3 (37.5%)
Extreme aggression towards property	2	1	2 (25%)	5 (62.5%)	4 (50%)	2 (25%)	2 (25%)	1 (12.5%)
Mild self-injurious behaviours **without serious injury** (no cuts, bruises, burns, etc)	2	1.5	3 (37.5%)	4 (50%)	3 (37.5%)	2 (25%)	2 (25%)	2 (25%)
Extreme physical aggression towards others **with physical injury**	1.5	1	4 (50%)	5 (62.5%)	2 (25%)	1 (12.5%)	2 (25%)	2 (25%)
Behavioural indicators of emotion	3	3	0	1 (12.5%)	3 (37.5%)	0	5 (62.5%)	7 (87.5%)
Mild verbal aggression	3	3	1	0	2	2	5	6

			(12.5%)		(25%)	(25%)	(62.5%)	(75%)
Avoidance	3	3	2 (25%)	1 (12.5%)	0	2 (25%)	6 (75%)	5 (62.5%)
Mild physical aggression towards others **without physical injury**	2	2	2 (25%)	3 (37.5%)	3 (37.5%)	2 (25%)	3 (37.5%)	3 (37.5%)
Extreme verbal aggression	1	1	5 (62.5%)	5 (62.5%)	1 (12.5%)	2 (25%)	2 (25%)	0
Extreme self-injurious behaviours **with serious injury**	1	1	5 (62.5%)	6 (75%)	1 (12.5%)	2 (25%)	2 (25%)	0
Increased physiological arousal	2	2	1 (12.5%)	1 (12.5%)	5 (62.5%)	4 (50%)	2 (25%)	3 (37.5%)
Defecation or urination	1	1	8 (100%)	6 (75%)	0	1 (12.5%)	0	1 (12.5%)
Contextually inappropriate sexual behaviours	1	1	8 (100%)	8 (100%)	0	0	0	0
Making themselves sick	1	1	6 (75%)	6 (75%)	2 (25%)	1 (12.5%)	0 D	1 (12.5%)
Removing items of clothing	1	1.5	6 (75%)	4 (50%)	2 (25%)	1 (12.5%)	0	2 (25%)

Ignoring or not talking to certain people	1.5	2	4 (50%)	2 (25%)	2 (25%)	3 (37.5%)	2 (25%)	3 (37.5%)
Increased motor activity	2.5	3	1 (12.5%)	0	3 (37.5%)	2 (25%)	4 (50%)	6 (75%)
Unusual behaviours	1	2	7 (87.5%)	2 (25%)	1 (12.5%)	4 (50%)	0	1 (12.5%)
Talking to self & others	1.5	2.5	4 (50%)	1 (12.5%)	2 (25%)	3 (37.5%)	2 (25%)	4 (50%)
Not reacting to things going on around them	**1**	**3**	**6** **(75%)**	**0**	**1** **(12.5%)**	**3** **(37.5%)**	**1** **(12.5%)**	**5** **(62.5%)**
Food-related behaviours	**1**	**3**	**6** **(75%)**	**1** **(12.5%)**	**1** **(12.5%)**	**2** **(25%)**	**1** **(12.5%)**	**5** **(62.5%)**

Note: Deaf group is represented by the colour grey.

Least Severe Outbursts

Content analysis of open-ended responses between the deaf and non-deaf group.

The table of themes and contributing definitions can be found in Appendix D. Content analysis of themes between both groups for least severe outbursts are presented in Table 7. Both groups reported signs of physiological arousal, aggression towards objects and self-depreciation, although this was reported more in the deaf group. Caregiver labelled emotions, however, was reported twice in the deaf group compared to once in the non-deaf group. Escaping behaviours was the most evident difference between these groups for the least severe outbursts, reported five times by the deaf group and only once for the non-deaf group. Non-compliance/ defiance was referred to by the deaf group but was only reported once in the non-deaf group. The deaf groups least severe outbursts also were reported to lead to increased behaviours which was not reported within the non-deaf group. The non-deaf group reportedly showed behaviours indicative of emotion and a higher report of verbal expression and self-injurious behaviour.

Table 7

Between groups comparison of themes within least severe outbursts

Comparison of themes	
No difference	Caregiver label emotion (2:2) Physiological arousal (2:2) Aggression towards objects (2:2)
Highest in deaf group	Escaping behaviours (5:1) Non-compliance/defiance (3:1) Self-deprecation (2:1)
Highest in non-deaf group	Behaviours indicative of emotions (1:4) Verbal expression (3:5) Self-injurious behaviour (0:2)

	Lead to increased behaviours/emotional distress (1:0)

Note: Numbers represent amount of times themes appear (deaf:nondeaf)

Descriptive analysis of responses to behavioural items pertaining to the least severe outbursts. Across the least severe outbursts there were thirteen out of twenty-two responses where the median was the same between both groups. Nine responses had a small difference between medians. There were no big differences within the least severe outbursts. Behavioural indicators of emotion were reported as an 'often/always' behaviour of least severe outbursts across both groups (Deaf M = 3; Non-deaf M =3). Extreme verbal aggression, mild and extreme physical aggression, extreme self-injurious behaviours, removing clothing, defecation or urination, contextually sexual inappropriate behaviours, food related behaviours, making themselves sick and unusual behaviours were all reported as 'rarely' occurring across both groups (Deaf M= 1; Non-Deaf M =1)

Table 8

Descriptive analysis of the responses for behavioural items of the least severe

	Median **(1=never/rarely;** **2=sometimes;** **3=always/often)**		**Never/rarely** **(0-2 times out of 10 outbursts)**		**Sometimes** **(3-7 times out of 10 outbursts)**		**Often/always** **(8-10 times out of 10 outbursts)**	
	Deaf	Non-Deaf	Deaf	Non-Deaf	Deaf	Non-Deaf	Deaf	Non-Deaf
Mild verbal aggression	**3**	**2**	**2** **(33.33%)**	**3** **(50%)**	**1** **(16.67%)**	**2** **(33.33%)**	**3** **(50%)**	**1** **(16.67%)**
Non-speech vocalisations	**3**	**2**	**0**	**1** **(16.67%)**	**2** **(33.33%)**	**3** **(50%)**	**4** **(66.67%)**	**2** **(33.33%)**
Mild aggression towards property	**2.5**	**1.5**	**2** **(33.33%)**	**3** **(50%)**	**1** **(16.67%)**	**3** **(50%)**	**3** **(50%)**	**0**
Ignoring or not talking to certain people	**2.5**	**1.5**	**1**	**3**	**2**	**3**	**3**	**0**

			(16.67%)	**(50%)**	**(33.33%)**	**(50%)**	**(50%)**	
Not reacting to things going on around them	**1**	**2**	**4** **(50%)**	**1** **(16.67%)**	**1** **(16.67%)**	**4** **(50%)**	**1** **(16.67%)**	**1** **(16.67%)**
Talking to self & others	2.5	2	2 (33.33%)	1 (16.67%)	1 (16.67%)	3 (50%)	3 (50%)	2 (33.33%)
Avoidance	2	2	2 (33.33%)	2 (33.33%)	2 (33.33%)	4 (66.67%)	2 (33.33%)	0
Removing items of clothing	1	1	5 (83.33%)	5 (83.33%)	1 (16.67%)	0	0	1 (16.67%)
Defecation or urination	1	1	6 (100%)	6 (100%)	0	0	0	0
Contextually inappropriate sexual behaviours	1	1	6 (100%)	6 (100%)	0	0	0	0

Food-related behaviours	1	1	6 (100%)	6 (100%)	0	0	0	0
Making themselves sick	1	1	6 (100%)	6 (100%)	0	0	0	0
Unusual behaviours	1	1	5 (83.33%)	4 (50%)	1 (16.67%)	2 (33.33%)	0	0
Mild self-injurious behaviours **without serious injury** (no cuts, bruises, burns, etc)	1	1.5	4 (66.67%)	3 (50%)	2 (33.33%)	1 (16.67%)	0	2 (33.33%)
Increased motor activity	1.5	2	3 (50%)	0	3 (50%)	4 (66.67%)	0	2 (33.33%)
Increased physiological arousal	1.5	2	3 (50%)	1 (16.67%)	2 (33.33%)	5 (83.33%)	1 (16.67%)	0

Note: Deaf group is represented by the colour grey

Descriptive analysis of outburst intensity features

Frequency. The mean of both groups indicated that most severe outbursts occur once a week, the deaf group showed a slightly higher frequency of most severe outbursts (M=2.25) compared to the non-deaf group (M=2). For both groups, least severe outbursts were more frequent than most severe with the means representing an average around 2 to 3 times a week. The least severe outbursts were slightly more frequent in the deaf group (M=3.83) than the non-deaf group (M=3.75).

Duration. The mean duration of the most severe outbursts was the same between both groups, lasting 30 minutes to an hour (M=3). The mean duration of least severe outbursts was also the same between both groups, lasting 15 to 30 minutes (M=2).

Intensity. Both groups were reported to be around 6 for intensity in most severe outbursts (deaf group M= 6.13), with the non-deaf group (M=6.25) being slightly closer to *'being as angry or upset as I have ever seen them'* which was represented as 7. Intensity of least severe outbursts between the deaf (M=3.33) and the non-deaf group (M=3.5), was very close with 1 representing *'Not angry or upset at all'*.

Eye contact. Both the non-deaf group (M=2.38) and deaf group (M=2.17) were within the same as baseline category for amount of eye contact during the least severe outbursts, however the non-deaf group appeared to show slightly less. During most severe outbursts again whilst similar, the deaf group showed slightly less eye contact (M=2.5) than the non-deaf group (M=2.38).

Recovery. The non-deaf group took more time to recover from the most severe outbursts 30 minutes to an hour, (M=3.25) than the deaf group (M=2.63) who took a mean around 15 to 30 minutes. The deaf group showed more time to recover from the least severe outbursts (M=2) 15 to 30 minutes, than the non-deaf group (M = 1.63) between 5 to 15 minutes.

Mean differences between factor scores for deaf and non-deaf

Sensory Factor. The non-deaf group scored higher on sensory factors than the deaf group. A Mann-Whitney U Test revealed no significant difference in the sensory factor scores of deaf (Md = 0.22, n = 8) and non-deaf (Md = 0.44, n =8), U = 45.50, z = 1.42, p = .16, r = .5.

Cognitive Demand Factor. The deaf group scored higher on the cognitive demand factor than the non-deaf group (deaf: Md = 0.78, n = 8, non-deaf: Md = 0.63, n =8; U = 18.00, z = -1.47, p = .14, r = .5).

Threat to Self Factor. The deaf group scored higher on the threat to self factors than the non-deaf group (deaf: Md = 0.90, n = 8) and non-deaf (Md = 0.50, n =8), U=28.50, z=-.373, p=.71, r=0.1).

Cross Settings Factor. The deaf group scored lower on the cross settings factor than the non-deaf group (deaf: Md = 0.25, n = 8) and non-deaf (Md = 0.36, n =8), U=32.00, z=.00, p= 1, r=0).

