EXPLORING THE EXPERIENCES OF CARERS FOR YOUNG PEOPLE WITH EMOTIONAL OUTBURSTS IN THE UK: INSIGHTS FROM AND BEFORE THE COVID-19 PANDEMIC

By

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Thesis Overview

The author is a Clinical Psychologist in training and is submitting this thesis as a partial fulfilment of the Doctor of Clinical Psychology course at the University of Birmingham. This thesis encompasses four chapters, the first of which is a meta-ethnography of qualitative studies on the experiences of ethnic minority carers for people with developmental difficulties in the last twenty years in the UK. The second chapter is an empirical qualitative research study that explores the lived experiences of carers for young people with emotional outbursts in the UK before and during the pandemic, and its clinical implications. The third and fourth chapters are press releases for the meta-ethnography and the empirical research respectively, which present the key findings of each paper for dissemination to the public. Supplementary information for the first and second chapters is provided in the form of appendices and references.

Dedication

To the carers who disclosed their experiences to me and allowed me to share their voices.

And to my parents for their constant support and encouragement.

Acknowledgements

Firstly, I would like to thank Dr Kate Woodcock for her support and continuous patience with me and my multitude of questions. I couldn't have done it without you, Kate! I also want to thank members of Kate's research team, Justin, Claudia, Alex, Grace and Tom so much for helping me with papers, resources and practising the interviews. I really value all the time and effort you put in to be there for me when I needed it.

I have the fondest regards for my fellow trainees Ula, Jasmine, Emily, Nandini and Charlie who have stuck with me through the tough times. I can't imagine having gone through this doctorate without them. They have been there when the thesis seemed never-ending and when I needed pick-me-ups. I am so glad they have been my protective factors throughout the doctorate.

Lastly, I save my unending gratitude for my parents who not only helped me proofread multiple drafts of the thesis but have always been there to believe in and support me. Their faith in me has been my guiding light through this course.

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The Experiences of Ethnic Minority Carers for People With Developmental Disabilities in The UK: A Meta-Ethnography

1.1 Abstract

Ethnic minority carers for people with developmental difficulties may face more health disparities and differences in factors such as acceptance of the diagnosis, access to services, barriers to communication with professionals and coping with religion than White ethnic carers. Yet, very few reviews and syntheses highlight their experiences, with most conducted in the US. Therefore, this meta-ethnography aimed at capturing the unique experiences of minority carers for people with neurodevelopmental difficulties and the wider sociocultural factors surrounding them. Six databases were systematically searched: PsychINFO, Web of Science, SCOPUS, Pubmed, CINAHL and Ovid Medline, which yielded 1434 papers, out of which 10 were included for analysis. A quality appraisal checklist [National Institute for Health and Care Excellence (NICE, 2012)] was applied to each study and Noblit and Hare's (1988) seven-step method was used to synthesize them. Four main themes were identified (Understanding the Diagnosis and Its Social and Cultural Implications; Lack of Support from Professionals, Family Members and Own Community; Barriers to Advocacy; Cultural Coping), that underlined how carers experienced the diagnosis, support and their own beliefs. A model of context was also designed to understand overarching systemic factors such as immigration and socio-cultural norms that influenced these experiences. This review offered insights into how wider contexts influenced carers' perceptions and the coping strategies they employed. It had implications for how services could support ethnic carers and the need for more awareness about developmental difficulties in ethnic communities.

1.2 Introduction

Context and rationale

The prevalence rates for neurodevelopmental disorders worldwide range from approximately 0.1% to 26% in recent years (Chiarotti & Venerosi, 2020; Elsabbagh et al., 2012) and have been studied widely. These disorders are often characterized by cognitive and behavioural symptoms such as ritualistic behaviours, hitting out, screaming and limited understanding of others' emotional states, which can put a large amount of pressure on caregivers due to their challenging nature. Families and others caring for people with neurodevelopmental disorders often experience stress, burnout, and other mental health issues due to the added and mostly lifelong nature of the care (Scherer et al., 2019). Caregivers who care for children with both neurodevelopmental difficulties and challenging behaviours have worse physical and mental health outcomes than those who care for children with either the former or latter, such as higher depression scores, issues with family relationships and lower social support due to lack of time (Estes et al., 2013; Gallagher & Whiteley, 2013; Lach et al., 2009). Therefore, carers experience more mental and physical health inequalities than non-carers, where higher intensity caregiving is associated with more health issues (Lambrias et al., 2023).

However, there are other socio-economic factors that can affect carers' mental and physical health outcomes. For instance, one study found that household income and severity of the disability moderated the severity of depression symptoms (Scherer et al., 2019). Many caregivers also reported that their health had deteriorated over time and mentioned lack of time, lack of social energy and worries about the future as the main factors contributing to this (Murphy et al., 2007). Sociocultural constructs such as medical systems and access to professional support also shape the experience of carers. Time-consuming advocacy activities such as insurance claims to cover medical treatments and the effects on household finances add to significant pressures of caring for the child (Green, 2007). Nevertheless, caregivers also developed different coping strategies and ways to view their situation in a different light (Young et al., 2020). Family and social support appeared as strong mediating factors for resilience and coping (Sadiki & Mashegoane, 2019). However, these studies were conducted in Western countries with largely Caucasian populations and allowed very little consideration of factors related to ethnicity, religion and socio-cultural backgrounds that could influence caregivers' experiences.

Accordingly, in Asian and other non-Caucasian societies, many studies highlight these ethnic and socio-political factors. For example, Nepalese caregivers experience distress due to factors such as low literacy, degree of the child's disability and low support from social workers and the government (Maridal et al., 2021). Other quantitative studies have reported that parents and caregivers in countries such as Pakistan, Kenya and China have high rates of depression and anxiety that are often influenced by factors such as low socioeconomic status, unemployment, limited educational levels and stigma (Azeem et al., 2013; Mbugua et al., 2011; Wang et al., 2013). Similarly in South Korea, the additional cost of raising a child with special needs was the main source of strain for caregivers (Oh & Lee, 2009), which was not mentioned much in studies where the dominant samples were Caucasian. In developing countries, there seems to be a higher financial burden on caregivers and higher rates of stigma associated with a child with additional needs as most costs are paid out of the carers' own pockets (Shahat & Greco, 2021).

Research has also pointed out differences between the experiences of immigrant carers. For instance, Asian American caregivers were more likely to feel distressed over the characteristics of their child's disability than Caucasian American carers (DeLambo et al., 2011). Systemic factors such as insurance coverage, lack of respite care and lack of adequate support from medical professionals were also twice as likely to be experienced by immigrant families than by their native counterparts in the US (DeLambo et al., 2011). Additionally, some qualitative studies have offered deeper insight into the challenges faced by immigrant families in Western countries. South Asian Muslim caregivers in America conveyed difficulties breaking cultural communication barriers with professionals, feeling judged by their own community, and trying to seek more traditional religious cures (Jegatheesan et al., 2010). Nevertheless, for Chinese families residing in New York, perceptions of duty, responsibility and collectively caring for their child helped them develop resilience in the face of challenges. Many parents also spoke about leaving their properties in China to access better care for their child in a foreign country and the difficulties of adapting to a new culture (Huang & Zhou, 2022). Clearly, cultural values, emigrating from a foreign country, and a sense of community play an important part in the experiences of immigrant parents.

Some of these findings have been summarized in reviews and syntheses. For instance, Alsharaydeh et al. (2019) found that in countries like US, UK and Australia, common experiences of immigrant carers included stigma and discrimination from others in their own and other communities, isolation and stress associated with that, challenges adapting to a new culture, difficulties with communication in a non-native language and financial struggles. Similarly, a meta-synthesis found that minority ethnic caregivers in the US experienced difficulties in accepting and understanding the diagnosis, stigma and discrimination, limited family and professional support, adherence to religious beliefs and conflicts with the patriarchal system. However, they also used spirituality, acceptance, and love for their child to build resilience and advocate for themselves and their children (Emmanuel et al., 2022).