Safety Factor. The deaf group scored higher on the safety factor items than the non-deaf group (deaf: Md = 0.75, n = 8) and non-deaf (Md = 0.63, n =8), U=26.50, z-.582, p =.56, r = .2).

States Factor. The deaf group scored higher on the states factor than the non-deaf group (deaf: Md = 0.88, n = 8) and non-deaf (Md = 0.75, n =8), U =19.00, z=-1.430, p = .153, r = .5.

Discussion

Summary of findings

The aim of this research was to explore the reliability of the emotional outburst questionnaire in deaf children by preliminary analysis of responses by up to two caregivers of deaf children. Secondly, we aimed to understand the transdiagnostic nature of emotional outbursts through the comparison of characteristics, contextual factors, and temporal features of emotional outbursts between deaf and non-deaf children. The analysis of the responses, relating to reliability of the questionnaire was limited due to low response rate. Key findings from the comparison of responses for the deaf and non-deaf group showed both similarities and differences indicating some transdiagnostic features and highlighting the need for further exploration of factors associated with being deaf. Verbal expression was found to be a common behaviour across both groups, but the type of expression differed. Furthermore, verbal expression was more commonly used in the most severe outbursts. The deaf group were less likely to show food related behaviours and to not react to what is going on around them. The use of escape behaviours was referred to more by the caregivers of the deaf group in the open-ended questions but appeared to be a common behaviour across the two groups when asked explicitly in the behavioural items. Outburst intensity features were similar across the two groups. The deaf group showed slightly more eye contact and took less time in recovery. Factor scores indicated that in the deaf group, physiological states and perceived cognitive demand are more likely to trigger an emotional outburst than in the non-deaf group. Children in the non-deaf group were more likely to be triggered by non-sensory stimulus. Findings and limitations are discussed.

Most Severe Outburst Characteristics

The findings from both the open-ended questions, and the results pertaining to the behavioural item responses are discussed for the most severe outbursts. In general, outburst characteristics were described similarly. Most difference was identified in food related behaviours which were often/always present in the most severe outbursts of the non-deaf group and rarely in the deaf group. This encompasses behaviours such as grabbing for, seeking for, pleading for or stealing food. Whilst the groups were matched as closely as possible, there were some differences in additional diagnoses. The non-deaf group included two datasets regarding children with sensory processing disorder and one child with Cornelia de Llange Syndrome. A review investigating behavioural phenotypes in Cornelia de Lange syndrome did not highlight food seeking as a key behavioural component (Mulder et al., 2016), however within sensory processing disorder children can display behaviours associated with seeking out food for a variety of reasons. This diagnosis may account for the difference, given the small number of participants.

Secondly, the behaviour of not reacting to things going on around them which again was often/always demonstrated in the non-deaf group and rarely in the deaf group. These findings may be linked with the open-ended questions which highlighted that loss of control was reported more in the non-deaf group than the deaf group. Certainly, a loss of control can be a dissociative type of behaviour which may account for not being aware of surroundings (Holmes et al., 2005). This type of behaviour is especially common in children who have experienced trauma. Trauma impacts on neurological processing accounting for difficulties in sensory processing and emotional regulation (Harricharan et al., 2016). The behaviours displayed by the non-deaf group and rarely displayed by the deaf group are indicative of childhood trauma responses, which may be a mechanism of their emotional outbursts, not present within the deaf group. This difference is a hypothesis, as exploration of trauma history was not conducted within this study.

A common and consistent finding was that verbal expression was displayed in the most severe outbursts across both groups. Verbal expression was referred to similarly, between deaf and non-deaf in the open-ended analysis, however, the behavioural item responses show some difference between groups. Deaf were more likely to ‘make non-speech vocalisations’ whilst the non-deaf were more likely to ‘talk to self and others’. Whilst the differences in mechanisms of the emotional outbursts remains unclear, the findings support previous research showing that poor verbal language development was associated with an increase child’s behavioural problems (Boerrigter et al., 2019). These findings demonstrate further evidence to indicate that poorer verbal language development may impact on emotional regulatory skills, which could be associated with the neurocognitive processes (Fellinger et al., 2012). Verbal expression is thought to be controlled through biological processes, in response to painful, threatening, or stressful stimuli (Winslow, 2014). It is clear the use of verbal expression is not exclusive to one specific disorder or related to being deaf. The literature suggests that the type (intonation, pitch, frequency etc) of vocalisations can be a way of expressing varying emotional experiences (Green et al., 1998: 2011; Potegal & Davison, 2003), however understanding this was beyond the scope of this paper. Certainly, there appears a need to consider the type of verbal expression, in relation to the context of an outburst to understand the emotional experience of the individual.

References of aggression to others was a distinguishing feature for the most severe outbursts amongst both groups, although referred to slightly more in the deaf group. The behavioural item responses indicated that mild aggression was present across both groups, and extreme aggression was present sometimes in the deaf group. Whilst the difference is small, it is important to highlight that aggression to others, including extreme aggression appears to be increased in the deaf group. Furthermore, behavioural items indicated that aggression to objects was more frequent in the deaf group, although a salient feature amongst both groups in the open-ended questions. As deaf children have an increased likelihood of poorer verbal language development, it could be hypothesised that acting out aggressively to others and objects is a way of communicating distress. The use of sign language and sign comprehension appears to rely on the bilateral parietal cortex, more than the use of spoken language (Emmorey et al., 2014). When the prefrontal cortex neurons (responsible for emotional regulation) are activated, the neurons within the bilateral parietal cortex become less activated (Hall et al., 2020). Thus, when a deaf child, reliant on sign language becomes dysregulated the ability to both comprehend and use sign language may decrease, resulting in assertion of distress in ulterior ways.

Least Severe Outburst Characteristics

The findings from both the open-ended questions, and the results pertaining to the behavioural item responses are discussed for the least severe outbursts. There were inconsistencies between themes found in the open-ended questions and findings from the behavioural item responses. Verbal expression was highest in the non-deaf group from the open-ended responses, however from the behavioural items both mild verbal aggression and non-speech vocalisations were reported to be 'often/always' within the deaf group in comparison to 'sometimes' in the non-deaf group. The caregivers of the non-deaf group may find that verbal expression differentiates the least severe outbursts because their child is able to express something about their distress verbally. This is conducive with the hypothesis from the most severe outbursts, regarding emotional dysregulation. Being unable to verbalise distress in language, may result in an increased emotional dysregulation leading to use of non-verbal acts of expression or aggression.

Escape behaviour was referred to as a distinguishing feature of least severe outbursts more commonly in the deaf group from the analysis of open-ended questions. Behavioural item responses indicated on the other hand, that this behaviour type was frequently shown in severe outbursts across both groups. As the open-ended questions indicated that this was more commonly referred to by the deaf group, it suggests that although it is present amongst both groups, caregivers of deaf children find this behaviour more salient when they picture least severe outbursts. In an empirical study, Reiffe (2012) found that deaf children did not report the use of avoidance tactics when approaching a problem and therefore, it may indicate why this behaviour is more noticeable during a severe outburst in deaf children. Given that deaf children do not self-report the use of avoidance and the salient nature of it for caregivers it is likely that deaf children behave in this way as an unconscious or biological 'fight-flight' response to stress (McCarty, 2016; McFadyen et al., 2020). It is possible, therefore, that avoidance in deaf children is a sign of a deaf child becoming emotionally dysregulated in comparison to the use of verbal language in non-deaf children.

Behaviour's indicative of emotion was reported more by caregivers of the non-deaf in the open-ended questions, whilst behavioural item responses indicated that this was 'often/always' displayed in least severe outbursts for both groups. Much literature has reported on the miscommunication and subsequent attachment difficulties within a family of a deaf child with hearing parents (Coulson-Thaker, 2020). The findings relating to the characteristics of the outbursts appear conducive to this experience. The deaf group had more reported unexpected outbursts than the non-deaf group, whilst the non-deaf group had reported more increased motor activity and behaviours indicative of emotion. This could indicate that there is a discrepancy between the receptiveness of hearing parents to deaf children, so that the outbursts appear unexpected because there is a lack of understanding of the indicators of distress. Certainly, the literature reports that deaf children within hearing families experience miscommunication impacting on the parent-child interaction (Curtin et al., 2021). Not only may this be representative of the parents' ability to read the child's emotional state, but the way in which deaf children show their distress. Despite this, there is no standard observational way to measure parent-child interaction which would promote supportive interventions and positive outcomes (Curtin et al., 2021); this research promotes the need for specific assessments localised on the way in which the parent and deaf child communicate.

Contextual Factors

No significant differences were found between the deaf and non-deaf group factors scores, which supports the findings of Chung et al (2020), showing that emotional outbursts are transdiagnostic. This finding should be approached with some caution as there may be chance of a type II error, specifically with such a small sample and the use of a non-parametric test. Rather, the effect size has been interpreted to highlight any practical differences between groups.

Differences between the groups were small but seemed to show that within the deaf group, physiological states and perceived cognitive demand were more likely to trigger an emotional outburst than in the non-deaf group. Considering the findings of this study relating to both characteristics and temporal features of outbursts, it could be stipulated that deaf children's distress is triggered by an inability to effectively communicate the feelings associated with either physiological discomfort or perceived increased demands. A qualitative study looking at the experiences of parenting a deaf child, highlighted the various communication difficulties that can arise for example, parents may not be as fluent as the child in sign language (Flaherty, 2015). Furthermore, the psychological impact associated receiving a diagnosis of deafness for child was highlighted and should not be disregarded

(Flaherty, 2015). Parental stress is known to impact on the brain-to-brain synchrony between parent and child, meaning that even the non-verbal communication between parent and is hindered (Azhari et al., 2019). Parents of children who are deaf show high levels of parental stress (Hintermair, 2006). If the parent is less able to respond effectively, the child may attempt to attend to the distress through use of escape/ avoidance at the perceived demand. These explanations are merely theoretical, and there is a need to understand the child's lived experience which the questionnaire is unable to capture.

Non-deaf children are more triggered by sensory stimulus which may be an indication of the neurological disorder and experiencing sensory overload. Little is known about sensory overload in deaf children, however there is a sensory deprivation of hearing which may impact on the difference in results. Within the literature, there is inconclusive debate regarding neurological compensation resulting in any sensory enhancement in deaf children (Coulson-Thaker, 2020). The lack of tangible evidence may be due to a scarcity of studies exploring clinically based sensory processing in deaf children (Coulson-Thaker, 2020). In fact, hearing loss has been used as an exclusion criterion in a systematic literature review of interventions for young people with sensory processing needs (Arbesman & Lieberman, 2010). Given that sensory stimulus may account for some variation in mechanisms of emotional outbursts between the two groups, it may be related to the seeking of food in the non-deaf group as a way of sensory seeking which would not be needed in the deaf group.

Temporal Features

Interestingly, there were limited differences between the deaf and non-deaf group relating to temporal features of outbursts. Frequency of outbursts (least and most severe) were similar across groups. The limited size of the sample may impact on this, given that there was a slightly higher occurrence in the deaf group there may need to be further investigation, with a larger sample group. Eye contact was very similar, with slightly more eye contact being shown in the deaf group in least severe and slightly less in the deaf group in the most severe. Eye contact has been shown to be linked with parts of the brain labelled the 'social brain', which stimulates social processing of situations, including empathy and theory of mind (Senju & Johnson, 2009). A tentative explanation may be that during that during the least severe outbursts, deaf children are using eye contact to stimulate connection and communication of distress however, further investigation is needed.

Recovery was the only temporal feature that showed any outstanding difference with the non-deaf group taking longer to recover from the most severe outbursts than the deaf group. From characteristics, the non-deaf group experience more loss of control and were more likely to not be aware of what was going on around them. These findings suggest that non-deaf children experience outbursts in more of a dissociative state. Dissociation occurs as an unconscious avoidance mechanism whereby emotions are experienced as overwhelming (Zerubavel & Messman-Moore, 2013). As sensory stimulus appears to be a trigger for non-deaf children, it could be speculated that in response to over or under arousal of sensory systems a dissociative state emerges (Rogers & Ozonoff, 2005). If the child experiences this state, it may take longer to become grounded back into the present. Interestingly, the deaf group took more time to recover from the least severe outbursts. From the characteristics of the outbursts, it seems that least severe outbursts of deaf children encompass a level of communication or frustration, and it may be that this behaviour does not resolve the underlying issue, meaning it takes longer for them to recover given it is still left unresolved.

Limitations

The current measures lack validation within the deaf population (Bigler et al., 2018). The Emotional Outburst Questionnaire (EOQ; Chung et al., 2020) has recently been constructed to examine emotional outbursts transdiagnostically, however this measure has not been examined or validated in a deaf sample. To facilitate research within the field of emotional outbursts within deaf children, it is important that an appropriate measure is validated for use. Given the limited sample size, validation was not possible within the deaf sample and therefore this is still needed.

The results of this study are biased to deaf children of hearing parents. Furthermore, to understand experiences which relate exclusively to being deaf, studies need to examine and compare experiences of deaf children to deaf parents as well as to hearing parents as much of the discussion refers to a miscommunication between parent and child, which would not be present in deaf parent-child dyads. As previously mentioned, there appears a lack of appropriate measures for the deaf population. The use of a wordy questionnaire limits the number of deaf parents able to respond, given average reading age is around seven years (Dominguez & Alegria, 2010).

Comparison between groups was limited to non-significant findings, due to the small sample, which hinders the ability to draw any definitive conclusions regarding the differences in outbursts between deaf and non-deaf children. When comparing data from two small samples, findings are less likely to be generalisable to the wider population of the reflected sample e.g. deaf children. Furthermore, it is difficult to determine whether differences are due to being deaf or random variability between individuals, as is the difficulty with smaller sample sizes (Hackshaw, 2008). Utilising a different methodology, such as a cohort of case studies may have increased the clinical utility of the findings and provided a grounding for larger sample studies. Smaller sample size studies are still beneficial as they provide hypothetical conclusions, so that larger studies can focus on the specific findings of interest in a less time-consuming way (Hackshaw, 2008). The use of comparative analysis between the two groups, whilst could not offer significant findings, did provide scope for larger confirmatory studies.

There are some analytical limitations of this study. The factor scores were based on exploratory factor analysis of the non-refined scores of responses within another sample (Chung et al., 2020). Whilst this may hold some limitations, non-refined factor scores are considered more stable across samples (DeStafano et al., 2009; Grice & Harris, 1998). As the previous study analysis was exploratory, confirmatory factor analysis has yet to be done and thus, the factors referred to within this study do not have an established validity. The comparative analysis utilised within this research was limited to descriptive statistics, due to the small number of participants. This research could have been strengthened by statistical analysis whereby confounding variables were considered such as degree of deafness, gender, additional diagnosis etc.

Conclusions

Deaf children appear to experience emotional outbursts due to emotional dysregulation, which is likely to be hindered by the inability to acquire a verbal language. Speculatively, the miscommunication which can occur between deaf children and hearing parents may also hinder the emotional regulatory capacity, in turn resulting in severe emotional outbursts whereby the child acts out physically. In comparison, non-deaf children appear to experience emotional outbursts in response to sensory overload which in turn triggers a dissociative state. The caregivers of deaf children should be supported to process the impact of parenting a deaf child, to decrease the level of stress and increase the ability to respond to the child. Furthermore, families of deaf children should be supported in acquiring and using sign language.

References

Achenbach, T. M. (1991). Manual for the Child Behavior Checklist/4-18 and 1991 profile. *University of Vermont, Department of Psychiatry,*

Achenbach, T. M., & Rescorla, L. A. (2000). *Manual for the ASEBA preschool forms and profiles*. Burlington, VT: University of Vermont, Research center for children, youth ….

Alshenqeeti, H. (2014). Interviewing as a data collection method: A critical review. *English Linguistics Research, 3*(1), 39-45.

Arbesman, M., & Lieberman, D. (2010). Methodology for the systematic reviews of occupational therapy for children and adolescents with difficulty processing and integrating sensory information. *American Journal of Occupational Therapy, 64*(3), 368-374.

Azhari, A., Leck, W. Q., Gabrieli, G., Bizzego, A., Rigo, P., Setoh, P., Bornstein, M. H., & Esposito, G. (2019). Parenting stress undermines mother-child brain-to-brain synchrony: A hyperscanning study. *Scientific Reports, 9*(1), 1-9.

Bailly, D., Dechoulydelenclave, M. B., & Lauwerier, L. (2003). Hearing impairment and psychopathological disorders in children and adolescents. Review of the recent literature. *L'Encephale, 29*(4 Pt 1), 329-337.

Barker, D. H., Quittner, A. L., Fink, N. E., Eisenberg, L. S., Tobey, E. A., Niparko, J. K., & CDaCI Investigative Team. (2009). Predicting behavior problems in deaf and hearing children: The influences of language, attention, and parent–child communication. *Development and Psychopathology, 21*(2), 373.

Bigler, D., Burke, K., Laureano, N., Alfonso, K., Jacobs, J., & Bush, M. L. (2019). Assessment and treatment of behavioral disorders in children with hearing loss: a systematic review. *Otolaryngology–Head and Neck Surgery, 160*(1), 36-48.

Blaxter, L. (2010). *How to research*. McGraw-Hill Education (UK).

Boerrigter, M., Vermeulen, A., Marres, H., Mylanus, E., & Langereis, M. (2019). Frequencies of behavioral problems reported by parents and teachers of hearing-impaired children with cochlear implants. *Frontiers in Psychology, 10*, 1591.

Calderon, R., & Greenberg, M. (2003). Social and emotional development of deaf children. *Oxford Handbook of Deaf Studies, Language, and Education, 1*, 177.

Chandler, S., Charman, T., Baird, G., Simonoff, E., Loucas, T., Meldrum, D., Scott, M., & Pickles, A. (2007). Validation of the social communication questionnaire in a population cohort of children with autism spectrum disorders. *Journal of the American Academy of Child & Adolescent Psychiatry, 46*(10), 1324-1332.

Chesnut, S. R., Wei, T., Barnard-Brak, L., & Richman, D. M. (2017). A meta-analysis of the social communication questionnaire: screening for autism spectrum disorder. *Autism, 21*(8), 920-928.

Ching, T. Y., Scarinci, N., Marnane, V., Sjahalam-King, J., Button, L., & Whitfield, J. (2018). Factors influencing parents' decisions about communication choices during early education of their child with hearing loss: A qualitative study. *Deafness & Education International, 20*(3-4), 154-181.

Chung, J., Mevorach, C., & Woodcock, K. (2020). Establishing the transdiagnostic contextual pathways of emotional outbursts.

Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences* (2nd ed.). Lawrence Erlbaum Associates, Publishers.

Collins, L. M. (2007). Research design and methods.

Coulson-Thaker, K. (2020). *Exploring Sensory Processing among Hearing Impaired and Culturally Deaf Children*

Curtin, M., Herman, R., Cruice, M., & Morgan, G. (2021). Assessing parent–child interaction in infant deafness. *Current Opinion in Otolaryngology & Head and Neck Surgery, 29*(3), 200-203.

DiStefano, C., Zhu, M., & Mindrila, D. (2009). Understanding and using factor scores: Considerations for the applied researcher. *Practical Assessment, Research, and Evaluation, 14*(1), 20.

Domínguez, A., & Alegria, J. (2010). Reading mechanisms in orally educated deaf adults. *Journal of Deaf Studies and Deaf Education, 15*(2), 136-148.

Dominick, K. C., Davis, N. O., Lainhart, J., Tager-Flusberg, H., & Folstein, S. (2007). Atypical behaviors in children with autism and children with a history of language impairment. *Research in Developmental Disabilities, 28*(2), 145-162.

Eaton, C., Tarver, J., Shirazi, A., Pearson, E., Walker, L., Bird, M., Oliver, C., & Waite, J. (2021). A systematic review of the behaviours associated with depression in people with severe–profound intellectual disability. *Journal of Intellectual Disability Research, 65*(3), 211-229.

Emmorey, K., McCullough, S., Mehta, S., & Grabowski, T. J. (2014). How sensory-motor systems impact the neural organization for language: Direct contrasts between spoken and signed language. *Frontiers in Psychology, 5*, 484.

Erlingsson, C., & Brysiewicz, P. (2017). A hands-on guide to doing content analysis. *African Journal of Emergency Medicine, 7*(3), 93-99.

Fellinger, J., Holzinger, D., & Pollard, R. (2012). Mental health of deaf people. *The Lancet, 379*(9820), 1037-1044.

Flaherty, M. (2015). What we can learn from hearing parents of deaf children. *Australasian Journal of Special and Inclusive Education, 39*(1), 67.

Fortnum, H. M., Marshall, D. H., & Summerfield, A. Q. (2002). Epidemiology of the UK population of hearing-impaired children, including characteristics of those with and without cochlear implants—audiology, aetiology, comorbidity and affluence. *International Journal of Audiology, 41*(3), 170-179.

Goodman, R. (1997). The Strengths and Difficulties Questionnaire: a research note. *Journal of Child Psychology and Psychiatry, 38*(5), 581-586.

Green, J. A., Gustafson, G. E., & McGhie, A. C. (1998). Changes in infants' cries as a function of time in a cry bout. *Child Development, 69*(2), 271-279.

Green, J. A., Whitney, P. G., & Potegal, M. (2011). Screaming, yelling, whining, and crying: Categorical and intensity differences in vocal expressions of anger and sadness in children's tantrums. *Emotion, 11*(5), 1124.

Grice, J. W., & Harris, R. J. (1998). A comparison of regression and loading weights for the computation of factor scores. *Multivariate Behavioral Research, 33*(2), 221-247.