For majority Caucasian carers in Western countries, a meta-ethnography found that there were similar concerns with respect to limited support from services, difficulty accepting the diagnosis, stigma, acceptance, and the emotional strain (Corcoran et al., 2015). However, there are limited meta-ethnographies and synthesis of the experience of immigrant or minority carers in Western countries, even though there are many commonalities between the themes found by qualitative studies. Moreover, the syntheses conducted so far have focused on the US, where financial burdens are more considerable due to requiring insurance and paying for private practices. In the UK however, there might be other factors that play a more significant role due to the availability of the National Health Service (NHS). Additionally, special education standards are different in the US and the UK. In the US, children and young persons are required to have a diagnosis of a disability or special need to access additional support whereas in the UK, children are given that support from teaching assistants based on need, regardless of a formal diagnosis (Marsh, 2019). Thus, there are clear differences in the wider systems in the US and UK and it is important to consider the experiences of ethnic minority carers within these contexts in the UK.

Aims and Research Questions

This meta-ethnography was designed to fill the gap in the literature for minority carers for people with neurodevelopmental disabilities in the UK. Therefore, the aim was to capture and synthesize minority carers’ unique experiences. It also aimed to identify the wider sociocultural factors involved in shaping these experiences. The research questions were as follows:

1. What is the experience of carers from ethnic minority groups in the UK in caring for people with neurodevelopmental disorders?
2. How do wider sociocultural and economic factors influence these experiences?

1.3 Methods

Structure

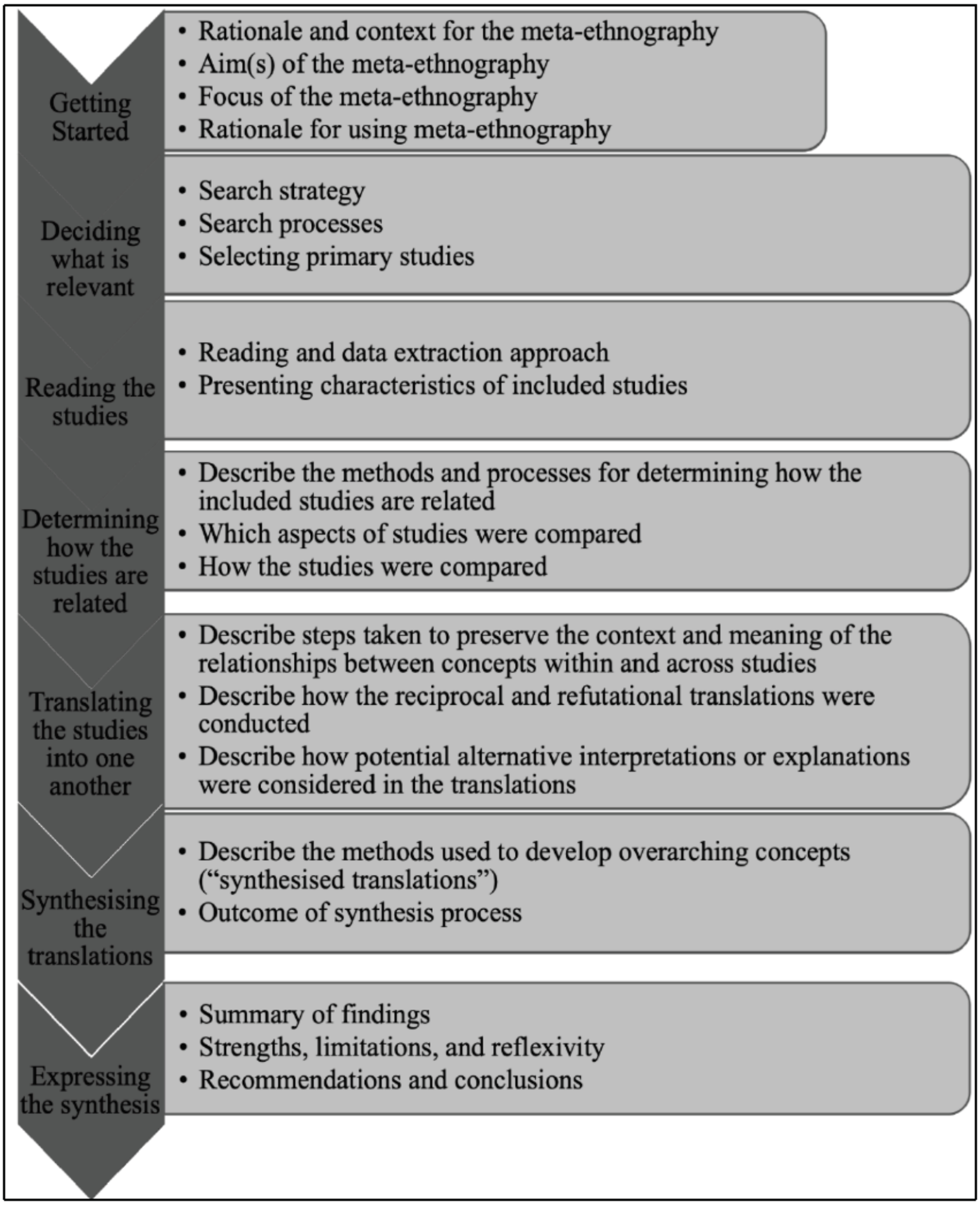
Meta-ethnography is a seven-step evidence-based process of synthesizing key concepts and information from qualitative studies (France et al., 2019), originally developed by Noblit and Hare (1988). In this review, it involved methodical comparisons of themes and concepts from each qualitative study to develop overarching ideas (France et al., 2019). One of the important steps in this meta-ethnography was to preserve the original contextual meanings of the ideas in studies. However, although there were steps to conducting a meta-ethnography, the process was mainly iterative and often involved an overlap of the steps (Sattar et al., 2021).

This synthesis focused on purely qualitative experiences of carers due to the richness and depth of data about their experiences, and in order to increase transparency, compared to narrative syntheses (Sattar et al., 2021). The research questions also focused on identifying wider contextual and environmental factors overarching the experiences of carers to create new understandings of their experiences. Thus, it was decided that a meta-ethnography would be the best fit to answer the research questions for this review.

France et al. (2019) developed guidelines (eMERGE) to increase confidence and uniformity in the reporting of meta-ethnographies. These guidelines were used to report the findings of this review. A full list of the phases of meta-ethnography and the steps detailed by France et al. (2019) is provided in Figure 1.1. A further description of the eMERGE criteria can be found on their webpage.

Figure 1.1

eMERGE step-by-step guidelines



Getting Started
- Rationale and context for the meta-ethnography
- Aim(s) of the meta-ethnography
- Focus of the meta-ethnography
- Rationale for using meta-ethnography

Deciding what is relevant
- Search strategy
- Search processes
- Selecting primary studies

Reading the studies
- Reading and data extraction approach
- Presenting characteristics of included studies

Determining how the studies are related
- Describe the methods and processes for determining how the included studies are related
- Which aspects of studies were compared
- How the studies were compared

Translating the studies into one another
- Describe steps taken to preserve the context and meaning of the relationships between concepts within and across studies
- Describe how the reciprocal and refutational translations were conducted
- Describe how potential alternative interpretations or explanations were considered in the translations

Synthesising the translations
- Describe the methods used to develop overarching concepts (“synthesised translations”)
- Outcome of synthesis process

Expressing the synthesis
- Summary of findings
- Strengths, limitations, and reflexivity
- Recommendations and conclusions

Phase 1: Getting started

The first step of a meta-ethnography was to identify an area of interest on which to base a search of the databases (Sattar et al., 2021). After determining whether there were numerous qualitative studies conducted in the area, the topics covered by them and gaps in research, a research question was formed, along with inclusion and exclusion criteria for the systematic screening of studies.

The area of interest in this study was the experience of ethnic minority caregivers caring for people with neurodevelopmental disorders. The search strategy used was primarily comprehensive in nature, in that it was exhaustive (France et al., 2019). Before identifying the final set of search strings, a list of all the synonyms of keywords from the research question were made and discussed with others in the research team. Some previous reviews were also consulted at this stage. For instance, terms and synonyms for neurodevelopmental disorders were adapted from Woodcock & Blackwell's (2020) review and other terms corresponded to strings in Akbar & Woods's (2019) systematic review of minority ethnic parents in Western countries.