Godovich, S. A., Adelsberg, S., & Roy, A. K. (2020). Parental responses to temper outbursts in children with ADHD: The role of psychological factors. *Journal of Attention Disorders, 24*(14), 2054-2063.

Hall, M. L., Hall, W. C., & Caselli, N. K. (2019). Deaf children need language, not (just) speech. *First Language, 39*(4), 367-395.

Hall, N. J., Colby, C. L., & Olson, C. R. (2020). Novel Interaction between Prefrontal and Parietal Cortex during Memory Guided Saccades. *bioRxiv,*

Hanley, J. A., & McNeil, B. J. (1982). The meaning and use of the area under a receiver operating characteristic (ROC) curve. *Radiology, 143*(1), 29-36.

Harricharan, S., Rabellino, D., Frewen, P. A., Densmore, M., Théberge, J., McKinnon, M. C., Schore, A. N., & Lanius, R. A. (2016). fMRI functional connectivity of the periaqueductal gray in PTSD and its dissociative subtype. *Brain and Behavior, 6*(12), e00579.

Hintermair, M. (2006). Parental resources, parental stress, and socioemotional development of deaf and hard of hearing children. *The Journal of Deaf Studies and Deaf Education, 11*(4), 493-513.

Holmes, E. A., Brown, R. J., Mansell, W., Fearon, R. P., Hunter, E. C., Frasquilho, F., & Oakley, D. A. (2005). Are there two qualitatively distinct forms of dissociation? A review and some clinical implications. *Clinical Psychology Review, 25*(1), 1-23.

Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics,* , 159-174.

McCarty, R. (2016). The fight-or-flight response: A cornerstone of stress research. *Stress: Concepts, cognition, emotion, and behavior* (pp. 33-37). Elsevier.

McFadyen, J., Dolan, R. J., & Garrido, M. I. (2020). The influence of subcortical shortcuts on disordered sensory and cognitive processing. *Nature Reviews Neuroscience, 21*(5), 264-276.

Miller, A. R., Gardiner, E., & Harding, L. (2018). Behavioural and emotional concerns reported by parents of children attending a neurodevelopmental diagnostic centre. *Child: Care, Health and Development, 44*(5), 711-720.

Mitchell, T. V., & Quittner, A. L. (1996). Multimethod study of attention and behavior problems in hearing-impaired children. *Journal of Clinical Child Psychology*, *25*(1), 83-96.

Mitchell, R. E., & Karchmer, M. (2004). Chasing the mythical ten percent: Parental hearing status of deaf and hard of hearing students in the United States. *Sign Language Studies, 4*(2), 138-163.

Moeller, M. P. (2007). Current state of knowledge: psychosocial development in children with hearing impairment. *Ear and Hearing, 28*(6), 729-739.

Mulder, P. A., Huisman, S. A., Hennekam, R. C., Oliver, C., Van Balkom, I. D., & Piening, S. (2017). Behaviour in Cornelia de Lange syndrome: a systematic review. *Developmental Medicine & Child Neurology, 59*(4), 361-366.

Potegal, M., Carlson, G., Margulies, D., Gutkovitch, Z., & Wall, M. (2009a). Rages or temper tantrums? The behavioral organization, temporal characteristics, and clinical significance of angry-agitated outbursts in child psychiatry inpatients. *Child Psychiatry and Human Development, 40*(4), 621-636.

Potegal, M., & Davidson, R. J. (2003). Temper tantrums in young children: 1. Behavioral composition. *Journal of Developmental & Behavioral Pediatrics, 24*(3), 140-147.

Quittner, A. L., Barker, D. H., Cruz, I., Snell, C., Grimley, M. E., Botteri, M., & CDaCI Investigative Team. (2010). Parenting stress among parents of deaf and hearing children:

Associations with language delays and behavior problems. *Parenting: Science and Practice, 10*(2), 136-155.

Rieffe, C. (2012). Awareness and regulation of emotions in deaf children. *British Journal of*

Roberts, C., & Hindley, P. (1999). Practitioner review: The assessment and treatment of deaf children with psychiatric disorders. *Journal of Child Psychology and Psychiatry, 40*(2), 151-167.

Rutter, M., Bailey, A., & Lord, C. (2003). SCQ. *The Social Communication Questionnaire.Torrance, CA: Western Psychological Services,*

Developmental Psychology, 30(4), 477-492.

Rogers, S. J., & Ozonoff, S. (2005). Annotation: What do we know about sensory dysfunction in autism? A critical review of the empirical evidence. *Journal of Child Psychology and Psychiatry, 46*(12), 1255-1268.

Saki, N., Bayat, A., Moniri, S., & Moogahi, N. K. (2019). The influence of cochlear implantation on aggression behaviors in children. *International Journal of Pediatric Otorhinolaryngology, 127*, 109669.

Senju, A., & Johnson, M. H. (2009). The eye contact effect: mechanisms and development. *Trends in Cognitive Sciences, 13*(3), 127-134.

Sparrow, S. S., Balla, D. A., Cicchetti, D. V., & Harrison, P. L. (1984). Vineland adaptive behavior scales.

SPSS, I. (2013). IBM SPSS statistics for windows. *Armonk, New York, USA: IBM SPSS*

Stevenson, J., Kreppner, J., Pimperton, H., Worsfold, S., & Kennedy, C. (2015). Emotional and behavioural difficulties in children and adolescents with hearing impairment: A systematic review and meta-analysis. *European Child & Adolescent Psychiatry, 24*(5), 477-496.

Theunissen, S. C., Rieffe, C., Kouwenberg, M., De Raeve, L. J., Soede, W., Briaire, J. J., & Frijns, J. H. (2014). Behavioral problems in school-aged hearing-impaired children: the influence of sociodemographic, linguistic, and medical factors. *European Child & Adolescent Psychiatry, 23*(4), 187-196.

Vaccari, C., & Marschark, M. (1997). Communication between parents and deaf children: Implications for social-emotional development. *Journal of Child Psychology and Psychiatry, 38*(7), 793-801.

Van Eldik, T., Treffers, P. D., Veerman, J. W., & Verhulst, F. C. (2004). Mental health problems of deaf Dutch children as indicated by parents' responses to the child behavior checklist. *American Annals of the Deaf, 148*(5), 390-395.

Van Eldik, T. (2005). Mental health problems of Dutch youth with hearing loss as shown on the Youth Self Report. *American Annals of the Deaf, 150*(1), 11-16.

VanOrmer, J. L., Rossetti, K. G., & Zlomke, K. R. (2019). The Development of Behavioral Difficulties in Hard-of-Hearing and Deaf Youth. *Child & Family Behavior Therapy, 41*(4), 179-200.

Vostanis, P., Hayes, M., Du Feu, M., & Warren, J. (1997). Detection of behavioural and emotional problems in deaf children and adolescents: comparison of two rating scales. *Child: Care, Health and Development, 23*(3), 233-246.

Winslow, J. (2014). *Distress Vocalization.* Springer Link. https://link.springer.com/referenceworkentry/10.1007/978-3-642-27772-6_277-2

Wong, C. L., Ching, T. Y., Cupples, L., Button, L., Leigh, G., Marnane, V., Whitfield, J., Gunnourie, M., & Martin, L. (2017). Psychosocial development in 5-year-old children with hearing loss using hearing aids or cochlear implants. *Trends in Hearing, 21*, 2331216517710373.

World Health Organization. (2021). *Home/Newsroom/Fact sheets/Detail/Deafness and hearing loss*. https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss.

Zerubavel, N., & Messman-Moore, T. L. (2015). Staying present: Incorporating mindfulness into therapy for dissociation. *Mindfulness, 6*(2), 303-314.

University of Birmingham Press Release
Date: 04/06/2021

Social Support Could Improve Family Outcomes in Families of Children with Neurodevelopmental Disorders

Mothers of children with neurodevelopmental disorders, such as autism or attention deficit/hyperactivity disorder, could benefit most from social support to help them cope with parental stress, according to new research at the University of Birmingham.

The findings, suggest that the use of social support in mothers, can weaken the relationship between parental stress and child challenging behaviour.

Children who have a neurodevelopmental disorder are more likely to display challenging behaviour which includes externalising behaviours such as physical and verbal aggression, shouting and self-injurious behaviour, all of which can contribute to parental stress. In turn, parental stress can contribute to child challenging behaviour resulting in a transactional relationship.

The researchers, in the University's School of Psychology, reviewed eleven studies reporting on child challenging behaviour, parental stress in mothers and an aspect of maternal psychological resilience.

The term psychological resilience is much debated, therefore constructs of psychological resilience were investigated separately to establish which of these constructs hold promise for supporting these families. The utilising of social support appeared to be the most advantageous resilient construct. Cognitive framing also showed some promise.

Tamara Heyes, a Clinical Psychology Doctoral student, is the lead author of this review. She says: "Whilst it is understood that parenting a child with neurodevelopmental disabilities is challenging, much of the interventions focus on behavioural change in the children – which is often at responsibility of the parent. This review not only highlights the impacts of parental stress, but the importance of supporting the parents of these children."

In the review, the quality of the selected studies was also assessed. In most papers it was unclear whether mothers were informed of the objective of the study they took part in, and most samples were relatively small with much recruitment from supportive networks and places. It therefore seems that research in this area is limited to mothers who already access some level of support and that future research should include a much broader cross section of participants.

"When we assess research that has limited generalisability, we are constrained by the implications of this" explained Heyes. "I certainly feel that more should be done to engage parents of children with neurodevelopmental disabilities to not only collect more generalisable data, but to offer the types of social support we know to be efficacious".

For media enquiries please contact: [redacted]

Notes to editor:

- The University of Birmingham is ranked amongst the world's top 100 institutions. Its work brings people from across the world to Birmingham, including researchers, teachers and more than 6,500 international students from over 150 countries.

University of Birmingham Press Release
Date: 04/06/2021

Deaf Children May Experience Emotional Outbursts as a Way of Expressing Distress

The mechanisms of emotional outbursts in deaf children appear to differ from their non-deaf peers, according to new research at the University of Birmingham.

Differences between the emotional outbursts could be indicative of the mechanisms of the outbursts. Deaf children appear to experience emotional outbursts as an expression of emotional distress, leading to dysregulation. Non-deaf children appear to experience outbursts in response to sensory stimulus, which results in a more dissociative state.

Background

There is a high prevalence of emotional outbursts experienced by children who are deaf. Despite this, there is limited research into the development and characteristics of the outbursts. 90% of deaf children are born to hearing parents. Deafness may impact on emotional regulatory systems, both through neurological impact but also due to the communication differences between the caregiver and the child. There is co-variation of deafness with other neurological disorders, however emotional outbursts should not be characterised by these. We must understand the mechanisms underpinning emotional outbursts for efficacious and individualised interventions.