The final systematic search of databases was conducted on the 7th of November 2022. Six databases were searched: PsychINFO, Web of Science, SCOPUS, Pubmed, CINAHL and Ovid Medline, after discussion with a research supervisor and agreement about these being the most relevant to research in Psychology. Moreover, these databases also matched those chosen by other meta-syntheses such as in Shorey et al.'s (2020) review. These databases were searched for articles in the English language from the date of the database's foundation till 2022. An initial search was performed on the 4th of November 2020 with the seven search strings shown in Table 1.1. However, it was decided upon further consideration that strings 4 and 5 would be merged to make one search string. Therefore, the final search had six strings and combined these using the Boolean operator 'AND'. Additionally, the bibliographies of two reviews were searched by hand to identify any articles that may have been left out in the search. Upon searching these two syntheses (Akbar & Woods, 2019; Shorey et al., 2020), three papers were identified in the UK, which were already included in the search results. This indicated the limited availability of published research around this topic in the UK.

Table 1.1

Initial search strings

Number	Search String
1.	carer* OR caregiver* OR famil* OR mother* OR father* OR foster care* OR foster parent* OR adoptive parent* OR parent*)
2.	mental health* OR stress* OR depress* OR anxiet* OR mental wellbeing* OR experience OR percept*
3.	intellectual disabil* OR learning disabil* OR autis* OR developmental delay* OR developmental disabil* OR ASD* OR special need* OR neurodev* disorder OR neurodev* disabil* OR neurodivergent* OR neurodiverse OR sensory processing disorder OR Aspergers OR attention deficit hyperactivity disorder or prader willi syndrome* OR williams syndrome OR fragile x syndrome OR attention disorder* OR down syndrome OR Angelman Syndrome OR CHARGE Syndrome OR Coffin-Lowry Syndrome OR Coffin Siris Syndrome OR Cornelia de Lange Syndrome OR Cri du Chat Syndrome OR Foetal Alcohol Syndrome OR Lesch-Nyhan Syndrome OR Mowat-Wilson Syndrome OR Neurofibromatosis Type 1 OR Noonan Syndrome OR Rett Syndrome OR Rubinstein-Taybi Syndrome OR Triple-X Syndrome OR klinefelter syndrome OR XXY syndrome OR Tuberous Sclerosis Complex OR Turner Syndrome OR Wolf-Hirschhorn Syndrome OR XYY Syndrome
4.	Qual* OR interview*
5.	content analysis* OR thematic analysis* OR IPA* OR phenomenolog* OR narrative* OR grounded theor*
6.	Ethnic minort* OR racial* OR religi* OR cultur* OR immigra*
7.	UK OR United Kingdom* OR England* OR Scotland* OR Wales* OR Ireland*

EndNote 20 was used to import papers, find duplicate results, and sort the papers out according to inclusion and exclusion criteria at different stages of screening. After duplicates were extricated, titles, then abstracts and full texts were screened by the main reviewer. Studies with mixed methods designs were not included as they often did not report rich qualitative data or participant quotes. Studies with mixed Caucasian and ethnic carers were included if they had clearly identified and reported significant data and quotes from ethnic carers. As the focus was on the caring experiences of caregivers, any studies that solely focused on carers' definitions of neurodevelopmental disabilities, views about medicines, and perceptions of their child's dignity or language preferences were not included. Other studies that included carers' experiences of coping strategies, education and health services and getting their children married were included as they were part of the general caregiving experience. A full list of inclusion and exclusion criteria is presented in Table 1.2. A diagram of the screening stages using PRISMA criteria (Page et al., 2021) is presented below (Figure 1.2).

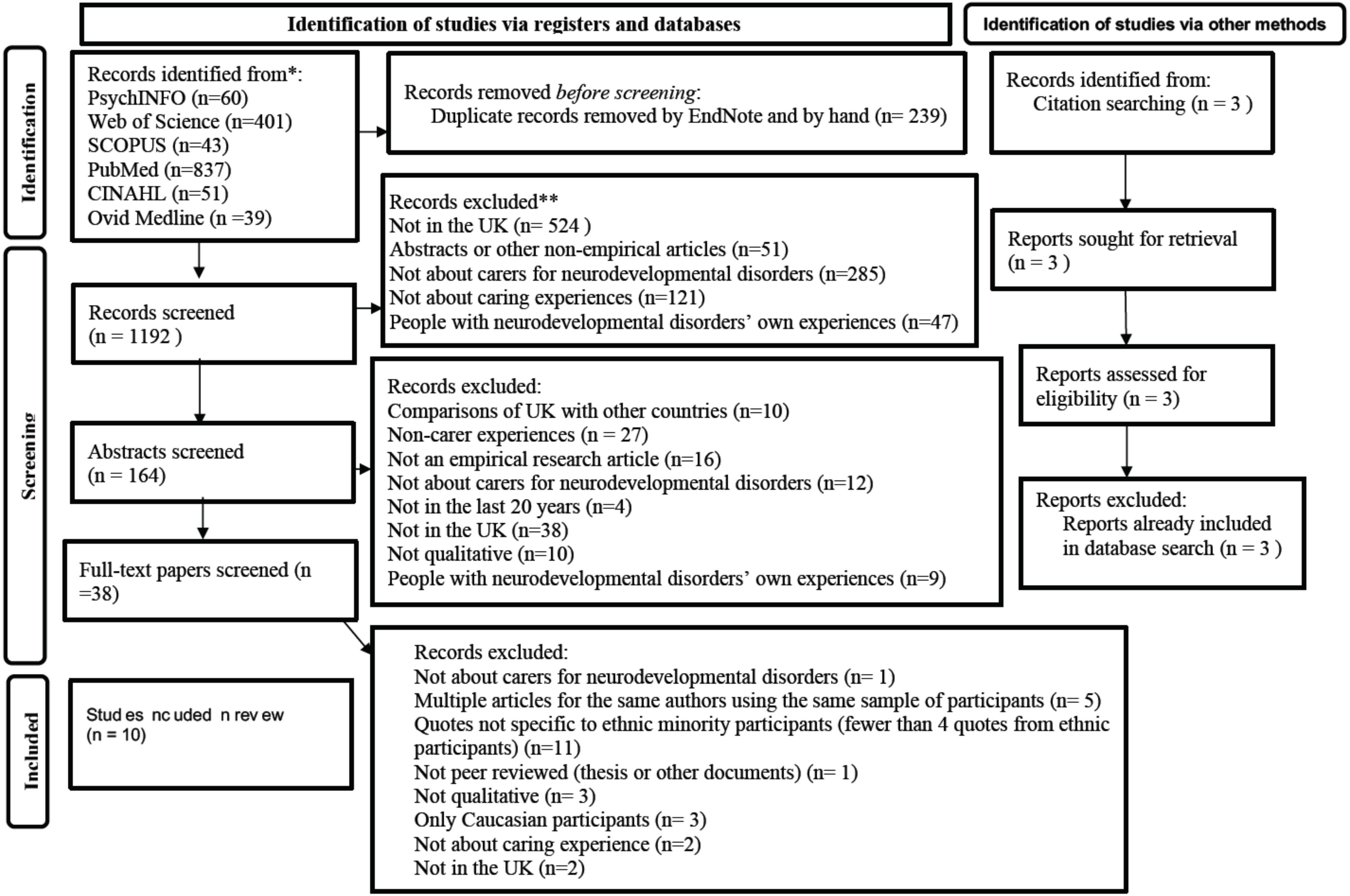
Table 1.2

Inclusion criteria

Inclusion conditions
In the UK
Containing at least 50% ethnic minority participants
Includes majority accounts (quotes) of carers' experiences
Carers' experiences, not opinions, of caregiving
In the last 20 years
Experiences of carers for people with neurodevelopmental difficulties
Empirical qualitative research
Peer reviewed and published
Sample of participants used only in one study by the researcher
English language papers only

Figure 1.2

PRISMA 2020 diagram with exclusion criteria


Identification of studies via registers and databases
Identification of studies via other methods
Identification
Screening
Included
Records identified from*:
PsychINFO (n=60)
Web of Science (n=401)
SCOPUS (n=43)
PubMed (n=837)
CINAHL (n=51)
Ovid Medline (n =39)
Records removed *before screening*:
Duplicate records removed by EndNote and by hand (n= 239)
Records screened
(n = 1192)
Records excluded**
Not in the UK (n= 524)
Abstracts or other non-empirical articles (n=51)
Not about carers for neurodevelopmental disorders (n=285)
Not about caring experiences (n=121)
People with neurodevelopmental disorders' own experiences (n=47)
Abstracts screened
(n = 164)
Records excluded:
Comparisons of UK with other countries (n=10)
Non-carer experiences (n = 27)
Not an empirical research article (n=16)
Not about carers for neurodevelopmental disorders (n=12)
Not in the last 20 years (n=4)
Not in the UK (n=38)
Not qualitative (n=10)
People with neurodevelopmental disorders' own experiences (n=9)
Full-text papers screened (n =38)
Records excluded:
Not about carers for neurodevelopmental disorders (n= 1)
Multiple articles for the same authors using the same sample of participants (n= 5)
Quotes not specific to ethnic minority participants (fewer than 4 quotes from ethnic participants) (n=11)
Not peer reviewed (thesis or other documents) (n= 1)
Not qualitative (n= 3)
Only Caucasian participants (n= 3)
Not about caring experience (n=2)
Not in the UK (n=2)
Studies included in review
(n = 10)
Records identified from:
Citation searching (n = 3)
Reports sought for retrieval
(n = 3)
Reports assessed for eligibility (n = 3)
Reports excluded:
Reports already included in database search (n = 3)

Phase 2: Reading Studies

After screening the full texts, the papers were critically appraised by the researcher using the National Institute for Health and Care Excellence (NICE) (Appendix A) guidelines for qualitative studies. The guidelines assessed each paper on its appropriateness, clearness, study design, data collection, role of researcher, clarity of context, reliability of methods, data analysis, findings and conclusions and ethical considerations (NICE, 2012). These guidelines were chosen as they provided detailed notes and questions for each quality criteria that allowed the rater to sort the criteria as ‘met’, ‘unmet’ or ‘partially met’. It also allowed the rater to provide the studies with an overall evaluation of ‘—’, where no or very few criteria were met, ‘+’ where some criteria not fulfilled were unlikely to affect the outcome and ‘++’, where all or most criteria were met. All studies either fell in the ‘+’ or ‘++’ categories. The full table of appraisal outcomes is given in Appendix B. The purpose of the quality appraisal was to enhance the thoroughness of the synthesis and provide a systematic way of assessing papers, not to select the soundest study. Therefore, none of the studies were excluded solely based on the quality appraisal.

The next step involved reading and re-reading the studies, which was when the process of synthesizing information began (Sattar et al., 2021). This stage consisted of reading studies repeatedly and familiarizing oneself with the key themes and data in papers. First order concepts were the participant’s own words usually recorded as quotes, second order concepts referred to the primary authors’ interpretation of participant quotes and third order concepts were the reviewers’ interpretations. An Excel spreadsheet was used to extract this raw data verbatim by the researcher to preserve important concepts. This data was mainly collected from the results and discussion sections of each paper as these contained the most relevant concepts. Other contextual information from the studies was recorded elsewhere. First and second order themes were colour coded to maintain the distinctions and notes were made next to each theme which formed the basis for third order interpretation. It should be noted that reading the studies and concepts was not limited to this stage and was an iterative process to ensure adherence to the original interpretations and backgrounds of the studies (Sattar et al., 2021).

While reading the studies, it was also important to pay attention to the context in which they were conducted. Thus, at this stage a table of study characteristics and contexts was created (Appendix C). Moreover, a reflective column was kept by the researcher in an Excel sheet to capture reflexivity and thoughts while reading the studies. Contextual information and the way it might have influenced first and second order concepts was also made note of in the third order interpretations. An example of the data extraction table for one of the studies (Marku et al., 2022) is in Appendix D.

Phase 3: Determining how studies are related

Concepts used to explain data were derived by ‘comparing instances’ and forming ‘meaningful ideas’(France et al., 2014, pp.9). These new concepts were then used to encompass key ideas and themes from studies and are largely part of the ‘translation’ stage of the meta-synthesis. However, before that, themes and metaphors from studies were juxtaposed against each other to determine how studies were related. Thus, a table of themes was created and colour coded to show the associations and common concepts between them, where shared cell colours highlighted common metaphors. The third order notes from the extraction table were also used in this process to help inform shared ideas between themes.

Other contextual factors from studies such as aims, gender and age of participants and ethnicity were also compared to take into account their influence on concepts.

Apart from one study (Durling et al., 2018) that explored the meaning of becoming parents for people with intellectual disabilities and the impact on their families, most themes from other studies corresponded with each other. At this stage, themes or metaphors that were not related to metaphors in other studies were removed from the analysis to prepare for the next stage and create a more cohesive synthesis relevant to the research questions. For example, the theme 'understanding what marriage entails' did not relate to any other metaphors across studies and was consequently not considered when translating studies into one another. The table of colour coded themes can be found in Appendix E.

Phase 4: Translating and synthesizing studies

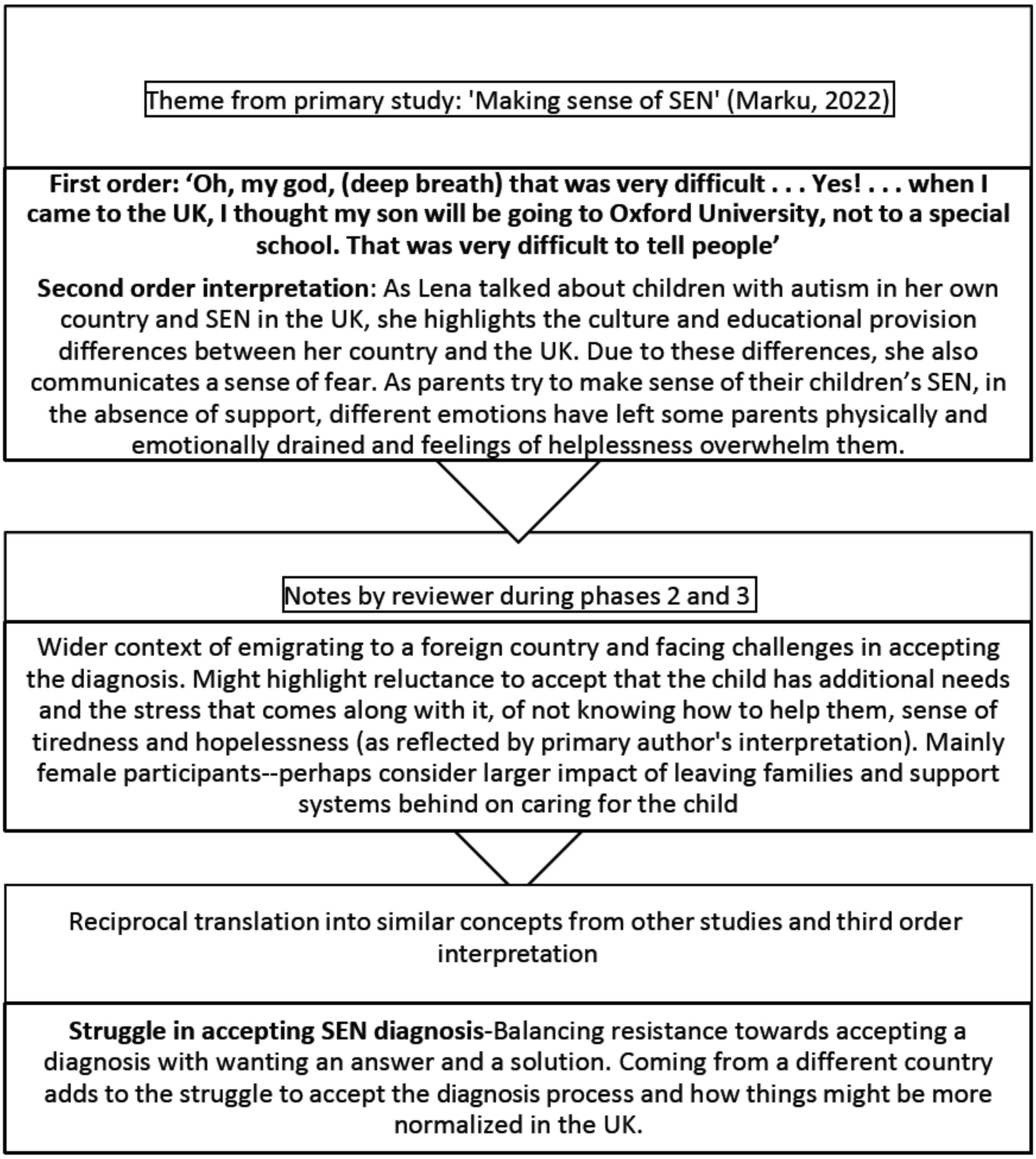
Translating studies into one another involved comparing the metaphors and concepts in one study to others (Noblit & Hare, 1988). This helped the researcher determine whether the concepts were similar or dissimilar to each other and categorise them into overarching concepts or third order concepts (Sattar et al., 2021). The translation process involved reciprocal or refutational translations. If the concepts within studies were similar in their explanations and focus, they were synthesised in reciprocal translations; if they seemed to refute each other, they were organised in refutational translations (Atkins et al., 2008). The characteristics of each paper such as population characteristics, background, and location of the study were referred to, to help preserve the context of where the data originated from. This also helped preserve the richness of the data (France et al., 2019). Nevertheless, it was often unclear what exact method should be used for the translation process. Therefore, Sattar et al.'s (2021) paper was used as a guide.