Method

A cross-sectional, comparative study design was carried out. Online questionnaires were provided to caregivers of deaf children aged between 6 and 25 years. Data from this study was compared with data from the larger study (Chung et al., 2020), after selecting a comparison group of non-deaf young people with as closely matched demographics as possible. Comparison of the deaf (N=8) and non-deaf (N=8) group responses relating to behavioural characteristics (using both open-ended answers and behavioural item responses) and outburst intensity features of both most and least severe emotional outbursts. Comparison between the groups was also conducted looking contextual pathways of outbursts.

Results

Verbal expression was the most common behavioural characteristic expressed amongst both groups. Escape behaviours were a more salient characteristic of the least severe outburst for deaf children. Non-deaf children were more likely to not respond to things around them and engage in food related behaviours for the most severe outbursts. Deaf children were more likely to react to perceived cognitive demand and physiological states whilst non-deaf children were more triggered by sensory stimulus.

For media enquiries please contact: [redacted]

Notes to editor:

- The University of Birmingham is ranked amongst the world's top 100 institutions. Its work brings people from across the world to Birmingham, including researchers, teachers and more than 6,500 international students from over 150 countries.

Appendix A: NHS Ethics Approval from local Heath Research Authority

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Miss Tamara Heyes
Clinical Psychologist in Training

Birmingham and Solihull Mental Health Foundation
Trust
50 Summer Hill Road
Darwin House, The Academy
B1 3RB

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

10 December 2020

Dear Miss Heyes

HRA and Health and Care

Study title:	**The development and evaluation of the Emotional Outburst Questionnaire: A study focussing on emotional outburst profiles in deaf and hearing impaired children and young people**
IRAS project ID:	**275381**
Protocol number:	**RG_19-262**
REC reference:	**20/WM/0239**
Sponsor	**The University of Birmingham**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **275381**. Please quote this on all correspondence.

Yours sincerely,

[redacted]

Harriet Wood

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Dr Birgit Whitman* **List of Documents**

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Cover Letter [response to 'response incomplete']		20 November 2020
Covering letter on headed paper [Covering letter]	1	04 September 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of insurance]	1	04 August 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [CT insurance]		01 August 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [EL PL insurance]		01 August 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance query/clarification]		07 December 2020
IRAS Application Form [IRAS_Form_13082020]		13 August 2020
Letter from statistician [Letter from statistician]	1	16 September 2019
Letters of invitation to participant [Recruitment letter]	1	16 December 2019
Letters of invitation to participant [social media advert]	1	16 December 2019
Non-validated questionnaire [Emotional outburst questionnaire]	1	16 December 2019
Non-validated questionnaire [Demographic Questionnaire]	1	19 December 2019
Organisation Information Document [Organisation Information Document]	2	28 September 2020
Participant consent form [Participant information and consent form]	3	03 November 2020
Participant consent form [postal consent form]	3	03 November 2020

Participant information sheet (PIS) [Young person's information sheet 6-9]	2	28 September 2020
Participant information sheet (PIS) [Parent information sheet]	3	23 October 2020
Participant information sheet (PIS) [YP Information Sheet 10-15]	4	27 November 2020
Participant information sheet (PIS) [young persons information sheet 16 - 25]	4	27 November 2020
Research protocol or project proposal [research protocol]	6	28 September 2020
Response to Request for Further Information [Ethical Review amendments and changes]		23 October 2020
Schedule of Events or SoECAT [HRA validated]	1	10 December 2020
Summary CV for Chief Investigator (CI) [CI Summary CV]	1	04 December 2019
Summary CV for supervisor (student research) [Principle Investigator CV]	1	16 December 2019
Validated questionnaire [Social Communication Questionnaire]	1	12 May 2020

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
There is only one participating NHS organisation therefore there is only one site type.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.	No study funding will be provided to sites as per the Organisational Information Document.	A Principal Investigator should be appointed at study sites.	Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix B: The Emotional Outburst Questionnaire (Chung et al., 2020).

Emotional Outburst Questionnaire

* **Emotional Outburst Questionnaire: Parent/Caregiver Information Sheet**

We would like to invite you to take part in a research study being conducted at the School of Psychology, University of Birmingham. This research is a follow-on study to the Stay Calm project led by Justin Chung and Dr Kate Woodcock. The Stay Calm project aims to further our understanding of emotional outbursts in children and young people, with a particular focus on people with neurodevelopmental disorders and/or people who have experienced childhood trauma/adversity. The project aims to identify the different pathways and associated mechanisms that lead to emotional outbursts. We hope that this information will contribute to the development of intervention strategies for emotional outbursts in future work.

My name is Tamara Heyes. I am a clinical psychology doctoral student hoping to support the development of this measure for use in children and young people who are deaf, or hearing impaired. If you have any further questions, please contact Tamara Heyes at

Aims of the study Emotional outbursts can be a particularly significant problem for individuals with neurodevelopmental disorders and/or learning disability. Currently, researchers conduct interviews with parents/caregivers to gather information about the characteristics of emotional outbursts, which may be important in finding out the underlying problems that lead to emotional outbursts. Research in this area may be increased through a more time efficient way of collecting information, as interviews can be inconvenient and timely.

Therefore, a new questionnaire has been developed (the Emotional Outburst Questionnaire) to be more efficient in measuring emotional outbursts in young people. It is also understood that children and young people who have a diagnosis of deafness experience a high level of emotional outbursts. By asking for you to complete it, I am hoping to gather enough responses to ensure that the questionnaire accurately measures emotional outburst characteristics within children and young people who have a diagnosis of deafness. I hope that researchers and clinicians will be able to use this questionnaire in future so that more research can be done to find helpful ways of supporting you and your young person or child. Furthermore, I hope that the questionnaire will provide more details about emotional outbursts, which may give us insight into what causes emotional outbursts, and help to develop and test new intervention/support strategies.

Where will the research take place? The research will take place online or with a postal questionnaire.

Who will be involved in collecting the data? Tamara Heyes and Dr Kate Woodcock will be involved, alongside other members of the research team.

---

* ***What will we ask you to do?*** Your participation is entirely voluntary. We will ask you to complete the Emotional Outburst Questionnaire and to provide some demographic information, such as the age, gender, severity of deafness and diagnosis (if applicable) of the individual you care for. We will also ask whether the individual you care for has experienced past traumatic or adverse events, but you can choose to not answer if you or the individual you care for are not comfortable with this

question. We will also ask you to complete the Social Communication Questionnaire, which is a brief questionnaire looking at problems in communication and social functioning skills, which are common in certain neurodevelopmental disorders, including autism. It is important that only one parent/caregiver completes the Emotional Outburst Questionnaire initially. There is an opportunity for a second parent/caregiver to complete the questionnaire if they wish to do so (see below).

A young person information sheet has been included at www.katewoodcock.com/staycalm and you can choose the most appropriate one given the age range the individual you care for currently reads at. Whilst you are the person completing the questionnaire, we ask that the individual you care for also reads the information sheet so they are aware that you are participating. We understand that for some people, they may not have the capacity to understand the participant information sheet, however if you feel it is in their best interest for you to complete the questionnaire, then we ask that you still provide consent. By consenting, you are saying that the young person has been informed and understands or that you are acting in the best interest of the young person.

How long will it take? We anticipate that the questionnaire will take no more than 1 hour to complete (most likely around 30 minutes).

What kinds of information will be recorded and what will we do with it? We will be asking you about emotional outbursts characteristics and demographic information. The link will be provided through a third-party who knows you and already holds your information e.g. school. The information you provide for the purpose of the questionnaire can in no way be linked to you, therefore it will be anonymous. The responses to the questionnaire will only be linked to an identifier code, if you opt to complete the questionnaire a second time. No one will be able to trace the information to you or the individual you care for.

We will use the information to check that the questionnaire is measuring characteristics of emotional outbursts accurately, and to check if other factors such as age might affect the responses. Your anonymous responses will be combined with responses from other participants, and the data will be presented in reports, conferences, and presentations, and made available to other researchers after the study ends.

If you and/or a second parent/caregiver are willing and able to complete the questionnaire for a second time, please enter your email address when prompted, so that we can send you another questionnaire link in 2 weeks' time. The data from the second time you complete the questionnaire will be useful for checking to see if we can gather consistent responses from the questionnaire. Please note that this is completely voluntary, and that your email address will not be linked to your questionnaire responses. Your email address will be deleted as soon as we send the link, so it will only be stored for 2 weeks. Should you wish to complete the questionnaire via hard copy, please request two questionnaires from the third party providing these to you. You will send one initially, and a second one two weeks later. These can only be linked through an identifier code written on the two questionnaires.

Are there any risks that individuals taking part in the study might face? As we are asking questions around the behaviours associated with emotional outbursts, it could cause some distress as we understand this is a sensitive topic.

If you feel that additional support may be beneficial for you, I have included some services which may be able to help. The Challenging Behaviour Foundation.
Website: www.challengingbehaviour.org.uk
Email: support@thecbf.org.uk
Telephone: 0300 666 0126 The National Deaf Children's Society
Website: www.ndcs.org.uk Email: ndcs@ndcs.org.uk Telephone: 0808 800 8880 ***What are the potential benefits for participants from taking part?*** By completing this study, you will be helping add to research in the future looking at emotional outbursts so that

further understanding of these can be obtained. We hope that this will help to focus interventions and support for children and young people. This specific study is focussing on those diagnosed with deafness. This means that in the future it can be used to further understand emotional outbursts in children and young people with diagnosed deafness. ***If you decide to participate, what will happen after participation?*** As all the data we collect will be anonymous, individualised feedback reports will not be possible. However, after we have collected and analysed the data, we will summarise our findings to the charities and support groups from which we recruited you, so that they can relay the information to you. This may be in the form of a social media post, newsletter, or announcement on their website.

* ***Where will data be stored?*** If you provide it, your email address will be stored securely at the University of Birmingham for the 2 week period and then deleted. Other non-personally identifiable information you provide will be anonymised and will be stored at the University and made accessible to other researchers in future if you allow us to do so. ***Confidentiality*** Your questionnaire responses will be anonymous, so they cannot be traced back to you or the individual you care for. If you choose to provide your email address, it will not be linked in any way to your questionnaire responses. ***Consent*** By consenting to this study, you are saying that you have read and understood this information sheet. You are also saying that the individual who is the focus of your responses understands to the best of their ability what you are participating in. As above mentioned, should the individual not have capacity to understand, your consent means that you are acting in their best interest. If you have any concerns or queries, please contact us. ***Withdrawal*** By consenting, you are saying that you understand that even after agreeing to take part in the study you are free to stop and withdraw from the study at any time. However, please note that once you have submitted your questionnaire responses to us, we will not be able to identify and delete your responses from the database as they are anonymous and cannot be traced back to you. ***What if there is a problem?*** If you encounter any problems, please contact Tamara Heyes . In addition, should you wish to raise a complaint you can contact

Review The study has been reviewed and approved by the West Midlands - South Birmingham Research Ethics Committee, Health Research Authority. ***Further information*** If you require any further information, please contact Tamara Heyes at or

* *Please click on the relevant young person information sheet* [6 to 9 years information sheet] [10 to 15 years information sheet] [16 to 25 years information sheet]

○ Please confirm that the young person has read and understood the information about the study appropriate for them and gives their consent for you to take part. If the young person is aged under 16 and is not able to understand the study, please only tick this box if you believe it is in their best interests that you take part. If the young person you care for is aged 16 or over and does not give their consent for you to take part, please do not do so (1)

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* Please tick the box below to provide consent for taking part in this study.