To achieve the translation process, the studies were arranged in chronological order by the reviewer, starting with the most recent. Each concept from the first study was compared to concepts in the second study to check for reciprocal and refutational concepts. The reviewer's notes from phases 2 and 3 were also used to aid translation and for reflections on the context. The concepts from papers one and two were then compared to concepts from paper three and so on for all the ten papers. The translations were done only by the main reviewer and context was preserved by making note of participant characteristics and wider factors such as immigration in the reviewer's notes. These were then carried forward to the formation of third order constructs and line of argument synthesis. An example of how this was done for one of the themes in the first study is highlighted in Figure 1.3.

The translations were grouped into four main themes: (1) understanding the diagnosis and its social and cultural implications, (2) lack of support from professionals, family members and own community, (3) barriers to advocacy, (4) cultural coping. These themes were derived by careful considerations of how the translations related to one another. For instance, in 'cultural coping', the common concept was that of coping using cultural factors such as religious cures for disabilities or gaining personal strength from having faith. Similarly, refutational translations were also grouped into the themes they related best to. For example, having a fear of rejection from the community but simultaneously rejecting social norms that felt wrong were included in the wider theme of 'lack of support from professionals, family members and own community' as it related to ostracization from the community and a lack of support.

Figure 1.3

Example of preserving context in translation process



Theme from primary study: 'Making sense of SEN' (Marku, 2022)

First order: 'Oh, my god, (deep breath) that was very difficult . . . Yes! . . . when I came to the UK, I thought my son will be going to Oxford University, not to a special school. That was very difficult to tell people'

Second order interpretation: As Lena talked about children with autism in her own country and SEN in the UK, she highlights the culture and educational provision differences between her country and the UK. Due to these differences, she also communicates a sense of fear. As parents try to make sense of their children's SEN, in the absence of support, different emotions have left some parents physically and emotionally drained and feelings of helplessness overwhelm them.

Notes by reviewer during phases 2 and 3

Wider context of emigrating to a foreign country and facing challenges in accepting the diagnosis. Might highlight reluctance to accept that the child has additional needs and the stress that comes along with it, of not knowing how to help them, sense of tiredness and hopelessness (as reflected by primary author's interpretation). Mainly female participants--perhaps consider larger impact of leaving families and support systems behind on caring for the child

Reciprocal translation into similar concepts from other studies and third order interpretation

Struggle in accepting SEN diagnosis-Balancing resistance towards accepting a diagnosis with wanting an answer and a solution. Coming from a different country adds to the struggle to accept the diagnosis process and how things might be more normalized in the UK.

Researcher Position

Another main aspect to consider when conducting and reporting the meta-ethnography was the researcher's epistemological position and reflexivity. Epistemology is a division of philosophy that studies the theory of knowledge and how we can know what we know (Lyons & Coyle, 2011). This meta-ethnography adopted a contextualist epistemological position (Braun & Clarke, 2006) as it aligned with the aims of the review. This meant that while the carers' experiences were acknowledged as being their perceptions of reality, there was also a consideration for wider social contexts and systemic factors that influenced those experiences, such as immigration, cultural and religious norms and stigma. This stance was maintained when applying Noblit and Hare's (1988) seven phases and when considering the findings. Moreover, further thought was given to the researcher's own perceptions, background, professional position and experience, and the influence of any other researchers that could have impacted the data synthesis.

The researcher's position in this study was both of an outsider and an insider. The researcher was an outsider due to not being a parent and not experiencing the challenges associated with raising a child with additional needs. This meant that the researcher's views on these aspects of the carers' experiences was more objective. On the other hand, the researcher was an insider due to being from an ethnic minority community in the UK and having some knowledge and insight into perceptions of disability and stigma in the community. This may have contributed to some biases but also allowed for a richer interpretation of the data. As an outsider, it facilitated an impartial view of carers' experiences but as an insider, it allowed the researcher to better empathize and understand their experiences. It also facilitated a better understanding of wider systemic and socio-cultural factors influencing these experiences. However, as a trainee Clinical Psychologist the researcher also felt considerable empathy for their experiences, which might have led to an emphasis on the struggles they go through.

1.4 Findings

The results of the translation process are presented below. Four overarching themes were derived, which included several reciprocal and some refutational translations presented below. Table 1.3 also describes the prevalence of these translations and themes across studies.

Table 1.3

Prevalence of translations

Theme	**Translations**	**Studies that supported them**
Theme 1: Understanding the diagnosis and its social and cultural implications	Struggling in accepting SEN (special education needs) diagnosis	Heer et al., (2015); Marku (2022); Munroe et al., (2016); Rizvi (2017)
	Child's diagnosis as personal failure	Marku (2022); Munroe et al., (2016)
	Fear of rejection from community	Croot et al., (2012); Ellen Selman et al., (2018); Hatton et al., (2010); Rizvi (2017)
	Fear of the unknown/uncertain/unambiguous	Heer et al., (2015); Rizvi (2017)
	Loss of 'normal' child	Munroe et al., (2016); Rizvi (2017)
	Cultural understandings of disability	Durling et al., (2018); Habib et al., (2017); Munroe et al., (2016)
	Rejection of societal/cultural norms or standards	Croot et al., (2012); Ellen Selman et al., (2018); Munroe et al., (2016)
Theme 2: Lack of support from professionals, family members and own community	Lack of adequate information or inconsistent information	Akbar & Woods (2020); Heer et al., (2015); Hatton et al., (2010); Marku (2022)
	Loss of familial support	Habib et al., (2017); Marku (2022); Munroe et al., (2016)

	Battling with schools, professionals and services	Akbar & Woods (2020); Habib et al., (2017); Hatton et al., (2010); Heer et al., (2015); Marku (2022)
	Positive experiences with families and communities	Croot et al., (2012); Ellen Selman et al., (2018)
	Positive experiences with schools, professionals and services	Akbar & Woods (2020); Habib et al., (2017); Hatton et al., (2010); Marku (2022); Rizvi (2017)
Theme 3: Barriers to advocacy	Distress about helping the child	Munroe et al., (2016); Marku (2022)
	Language as preventing support	Akbar & Woods (2020); Marku (2022)
Theme 4: Cultural coping	Cures in the wider sociocultural context	Croot et al., (2012); Munroe et al., (2016)
	Faith as a protective factor	Akbar & Woods (2020); Croot et al., (2012); Durling et al., (2018); Rizvi (2017)

Theme 1: Understanding the diagnosis and its social and cultural implications

Throughout the papers, one common concept that stood out was how different participants made sense of the SEN diagnosis, which was explained under reciprocal translations. Most parents were distraught about it and felt they had failed. They experienced a lot of grief at the loss of a ‘normal’ child. This was also related to fears about the future for the child, what their care might look like and fears about the carers’ own mortality. A lot of stigma and shame was also perceived by parents, especially in the context of a fear of being rejected from their own communities. However, some carers also rejected these norms that made them feel like a failure and chose to overlook others’ perceptions, which fostered a sense of resilience and coping.

Reciprocal translations for theme 1

1. *Struggle in accepting SEN diagnosis*

For some parents, there was a sense that if only professionals saw the child differently or how their children differed from others with special needs, they might lead a normal life. Underlying this was the context that not all parents had accepted their child's diagnosis and struggled with the fact that a special school placement would be required. This led to them feeling disheartened and often angry at services for not putting their child in a mainstream school.

> "All the children her age were going to normal schools...why can't she go there as well?" (Rizvi, 2017)

Moreover, for many parents there was a sense of loss of a normal child and loss of all their expectations for the child. This led to distress and hopelessness, in the context of a society where disabilities meant the child was seen as abnormal and not able to do much. One participant described how having a normal child was more important for the father and led to a loss of his hopes and dreams for the child:

> "Nazia describes her husband's reaction to finding out about his son's disabilities, including grief and disappointment over the loss of the son he had expected:
> He (dad) was crying, he does love him, but he's like disappointed about what happened with his little boy" (Heer et al., 2015)

In the context of emigrating from another country, some parents had to leave behind any expectations for themselves and their children. This further led to a feeling of loss and despair around the child's diagnosis. Most often it was also in the context of societal expectations that pressurised parents and made them feel like they had to hide the diagnosis:

> "Oh, my god, (deep breath) that was very difficult . . . Yes! . . . when I came to the UK, I thought my son will be going to Oxford University, not to a special school. That was very difficult to tell people" (Marku, 2022)

2. *Child's diagnosis as personal failure*

This subtheme represented parents' experiences of sacrificing a lot in their own life to take care of their child. It also represents discarding any expectations and aspirations for the child's future, which caused a lot of distress. Many parents look on the child's abilities or lack of as personal failures or embarrassments, especially as it confirmed their fears for the future.

> "I am worried that my son will not do well . . . if I cannot help him, I feel that I have failed in life . . . I have given up everything, I was a secondary teacher back home and I came here, and I work in a shop" (Marku, 2022)

These feelings are underpinned by shame, guilt, stigma and judgement from others in the community. They also exist in the wider context of immigration from one country and sacrificing what parents knew in their home countries. Therefore, they might feel more at loss and guilty if the child's behaviour or 'condition' does not get better in the new country that they had high hopes for. Expectations for the child were lost, shame and stigma around the family name being carried by a child with additional needs who may not be able to have their own children:

> "The mothers' perceived need to keep their situations 'private' appeared linked to feelings of shame, embarrassment and perceived stigma:
>
> With the behaviour and everything I was so embarrassed ... people were always looking at me strangely." (Munroe et al, 2019)

3. *Fear of the unknown/uncertain/unambiguous*

Parents grappled a lot with the implications of what the diagnosis might mean for their child's development and what it might mean for their future, how it might impact the family and the child, how it might impact on caregiving responsibilities, how it might impact on carers' hopes and dreams for the future. This caused a great deal of distress about the uncertainties of care, especially in the context of having no one else to care for the child:

> "Mothers were concerned about future caregiving responsibilities, since they did not use formal or informal networks:
> She's getting bigger and bigger, sometimes I just keep thinking "what is going to happen to her?" I lay awake at night thinking, it's very difficult" (Heer et al., 2015)

Moreover, some parents worried about the long-term care of their child in the context of any future ill health or in the event of their death. In the context of collectivistic cultures, parents may not want to leave their children with care homes or in the care of strangers. However, other family members may not be willing to care for the child, which was a very real fear for parents:

> "After we are gone, how will Kiran be looked-after? There will be a time when I cannot do this anymore, so who will do it?" (Rizvi, 2017)

4. *Cultural understandings of disability*

For some cultural communities, neurodevelopmental disorders were an entirely new concept. Thus, they tended to describe the concept in their own way. This also related to how disabilities were understood in different cultures and the stigma and judgement that may underlie some of these meanings. As neurodevelopmental conditions may be hidden, a lot of carers faced difficulty in helping others in the community understand how their children functioned:

> "That's the problem with autism, you don't see it [...] people want to see a disability that's why, in my country in Africa they see someone in a wheelchair, that's disability, you cannot convince them that this person is able, this person can work [...] if they don't see it, this person is mad." (Munroe et al., 2016)

Often, language used to describe people with disabilities focused on their deficits and what they could or couldn't do compared to others. It also put them into categories to group people based on visible impairments:

> “Participants relayed how non- technical “everyday” language is used, based on descriptions of impairments and perceptions of what people are not able to do:
>
> A little simple minded ... don’t have much understanding, that’s all...she’s much better than her Mum” (Durling et al., 2018)

Refutational translations for theme 1

1. *Fear of rejection from community*

Parents might find it difficult to share their child’s diagnosis with the community (family, friends and society) for fear of their child or themselves being rejected or judged by others. This might be especially present in collectivistic cultures as the sense of community might be very strong and what other people might think matters greatly. It could be related to a lot of stigma and judgement in the community about the diagnosis but also to a lack of understanding about the diagnosis in the parents’ cultures. Therefore, some parents might be hesitant to take the child to family gatherings:

> “I tend to either arrange to go to a family wedding, this is being truthful this, either when he’s in respite care or the lady care worker takes him. I’m quite confident to take him round [shopping centre] I’m quite confident to take him to the park, the shops. When it’s an Asian family or a wedding or where’s there’s all Asian people I tend to, I never tend to take him.” (Croot et al., 2012)

This fear might be underpinned by previous experiences of being shamed by other members of the society and not wanting their child to face the stigma. They might also want to protect the child from others' judgements, having faced it themselves:

> "Zalaikha hides the diagnosis out of fear for her son being stigmatised:
> I don't want him to be labelled, you know like a story that's going around" (Akbar and Woods, 2020)

1. *Refutation: Rejection of societal/cultural norms or standards*

While some parents might fear being rejected and adhere to societal norms, others might reject the communities' norms, rejecting 'perfectionism' and risk being ostracized from their families, standing by what they believe to be right and what is good for their child. This created feelings of joy at raising their child the way they were and not feeling embarrassed about their child's additional needs:

> "Despite parents' reports of rejection and discrimination, several participants emphasised that they were not ashamed of their child:
> I'm not the kind of person who hides my child and I'm not afraid; I'm not ashamed that my son has autism ... I don't care what other people think" (Ellen Selman et al., 2018)

On one hand, this may have created a loss of their original cultural identity, but on the other hand they were creating a new identity in a country away from their home country. This process seemed to offer some strength to them and give them courage to move toward what felt right for their child and themselves:

> “The mentality here has really exposed me [...] that is why I don’t mix up with [African people] because my way of life is different from my country’s culture, whatever, I know I can say I dress like them, but most of the things they do, I can’t even bear it.” (Munroe et al., 2016)

> “It’s all a load of rubbish what they say people. Like when somebody’s got mental problems like he’s been cursed, the devil’s [inaudible] her or whatever have you and it’s not, it’s because his brain’s not functioning properly.” (Croot et al., 2012)

There was also a sense of moving away from societal judgement and realising that some places that they thought were ‘safe’ for them to gain strength from like the church may be the source of their isolation. Thus, while some found it difficult to move away from importance of such places in their life, it also helped them gain peace by avoiding constant judgement and ridicule:

> “Church is the worst place and that came as a shock to me, for Afro-Caribbean families church is very important, and it’s always been an important part of my life, but to find out that church people are the most judgemental people I’ve come across because they want to be sanctimonious and they want to be holier than thou and they want to go to church and everything has to be perfect, not knowing that church is for people who need help. We stopped going and maybe pray at home [...] because it’s just soul destroying.” (Munroe et al., 2016)

Theme 2: Lack of support from professionals, family members and own community

Many carers experienced lack of support from schools and staff members in different forms. This might have been in the form of inconsistent information or a feeling like they were battling services, especially with less social support from families. There was a sense of feeling excluded from decision making processes for ethnic minority carers due to language barriers and lack of cultural understanding from staff. However, some carers also had positive experiences with support from families and communities and positive experiences with services.