	Please tick the boxes if you agree (1)
I confirm that I have read the information provided on the previous webpage for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily (3)	○
I understand that my participation is voluntary, that I am free to withdraw at any time before submitting my responses, without giving any reason, without my medical care or legal rights being affected. (4)	○
I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. (5)	○
I agree to take part in the above study (6)	○

Q1 The term “*emotional outburst*” refers to a highly emotional or explosive episode, where at least one of the behaviours listed below (Q3) is displayed. Emotional outbursts may also be known as “*meltdowns*”, “*crisis*", “*blips*”, *"behavioural breakdown", “rages*”, “*temper outbursts*”, “*tantrums*”, or “*tempers*”.

In this questionnaire, we want you to think about the **most severe** and **least severe** emotional outbursts **within the past month** that the individual you care for has displayed and the characteristics associated with each type of emotional outburst, such as behaviours, frequency, and duration. In terms of the **severity** of emotional outbursts, we are referring to how disruptive and negatively impactful they are to the person and/or those around them **at the time** of the emotional outburst.

If you feel that the **severity** of emotional outbursts is always the same, please answer the questions relating to the **most severe** type. We recognise that some questions may be difficult to answer, as emotional outbursts can vary greatly depending on the context. However, please try to give an average for these questions, as this will help us to better understand emotional outbursts over a range of contexts.

First, we would like you to consider the **most severe** emotional outbursts that the individual you care for has displayed **within the past month**.

Q2 Please list **up to 20 words** to describe what distinguishes the **most severe** emotional outbursts. *(e.g. physically aggressive, screaming, at least an hour)*

____

____

____

____

____

Q3 During the **most severe** emotional outbursts, how often does the individual you care for display the following behaviours?

	Not applicable/never/rarely (0-3 times out of 10 outbursts) (1)	Sometimes (4-6 times out of 10 outbursts) (2)	Often/always (7-10 times out of 10 outbursts) (3)
Behavioural indicators of emotion *(e.g. angry or annoyed facial expressions, crying, signs of distress, whining)* (1)	○	○	○
Mild verbal aggression *(e.g. insults, name-calling, screaming, shouting, swearing)* (2)	○	○	○
Extreme verbal aggression *(e.g. threats of violence)* (3)	○	○	○
Non-speech vocalisations *(e.g. making sounds or noises)* (4)	○	○	○
Mild aggression towards property *(e.g. defacing walls, ripping clothing, slamming door, throwing objects down)* (5)	○	○	○
Extreme aggression towards property *(e.g. breaking objects, smashing windows, throwing objects dangerously)* (6)	○	○	○
Mild physical aggression towards others **without physical injury** *(e.g. biting, grabbing, hitting, kicking, pulling hair, pushing, scratching, spitting, throwing objects at people)* (7)	○	○	○
Extreme physical aggression towards others **with physical injury** *(e.g. biting, grabbing, hitting, kicking, pulling hair, pushing, scratching, throwing objects at people)* (8)	○	○	○

Mild self-injurious behaviours **without serious injury** (no cuts, bruises, burns, etc) *(e.g. banging head, biting, hitting self, hitting wall, holding breath, picking skin, pulling hair)* (9)	○	○	○
Extreme self-injurious behaviours **with serious injury** *(e.g. banging head, biting, hitting self, hitting wall, picking skin, picking rectum, pulling hair)* (10)	○	○	○
Talking to self & others *(e.g. agitated talking, repetitive speech, self-deprecating speech)* (11)	○	○	○
Increased motor activity *(e.g. flailing arms, non-directed kicking, pacing, repetitive behaviours, rushing about, stamping feet, tics)* (12)	○	○	○
Increased physiological arousal *(e.g. red face, salivating, sweating)* (13)	○	○	○
Avoidance *(e.g. dropping to floor, going to room, leaving situation, running away)* (14)	○	○	○
Removing items of clothing (15)	○	○	○
Defecation or urination (16)	○	○	○
Contextually inappropriate sexual behaviours (17)	○	○	○
Ignoring or not talking to certain people (18)	○	○	○
Not reacting to things going on around them (19)	○	○	○

Food-related behaviours *(e.g. grabbing, pleading for, seeking, or stealing food)* (20)	○	○	○
Making themselves sick *(e.g. retching or vomiting)* (21)	○	○	○
Unusual behaviours (22)	○	○	○

Q89 During the **most severe** emotional outbursts, how often does the individual you care for display the following behaviours?

	Not applicable/never/rarely (0-3 times out of 10 outbursts) (1)	Sometimes (4-6 times out of 10 outbursts) (2)	Often/always (7-10 times out of 10 outbursts) (3)
Behavioural indicators of emotion *(e.g. angry or annoyed facial expressions, crying, signs of distress, whining)* (1)	○	○	○
Mild verbal aggression *(e.g. insults, name-calling, screaming, shouting, swearing)* (2)	○	○	○
Extreme verbal aggression *(e.g. threats of violence)* (3)	○	○	○
Non-speech vocalisations *(e.g. making sounds or noises)* (4)	○	○	○
Mild aggression towards property *(e.g. defacing walls, ripping clothing, slamming door, throwing objects down)* (5)	○	○	○
Extreme aggression towards property *(e.g. breaking objects, smashing windows, throwing objects dangerously)* (6)	○	○	○
Mild physical aggression towards others **without physical injury** *(e.g. biting, grabbing, hitting, kicking, pulling hair, pushing, scratching, spitting, throwing objects at people)* (7)	○	○	○
Extreme physical aggression towards others **with physical injury** *(e.g. biting, grabbing, hitting, kicking, pulling hair, pushing, scratching, throwing objects at people)* (8)	○	○	○

Mild self-injurious behaviours **without serious injury** (no cuts, bruises, burns, etc) *(e.g. banging head, biting, hitting self, hitting wall, holding breath, picking skin, pulling hair)* (9)	○	○	○
Extreme self-injurious behaviours **with serious injury** *(e.g. banging head, biting, hitting self, hitting wall, picking skin, picking rectum, pulling hair)* (10)	○	○	○
Talking to self & others *(e.g. agitated talking, repetitive speech, self-deprecating speech)* (11)	○	○	○
Increased motor activity *(e.g. flailing arms, non-directed kicking, pacing, repetitive behaviours, rushing about, stamping feet, tics)* (12)	○	○	○
Increased physiological arousal *(e.g. red face, salivating, sweating)* (13)	○	○	○
Avoidance *(e.g. dropping to floor, going to room, leaving situation, running away)* (14)	○	○	○
Removing items of clothing (15)	○	○	○
Defecation or urination (16)	○	○	○
Contextually inappropriate sexual behaviours (17)	○	○	○
Ignoring or not talking to certain people (18)	○	○	○
Not reacting to things going on around them (19)	○	○	○

Food-related behaviours *(e.g. grabbing, pleading for, seeking, or stealing food)* (20)	○	○	○
Making themselves sick *(e.g. retching or vomiting)* (21)	○	○	○
Unusual behaviours (22)	○	○	○

* Advice and support around protecting the individual you care for is available via:
The Challenging Behaviour Foundation.Website: www.challengingbehaviour.org.uk
Email: support@thecbf.org.uk
Telephone: 0300 666 0126 The National Deaf Children’s Society
Website: www.ndcs.org.ukEmail: ndcs@ndcs.org.uk Telephone: 0808 800 8880

Q4 How often do the **most severe** emotional outbursts occur?

○ More than once a day (1)

○ Once a day (2)

○ 2-3 times a week (3)

○ Once a week (4)

○ 2-3 times a month (5)

○ Once a month (6)

○ Less than once a month (7)

○ Never (8)

Page Break

Q5 How long do the **most severe** emotional outbursts last?

- ○ A day or more (1)
- ○ 2 hours to a day (2)
- ○ 1-2 hours (3)
- ○ 30 minutes to 1 hour (4)
- ○ 15-30 minutes (5)
- ○ 5-15 minutes (6)
- ○ Less than 5 minutes (7)

Q6 How angry or upset does the person get during the **most severe** emotional outbursts?

- ○ 7 - As angry or upset as I have ever seen them (1)
- ○ 6 (2)
- ○ 5 (3)
- ○ 4 (4)
- ○ 3 (5)
- ○ 2 (6)
- ○ 1 - Not angry or upset at all (7)

Q7 Compared to baseline behaviour, how much eye contact does the person seek from you during the **most severe** emotional outbursts?

○ Less than baseline (1)

○ Same as baseline (2)

○ More than baseline (3)

Q8 How long does it take for the person to recover from the **most severe** emotional outbursts (i.e. from the end of emotional outburst behaviours to when behaviour is back to normal)?

○ A day or more (1)

○ 2 hours to a day (2)

○ 1-2 hours (3)

○ 30 minutes to 1 hour (4)

○ 15-30 minutes (5)

○ 5-15 minutes (6)

○ Less than 5 minutes (7)

End of Block: Emotional Outburst Questionnaire - Most severe

Start of Block: Emotional Outburst Questionnaire - Least severe

Q9 Now, we would like you to consider the least severe emotional outbursts that the individual you care for has displayed within the past month, that nevertheless disrupt and negatively impact them and/or those around them.

We are referring to episodes that are different from the person's normal or baseline behaviour. The term "*emotional outburst*" refers to a highly emotional or explosive episode, where at least one of the behaviours listed above (Q3) is displayed. Emotional outbursts may also be known as "*meltdowns*", "*crisis", "behavioural breakdown*", "*blips*", "*rages*", "*temper outbursts*", "*tantrums*", or "*tempers*".

If you feel that the severity of emotional outbursts is always the same, please tick the 'Not applicable' box below. Otherwise please click the blue arrow to continue.

☐ Not applicable (1)

Skip To: End of Block If Q9 = Not applicable

Q10 Please list **up to 20 words** to describe what distinguishes the **least severe** emotional outbursts. *(e.g. crying, red face, no more than 5 minutes)*

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Q11 During the **least severe** emotional outbursts, how often does the individual you care for display the following behaviours?