Reciprocal translations for theme 2

1. *Lack of adequate information or inconsistent information*

Parents were often given conflicting advice or information by professionals regarding linguistic choices or regarding what the diagnosis meant. Due to this inconsistency, there was a lack of trust in professionals' advice and anger about the little help they had received. Parents and families felt left out and uninformed and therefore felt frustrated, especially when their life was affected by the lack of knowledge. There was also a feeling of helplessness at not knowing what to do for their child, how to improve their lives:

> "For one mother, not being able to understand the diagnosis and not being given thorough explanations, led to an underestimation of the severity of the disability, as if it were something that would pass over time:

> "Nobody has told mum what to do or how to improve her [daughter with

> disabilities'] behaviour, explained it to her in mum's language and helped her understand. There are lots of things they could do which haven't been done. It's wrong isn't it, because nobody has ever tried to personally help mum. It's her life that's being affected, more than any of us [other daughters]. Nobody has ever tried to build that up with her, tried to speak to her in her language and then kind of try to tell her this is how it's done, I don't know." (Hatton et al., 2010)

This was also embedded in wider systemic factors such as the power that professionals and staff held in terms of the knowledge they had and the help they could offer. Contextual factors such as limited and overworked staff often directly affected their working relationships with parents. Hence, it led to conflicts between staff and parents, with parents ending up in a worse position that caused more anxiety:

> "…are professionals and sooner or later they do have the upper hand…I just keep ringing them every day, they don't even get back to me and half of the staff are rude" (Akbar and Woods, 2020)

Refutational translations for theme 2

1. *Loss of familial support*

This concept sat in the wider context of immigration from another the country and the impact that can have on family support systems; how it challenges families and leaves them feeling isolated. There was a sense of loss for what could have been support from family members back home, loss of a community and everyone coming together to care for the child. Parents also felt lost and lonely when dealing with challenging caregiving on their own:

> "I did not know that many people, and it is not like I can call my mum, or my sister to go and get him. They were back home" (Marku, 2022)

The same cultural community in the UK might be less understanding of the difficulties the family and child face than the community in their home country. This could also bring along with it a sense of rejection from one's own community and a feeling of hopelessness about getting back what they lost:

> "Many of the mothers felt they would have increased support had they remained in Africa, because their close family would have been more tolerant of their child's difficulties com- pared with the African communities in the United Kingdom. This suggests that the social isolation intensifying this difficult balancing act was a product of migration:
>
> They help a lot when I go home [Uganda], because I get a rest as well, I can go and visit friends because they will look after him. So it's not like here, like two of us all the time." (Munroe et al., 2016)

2. *Refutation: Positive experiences with families and communities*

Contrary to facing stigma and judgement from the community, some carers had positive experiences of acceptance by other families. Partly, this might have been more applicable to carers who had access to support groups in their community and extended family who lived in the same country:

> “If we do need help we normally ask family. They are all willing” (Croot et al., 2012)

> “Other immigrant parents also experienced positives of integrating into their own community in the UK and finding common ground and support. There was a sense of having found their own niche in a foreign country, which made them feel less isolated:
> I met other Somali families that I can speak my own language with, who have children same as mine ... I felt comfortable when I came back, and relieved by talking to all these families. There was an interpreter and it was explained ... I’ve learnt quite a number of things that we didn’t know before.” (Ellen Selman et al., 2018)

3. *Battling with schools, professionals and services*

A lot of carers faced a struggle between what they and professionals thought was right. This then bred unhappiness with the way the system is and nothing was being done to help them. Ethnic minority carers might also often be excluded from important decision- making processes and from disclosure of diagnosis. At times there could be inconsistent or very little information given to parents because of this exclusion. This could possibly be due to preconceptions of the limits of their understanding, which is underpinned by the wider context of lack of culturally sensitive services and little tailoring of advice:

> "This is culturally different in our country you know, we lie down with our children at night time for many years (to help them to sleep), but the speech and language therapist actually you know, she couldn't get this, she just started saying I do this and I do that." (Habib et al., 2017)

Ethnic carers were also more likely to be excluded due to difficulties with communication with family members. They often felt unheard, overseen and unvalued by school staff. This increased frustration with staff and services:

> "Family carers from minority ethnic communities were more likely to report negative experiences of service support, which was compounded by all minority ethnic families reporting that services did not communicate with family carers:
>
> My mum had no knowledge, she had no awareness and at that point we were overlooked" (Akbar and Woods, 2020)

4. *Refutation: Positive experiences with schools, professionals and services*

While some parents had negative experiences with services, others had positive experiences of working with professionals and accessing support. There was a sense of acceptance of the reality of the disability when making placement decisions and seeing that their children would be safe and happy at school:

> "There are more facilities, the teachers know what specialist attention Sehr needed . . . so the school was right for her. . . they let her learn at her own pace." (Rizvi, 2017)

However, considering wider social circumstances, some carers were at an advantage as both they and their spouses spoke English and worked with the National Healthcare Service (NHS), which might have made access to services easier, especially carers in Habib et al.'s (2017) study. Living in an area of higher socioeconomic status also impacted some of these experiences, as that meant availability of better schools. Moreover, carers' own resilience and perception of services impacted how they felt about the support received:

> "Respite services do help, they calm them [three children with disabilities] down and help them change their mood. But N is always happy there so I can't complain. She seems very happy there, they take her out to movies or something and help her mood so I do think they are very helpful... Respite is always so helpful, every time." (Hatton et al., 2010)

Theme 3: Barriers to advocacy

This concept represents the barriers that carers faced when trying to access better care of advocate for their child's needs, such as language and communication with the schools and professionals. Often these barriers created distress and affected carers' mental wellbeing as they stopped carers from doing the best for their child and accessing support.

Reciprocal translations for theme 3

1. *Distress about helping the child*

Carers experienced a sense of hopelessness and helplessness around supporting their children leading to distress and sadness. This was also linked to anxiety about the future and fears about advocating for the child as they grow. In addition to these feelings, caring for the child itself brought about immense exhaustion and feeling overwhelmed. Some carers felt lost on how to help their child and what to do to ease their distress:

> “I just keep stressing and worrying about how to help my daughter . . . It breaks my heart when I see her sad and do not know what to do.” (Marku, 2022)

> “It’s very difficult to have a child who’s got special needs, because ummm, they need 24 hour attention ... they need your input all the time, I’m exhausted.” (Munroe et al., 2016)

2. *Language as preventing support*

For most studies there was a heavy emphasis on communication barriers as catalysts for parents feeling like they lacked power, were unsupported and felt rejected by schools and the systems. Speaking English and having knowledge of the young person’s rights were seen as keys to accessing better support and advocacy.

This also reflected the lack of culturally supportive systems and how powerless carers can at times feel due to this. Thus, it often led to carers not being heard and informed about decisions, which in turn affected how well they could advocate for their child:

> “I was still learning English . . . I did not know what they were saying, what they wanted me to do. He was in school, and I was at home. I used to say to school to call my husband” (Marku, 2022)

> “Three Urdu and Punjabi-speaking parents’ voices were not sought during the SEND process with some parents unaware that their children actually had an EHCP.” (Akbar and Woods, 2020)

Theme 4: Cultural Coping

Almost all studies reflected a sense of coping through holding strong cultural and religious beliefs, which provided carers strength and increased resilience. There was a strong reliance on faith and leaning on the universe to give them answers when there seemed to be no way out. Many carers also saw faith and God as someone who had provided them with a ‘special’ child and that perhaps it was a test for them to cope with.

Reciprocal translations for theme 4

1. *Cures in the wider sociocultural context*

Due to feeling overlooked and unable to access proper support for their child and the distress that might come with it, carers might look to faith and religion for cures and answers. This might also represent a sense of mistrust in Western practices. A large part of this practice of seeking cures from religious leaders or turning to traditional practices is also embedded in the wider social context of emigration and cultural norms.

> "Mabinti appeared to draw upon cultural beliefs more so than the other mothers; perhaps because she had migrated most recently and had lived in Africa with Adam. She described the belief in a curse and sent money to Africa for 'sacrifices' to stop it:
>
> Your husband's family, they did not want you to have a child, then they sent something on you when you were pregnant [...] I sent money, £100, then they prayed and they give charity out ... after that he started talking" (Munroe et al., 2016)

Indeed, carers might also feel some peer pressure from the community to uphold traditional cures. Underlying these cures might be feelings of shame, stigma and denial of the diagnosis, but also belief in a higher power and a sense of hope.

> "I have taken her back to Pakistan to all these holy temples and things.
>
> This may have been a reflection on parents' understanding of the cause of disability, the severity of disability, negative experiences of relevant services and the hope for a cure these sources offered" (Croot et al., 2012)

2. *Faith as a coping mechanism*

To deal with the feelings of distress from the diagnosis and the hardships carers go through, they might attribute the cause of the disability to religion. This might be seen as a positive coping mechanism, which facilitated acceptance and helping carers move away from questioning why they might have been 'given' a child with additional needs. Therefore, there was an idea that there must be a reason behind everything, which gave carers strength. However, this protective factor was embedded in the wider cultural norms and might reflect some pressure from the community to conform to it.