	Not applicable/never/rarely (0-3 times out of 10 outbursts) (1)	Sometimes (4-6 times out of 10 outbursts) (2)	Often/always (7-10 times out of 10 outbursts) (3)
Behavioural indicators of emotion *(e.g. angry or annoyed facial expressions, crying, signs of distress, whining)* (1)	○	○	○
Mild verbal aggression *(e.g. insults, name-calling, screaming, shouting, swearing)* (2)	○	○	○
Extreme verbal aggression *(e.g. threats of violence)* (3)	○	○	○
Non-speech vocalisations *(e.g. making sounds or noises)* (4)	○	○	○
Mild aggression towards property *(e.g. defacing walls, ripping clothing, slamming door, throwing objects down)* (5)	○	○	○
Extreme aggression towards property *(e.g. breaking objects, smashing windows, throwing objects dangerously)* (6)	○	○	○
Mild physical aggression towards others **without physical injury** *(e.g. biting, grabbing, hitting, kicking, pulling hair, pushing, scratching, spitting, throwing objects at people)* (7)	○	○	○
Extreme physical aggression towards others **with physical injury** *(e.g. biting, grabbing, hitting, kicking, pulling hair, pushing, scratching, throwing objects at people)* (8)	○	○	○

Mild self-injurious behaviours **without serious injury** (no cuts, bruises, burns, etc) *(e.g. banging head, biting, hitting self, hitting wall, holding breath, picking skin, pulling hair)* (9)	○	○	○
Extreme self-injurious behaviours **with serious injury** *(e.g. banging head, biting, hitting self, hitting wall, picking skin, picking rectum, pulling hair)* (10)	○	○	○
Talking to self & others *(e.g. agitated talking, repetitive speech, self-deprecating speech)* (11)	○	○	○
Increased motor activity *(e.g. flailing arms, non-directed kicking, pacing, repetitive behaviours, rushing about, stamping feet, tics)* (12)	○	○	○
Increased physiological arousal *(e.g. red face, salivating, sweating)* (13)	○	○	○
Avoidance *(e.g. dropping to floor, going to room, leaving situation, running away)* (14)	○	○	○
Removing items of clothing (15)	○	○	○
Defecation or urination (16)	○	○	○
Contextually inappropriate sexual behaviours (17)	○	○	○
Ignoring or not talking to certain people (18)	○	○	○
Not reacting to things going on around them (19)	○	○	○

Food-related behaviours *(e.g. grabbing, pleading for, seeking, or stealing food)* (20)	○	○	○
Making themselves sick *(e.g. retching or vomiting)* (21)	○	○	○
Unusual behaviours (22)	○	○	○

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The Challenging Behaviour Foundation.Website: www.challengingbehaviour.org.uk
Email: support@thecbf.org.uk
Telephone: 0300 666 0126 The National Deaf Children's Society
Website: www.ndcs.org.ukEmail: ndcs@ndcs.org.uk Telephone: 0808 800 8880

Q12 How often do the **least severe** emotional outbursts occur?

○ More than once a day (1)

○ Once a day (2)

○ 2-3 times a week (3)

○ Once a week (4)

○ 2-3 times a month (5)

○ Once a month (6)

○ Less than once a month (7)

○ Never (8)

Q13 How long do the **least severe** emotional outbursts last?

- ○ A day or more (1)
- ○ 2 hours to a day (2)
- ○ 1-2 hours (3)
- ○ 30 minutes to 1 hour (4)
- ○ 15-30 minutes (5)
- ○ 5-15 minutes (6)
- ○ Less than 5 minutes (7)

Q14 How angry or upset does person get during the **least severe** emotional outbursts?

- ○ 7 - As angry or upset as I have ever seen them (1)
- ○ 6 (2)
- ○ 5 (3)
- ○ 4 (4)
- ○ 3 (5)
- ○ 2 (6)
- ○ 1 - Not angry or upset at all (7)

Q15 Compared to baseline behaviour, how much eye contact does the person seek from you during the **least severe** emotional outbursts?

○ Less than baseline (1)

○ Same as baseline (2)

○ More than baseline (3)

Q16 How long does it take for person to recover from the **least severe** emotional outbursts (i.e. from the end of emotional outburst behaviours to when behaviour is back to normal)?

○ A day or more (1)

○ 2 hours to a day (2)

○ 1-2 hours (3)

○ 30 minutes to 1 hour (4)

○ 15-30 minutes (5)

○ 5-15 minutes (6)

○ Less than 5 minutes (7)

End of Block: Emotional Outburst Questionnaire - Least severe

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Start of Block: Emotional Outburst Questionnaire - In general

* We would like you to consider **in general, all emotional outbursts** the individual you care for has displayed **within the past month**.

Q17 How often do emotional outbursts occur?

- ○ More than once a day (1)
- ○ Once a day (2)
- ○ 2-3 times a week (3)
- ○ Once a week (4)
- ○ 2-3 times a month (5)
- ○ Once a month (6)
- ○ Less than once a month (7)
- ○ Never (8)

Q18 When the individual you care for is in the following places, how often do emotional outbursts occur?

	Not applicable/never/rarely (0-3 times out of 10) (1)	Sometimes (4-6 times out of 10) (2)	Often/always (7-10 times out of 10) (3)
A place that makes them feel safe (1)	○	○	○
A place that makes them feel unsafe (2)	○	○	○
A place that they are familiar with *(e.g. at a relative/friend's house)* (3)	○	○	○
A place that they are unfamiliar with *(e.g. whilst on holiday away from home)* (4)	○	○	○
A place that they feel is private *(e.g. in their room)* (5)	○	○	○
A place that they feel is public *(e.g. at a shop)* (6)	○	○	○

Q19 When the individual you care for is with the following people, how often do emotional outbursts occur?

	Not applicable/never/rarely (0-3 times out of 10) (1)	Sometimes (4-6 times out of 10) (2)	Often/always (7-10 times out of 10) (3)
Someone that makes them feel safe *(e.g. a parent/caregiver)* (1)	○	○	○
Someone that makes them feel unsafe *(e.g. a dentist)* (2)	○	○	○
Someone familiar *(e.g. a teacher)* (3)	○	○	○
Someone unfamiliar *(e.g. a cashier at a shop)* (4)	○	○	○
Someone they like (5)	○	○	○
Someone they dislike (6)	○	○	○
Someone they are jealous of (7)	○	○	○

Q20 When the individual you care for is in the following states, how often do emotional outbursts occur?

	Not applicable/never/rarely (0-3 times out of 10) (1)	Sometimes (4-6 times out of 10) (2)	Often/always (7-10 times out of 10) (3)
Tired (1)	○	○	○
Hungry or thirsty (2)	○	○	○
Consumed too much of one type of food or drink *(e.g. caffeine)* (3)	○	○	○
Illness (4)	○	○	○
In pain (5)	○	○	○
In a bad mood or having a bad day (6)	○	○	○

Q21 When the following trigger events occur, how often do they lead to an emotional outburst?

	Not applicable/never/rarely (0-3 times out of 10) (1)	Sometimes (4-6 times out of 10) (2)	Often/always (7-10 times out of 10) (3)
Planned transition from one activity to another (1)	○	○	○
Change in own routine (2)	○	○	○
Change in another's routine (3)	○	○	○
Change in expectation (4)	○	○	○
Being fixated on a thought or idea (5)	○	○	○
Specific phobia or fear (39)	○	○	○
Food-related triggers (43)	○	○	○
Concerns for own property *(e.g. losing something or worried about losing something)* (6)	○	○	○
Not being given or not being able to do something the person wants (8)	○	○	○
Having to wait before being given or being able to do something (9)	○	○	○
Being asked to do something the person may or may not want to do (10)	○	○	○
Doing a boring task (11)	○	○	○
Doing a difficult task (12)	○	○	○
Doing a repetitive task (13)	○	○	○

Doing a new task (14)	○	○	○
Under time pressure*(e.g. getting ready in the morning)* (15)	○	○	○
Disagreement with others (18)	○	○	○
Being told off, criticised, or accused of making a mistake (19)	○	○	○
Being teased (20)	○	○	○
Being apart from parent(s)/caregiver (21)	○	○	○
Not receiving enough attention or being ignored (22)	○	○	○
Receiving too much attention (23)	○	○	○
Feeling of being treated unfairly (24)	○	○	○
Someone not understanding the individual you care for (25)	○	○	○
The individual you care for not understanding someone else (26)	○	○	○
Not understanding what is going on (40)	○	○	○
Receiving conflicting information (17)	○	○	○
Light is too bright (27)	○	○	○
Sudden or loud noises (28)	○	○	○
Temperature is too hot or too cold (29)	○	○	○
Particular smells or strong smells (30)	○	○	○

Touch-related over-sensitivity*(e.g. uncomfortable seat or sudden touch)* (31)	○	○	○
Other sensory-related triggers (33)	○	○	○
Medication side-effect (34)	○	○	○
Mood of parent/caregiver (35)	○	○	○
No reason/out of the blue (36)	○	○	○

Display This Question:

If Q21 = Other sensory-related triggers [Sometimes (4-6 times out of 10)]

Or Q21 = Other sensory-related triggers [Often/always (7-10 times out of 10)]

Q21.1 You had indicated that other sensory-related triggers ${Q21/ChoiceGroup/SelectedAnswers/33} lead to emotional outbursts. Please could you specify what these other triggers are?

____

Q22 How confident are you in your answers above (Q21) relating to the triggers that lead to emotional outbursts?

○ Not confident (1)

○ Quite confident (2)

○ Very confident (3)

Q23 How successful are the following management strategies in calming emotional outbursts of the individual you care for?

	Not applicable/never/rarely (0-3 times out of 10) (1)	Sometimes (4-6 times out of 10) (2)	Often/always (7-10 times out of 10) (3)
Physical or verbal comfort (1)	○	○	○
Discussion or persuasion (2)	○	○	○
Calming or relaxation strategies (3)	○	○	○
Giving them what they want (4)	○	○	○
Visual aids (5)	○	○	○
Punishment or threat of punishment (6)	○	○	○
Negotiation (7)	○	○	○
Actively ignoring behaviour (8)	○	○	○
Moving them or others from situation (9)	○	○	○
Distraction (10)	○	○	○
Showing empathy (11)	○	○	○

Q24 How often does the individual you care for display the following behaviours **after** emotional outbursts?

	Not applicable/never/rarely (0-3 times out of 10 outbursts) (1)	Sometimes (4-6 times out of 10 outbursts) (2)	Often/always (7-10 times out of 10 outbursts) (3)
Apologising (1)	○	○	○
Blaming others (2)	○	○	○
Seeking reassurance or comfort (3)	○	○	○
Appearing withdrawn (4)	○	○	○
Staying in a bad mood (5)	○	○	○
Feeling anxious (6)	○	○	○
Feeling sad (7)	○	○	○
Behaving as if nothing had happened (8)	○	○	○

Q25 How often are you there to witness the emotional outbursts when they occur?

○ Never/rarely (0-3 times out of 10 outbursts) (1)

○ Sometimes (4-6 times out of 10 outbursts) (2)

○ Often/always (7-10 times out of 10 outbursts) (3)

Appendix C: Demographic Questionnaire

Demographic questionnaire

Please provide the following **demographic information about the individual you care for**. We will use this information to check if these factors might affect the responses to the Emotional Outburst Questionnaire.

1	What is their year and month of birth?	*(dd/mm)*				
2	What is their gender?	Male ☐	Female ☐	Other ☐		
3	Which diagnosis/diagnoses does the person have? Note: as this questionnaire is anonymous, please do not include details of the person's diagnosis if it will render them identifiable (*e.g. if the person has a rare genetic mutation that only a handful of people have in the UK*).	Learning disability ☐	Learning difficulty (*e.g. dyslexia*) ☐	ASD ☐	ADHD ☐	
		Anxiety ☐	Depression ☐	Deafness ☐	Under diagnostic assessment ☐	
		Other ☐				
		No diagnosis ☐				
	Who made the diagnosis/diagnoses? (*e.g. GP, clinical psychologist*)					
	If you selected 'Deaf/hearing loss', please provide the following additional information.					
	What is the level of Deafness/hearing loss the individual has?	Mild ☐	Moderate ☐	Severe ☐	Profound ☐	
	What is the main form of communication the individual uses?	Verbal ☐	Sign language ☐			
	Do you have Deafness/hearing loss?	Yes ☐	No ☐			
4	Does the person take any medication for emotional outbursts?	Yes ☐	No ☐			
	If yes, what medication do they take?					

5	What is their current schooling or employment status?	Mainstream school ☐	Special school ☐	Further education (college) ☐	Higher education (university) ☐
		Employed ☐	In employment preparation ☐	Unemployed ☐	
6	Have they completed an IQ test?	Yes ☐	No ☐		
	If yes, please provide the following details regarding the most recent IQ test.				
	Who administered the test? (*e.g. educational psychologist, researcher*)				
	What test was used?				
	What was the score?				
7	Does/did the person have either a statement of special education needs (SEN) or an education, health and care (EHC) plan?	Yes ☐	No ☐		
8	Is/was the person on the special education needs (SEN) register?	Yes ☐	No ☐		
9	Have you ever had access to specific programmes, training, or interventions for the individual's emotional outbursts?	Yes ☐	No ☐		
	If yes, have these resources been effective in managing the individual's emotional outbursts?	Yes ☐	No ☐		
	When did you gain access to the resources?	Before the difficulties began ☐	Immediately or soon after the difficulties began ☐	A while after the difficulties began ☐	

Appendix D: Themes

LS Table of themes [exhaustive]

Themes	Examples
Lead to increased behaviours/emotional distress	‘can lead into more severe outbursts’
Escaping behaviours	‘leaving the situation’, ‘walking off’, ‘Walking off in huff’, ‘withdrawal into current occupation’, ‘disengaging’, ‘isolation’, ‘locking self in the bathroom’
Non-compliance/ defiance	‘not listening’, ‘contrariness’, ‘obstruction’, ‘refusing’, ‘verbal protests’, ‘not doing something routine eg putting on shoes’, ‘not listening/ responding’, ‘hard to reason with’, ‘stubborn/stand off’
Verbal expression	‘verbal protests’, ‘shouting’, ‘swearing’, ‘repetitive speech’, ‘verbal threats’, ‘whinging’, ‘moaning about person/adult in the house’ ‘arguing the toss about something routine’
Behaviour indicative of emotions	‘crying, ‘sighing’, ‘tantrums’
Caregiver label of emotion	‘frustrated’, ‘anger’, ‘upset’, ‘angry’
Aggression towards objects	‘overturn furniture’, ‘door slamming’, , ‘reactionary, lashes out at object that causes it, eg a broken pencil’
Self-deprecation	‘negative talk about self’, 'I have no friends'
Unexpected outburst	‘out of nowhere’
Physiological arousal	‘red face’, ‘panic attack’
Increased motor activity	‘jiggling legs’, ‘arms/hands flapping’
Self-injurious behaviour	‘slapping self’, ‘throwing self onto furniture’
Not applicable	‘N/A’

MS Table exhaustive

Themes	Examples
Verbal expression	‘screaming’, ‘verbally abusive’, ‘shouting’, ‘growling’, ‘shouts’, ‘swears’, ‘Very loud and screaming’, ‘tourettes like verbal noises’
Aggression to others	‘hitting out’, ‘use of weapons’, ‘biting’, ‘Physically aggressive towards me’, ‘physical aggression’ ‘hitting , aggressive’, ‘throwing things’, ‘explosive fighting’, ‘lashing out, punching, kicking, throwing’, ‘violence’, push and shove’, ‘threaten with knives’
Aggression to objects	‘breaks/snaps items’, ‘smashing’, ‘physically aggressive to property’, ‘slams doors’, ‘rips clothing’, ’slamming doors’, ‘Throwing possessions against walls and doors’, ‘emptying wardrobe onto floor, trashing bed’, ‘continued door slamming’, ‘causing damage’
Self-injurious behaviour	‘self-harm’, ‘banging head’, ‘getting knife to self harm’
Behaviour’s indicative of emotion	‘crying’, ‘uncontrollable panic attack’, ‘shaking’, ‘meltdowns’
Unexpected outburst	‘Sudden eruption’, ‘ebbs and flows’
Escaping behaviours	‘Barricading self in room’, ‘runs away’
Long duration	‘Relentless, several hours’, ‘can last for couple of hours’
High frequency	‘several times a day
Soothed by other	‘Can be regulated by spending time with him’
Increased motor activity	‘walking in circles’, ‘arms flying about’ ‘stomping very fast’, ‘climbing’, ‘hyper’, ‘stamping feet’, ‘invading other people’s personal space’
Complete loss of control	‘Complete loss of control’, ‘loss of reality…shock and bewilderment afterwards’
Caregiver labelling of emotions	‘Blind rage’, ‘Exhaustion’, ‘frustrated’, ‘agitated’

Appendix E: Subgroups

Table E1.

Subgroups

Social Support	
Wayment et al. (2019)	Three questions on social support adapted from a study examining loss of an infant to sudden infant death syndrome (SIDS; Lepore et al., 1996).
Zaidman-Zait et al. (2017)	The Social Support Scale (SSS) of the Canadian National Longitudinal Survey of Children and Youth (Statistics Canada, Special Surveys Division, 2007)
Pozo & Sarria, (2014)	The Checklist of Support for Parents of the Handicapped (CSPH; Bristol, 1979).
Ho, (2013)	The Family Support Scale (FSS; Dunstet al., 1984)
Norizan and Shamsuddin (2010)	COPE Inventory. Measurement of coping style was adapted from COPE inventory which contain 15 sub-scales (Carver et al. 1989) [Instrumentation social support, emotional social support subscales.]
Mobarak et al. (2000)	FSS (Dunst et al., 1984).
Plant & Sanders, (2007)	Three measures of social support were obtained – family/partner support, friend support and external/ professional support. Respondents were asked to rate how much support they receive from family/partner, friends and service providers in carrying out tasks in eight different care-giving areas on a Likert scale.
Cognitive Framing	
Seymour et al. (2013)	The Brief COPE (Carver 1997): Problem focused coping subscale
Norizan & Shamsuddin, (2010)	COPE Inventory (Carver et al. 1989): Acceptance subscale
Miranda et al. (2019)	Brief COPE (Carver, 1997; Spanish adaptation by Morán et al., 2010): Cognitive reframing subscale
Pozo & Sarria, (2014)	The Sense of Coherence Questionnaire (SOC; Antonovsky, 1987)
Growth	
Wayment et al. (2019)	Posttraumatic Growth Inventory (PTGI; Tedeschi and Calhoun, 1996)
Norizan & Shamsuddin, (2010)	COPE Inventory. Measurement of coping style was adapted from COPE inventory which contain 15 sub-scales (Carver et al. 1989). Optimist/growth subscale
Active Coping	

Miranda et al. (2019)	Brief COPE (Carver, 1997; Spanish adaptation by Morán et al., 2010): Engaged coping subscale
Halstead et al. (2018)	The Brief Resilience Coping Scale (Sinclair and Wallston 2004)
Zaidman-Zait et al. (2017)	Ways of Coping Questionnaire (WoC; Folkman and Lazarus, 1988): Engaged coping subscale
Connor and White, (2014)	Mindful attention awareness scale (MAAS; Brown & Ryan, 2003)
Norizan & Shamsuddin, (2010)	COPE Inventory. Measurement of coping style was adapted from COPE inventory which contain 15 sub-scales (Carver et al. 1989): Active coping subscale
Avoidance	
Miranda et al. (2019)	(Brief COPECarver, 1997; Spanish adaptation by Morán et al., 2010): Disengaged coping subscale
Zaidman-Zait et al. (2017)	Ways of Coping Questionnaire (WoC; Folkman and Lazarus, 1988): Disengaged coping subscale
Seymour et al. (2013)	The Brief COPE (Carver 1997): Maladaptive coping subscale

Appendix F: Reliability Scores

Table F1.
Resilience Measures Reliability

Study	**Resilience Measure and Cronbach’s alpha (α)**	**Social Support and Cronbach’s alpha (α)**
Miranda et al. (2019)	Brief COPE 0.71 (disengagement) 0.77 (engagement)	
Wayment et al. (2019)	PTG. 0.94	0.89
Halstead et al. (2018)	Brief Resilience Coping 0.73	
Zaidman-Zait et al. (2017)	WoC 0.61 to .79	. 0.88
Connor and White, (2014)	MAAS 0.90 Demonstrated convergent reliability with related constructs such as emotional intelligence and openness to experience (Baer, Smith, Hopkins, Krietemeyer, & Toney, 2006).	
Pozo and Sarria, (2014)	SoC 0.80	0.82
Ho, (2013)	FSS 0.77	

Seymour et al. (2013)	Brief COPE 0.66	
Norizan & Shamsuddin, (2010)	COPE Inventory 0.62 (active coping), 0.65 (acceptance), 0.68 (positive reinterpretation/ growth/optimism) 0.92 (religious coping)	0.75 (instrumental) 0.85 (emotional)
Plant and Saunders, (2007)	0.78 – 0.86 alpha	SS 0.83, 0.88, 0.93
Mobarak et al., (2000)	-	-

Table F2.

Parental Stress Measures Reliability

Study	**Cronbach's Alpha (α)**
Miranda et al. (2019)	0.91 (parental distress) 0.82 (dysfunctional parent–child interaction) 0.90 (difficult child)
Wayment et al. (2019)	0.81
Halstead et al. (2018)	0.90
Zaidman-Zait et al. (2017)	0.90
Connor and White (2014)	0.89
Pozo and Sarria (2014)	0.88
Ho, (2013)	.49 to .91
Seymour et al. (2013)	0.81
Norizan & Shamsuddin, (2010)	0.83 and test–retest reliability was 0.81. *PSS also correlated well with PSI (r = 0.75, P < 0.01) but less so with Perceived Stress Scale (r = 0.41, P < 0.01)*
Plant and Saunders, (2007)	0.82
Mobarak et al., (2000)	-

Table F3.

Child Challenging Behaviour Measures Reliability