> "Oh I am a special person, Allah chose me to give me a special kid. Anybody can raise up a bright kid" (Akbar and Woods, 2020)

> "Allah's way...all the will of Allah" (Durling et al., 2018)

Model of Context

In this section, a systemic model of the underlying factors influencing these concepts will be presented. This represents the outcome of the synthesis in different layers of context and meaning that influence the experiences of ethnic minority carers. All the studies described underlying concepts such as immigration, cultural norms, and stigma and judgement that shaped the unique experiences of carers. Thus, the model below was derived from those underlying concepts and grounded in the first and second order constructs.
However, the application of this model might be limited to the experiences of ethnic minority carers in the UK and may not resemble other carers' experiences.

The model allows for the appreciation of wider systemic factors that play upon the experiences of ethnic minority and immigrant carers. The outermost layer, ‘immigration’ represents the political and socio-economic contexts of how carers might move to another country in search of better facilities for their child and how their experiences might be compounded by this migration. Thus, immigration makes up the largest and widest systemic factor in the model. The second layer, cultural and religious norms, are more subjective to each ethnic group and my differ based on which country carers have been living in, for how long and the size of the religious community they have affiliations with. Nevertheless, after immigration, social and cultural norms often dictated how much faith carers had, how much stigma they experienced and how much support they found in the community. Thus, the next layer of stigma and judgement was directly related to cultural norms and indirectly related to immigration. However, all these underlying factors seemed to make up the unique experience of carers, including how supported they felt, how accepted they felt with their child in the community and the amount of distress they experienced.

The concept of the layers in this model was influenced by Bronfenbrenner’s Ecological Systems Theory (EST). It represents how individuals interact with the social, political and cultural systems around them, how these systems affect individuals and how individuals in turn affect the systems. Thus, EST posits that for any individual, several layers shape their experiences (Figure 1.4), starting with the innermost layer ‘the individual layer’, which might include close personal factors such as age, gender and health. The second layer (the ‘microsystem’) includes the individual’s immediate environment such as friends, family, school and work while the third layer (‘mesosystem’) includes the individual’s interactions with local communities, religious organisations and other socio-cultural groups. The fourth layer (‘exosystem’) may involve wider factors such as mass media and television programs that influence individuals’ perspectives and the fifth layer (‘macrosystem’) represents political, national and socio-economic factors impacting individuals. All these systems interact with each other to shape how individuals perceive their world and themselves. Therefore, in the context of the model below (Figure 1.5), the 'immigration' layer may represent the 'macrosystem', while 'cultural and religious norms' and 'stigma and judgement' may represent the meso and exosystems. The arrows between layers indicate how they might interact with each other. For example, while all the layers may influence the individual's experiences and vice versa, stigma and judgement may also heavily influence cultural norms and immigration and vice versa.

Figure 1.4

Ecological Systems Theory

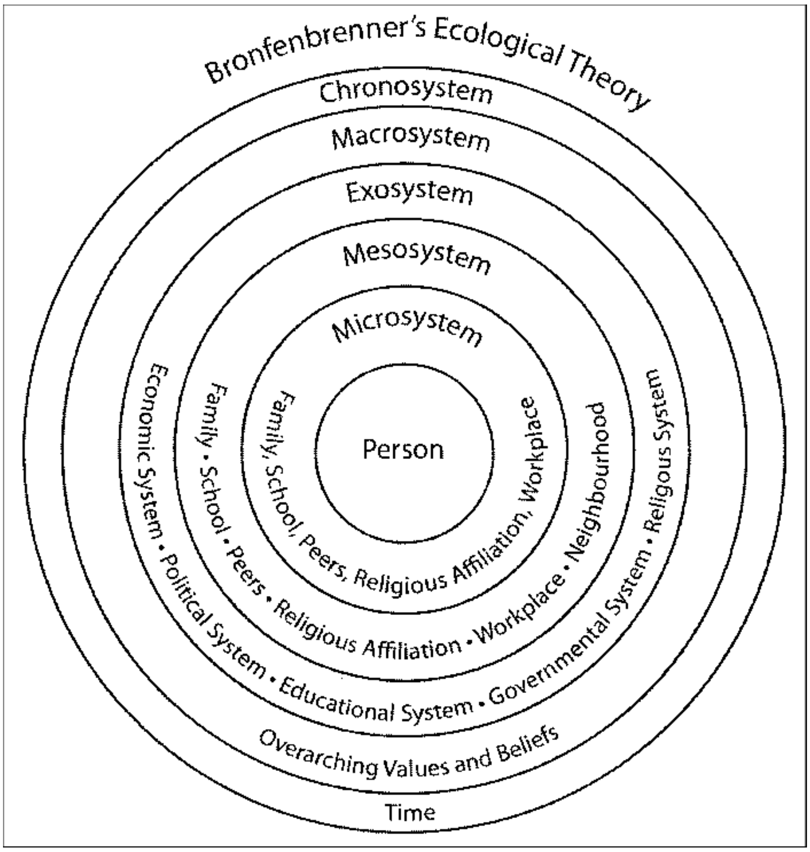
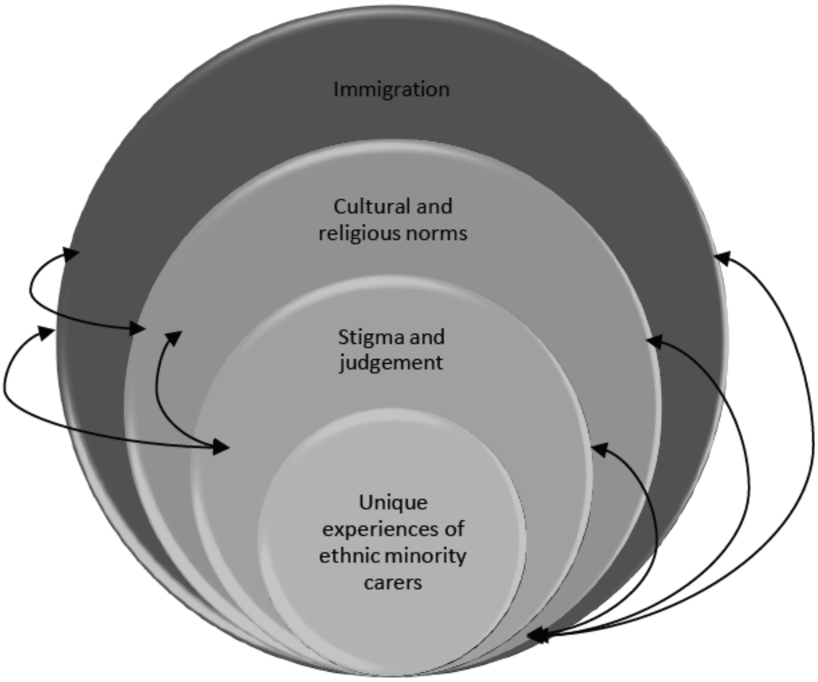


Figure 1.5

Model of context



This model helps answer the review question about the experiences of ethnic minority carers while sitting in the epistemological position of contextualism. It has applications for the services and professionals working with ethnic carers, which will be discussed in more detail later.

1.5 Discussion

This meta-ethnography explored the experiences of carers from ethnic minorities in the UK in caring for a young person with special needs. Following Noblit and Hare's (1988) methods, this review synthesised ten studies and presented four main third order concepts as themes. These were: (1) understanding the diagnosis and its social and cultural implications, (2) lack of support from professionals, family members and own community, (3) barriers to advocacy, (4) cultural coping.

The first theme represented a struggle for carers to understand and accept the diagnosis. Parental feelings of hopelessness, distress, guilt and sadness over the loss of a typically developing child were reflected in other studies as well (Ooi et al., 2016; Shorey et al., 2020). The second theme highlighted the battle that parents might experience with professionals and schools to get some support. This also corresponded with the findings of another review (Griffith & Hastings, 2014), however they included studies with a mix of ethnicities, not just ethnic minorities. This could mean that the experience of feeling unsupported by special needs education professionals is experienced universally by carers from all ethnicities. Nevertheless, for ethnic carers language barriers might pose as additional significant challenges, especially in the context of emigrating to a new country and learning to adapt to a new culture. This might leave carers feeling powerless and helpless about accessing support for their child. This was also reflected in the third concept of barriers to advocate for their child and led to feelings of distress and sadness. On the other hand, there were positive accounts of the experiences with communities and professionals, however factors such as location of the study, sample selection and education level must be taken into consideration. For instance, in Habib et al.'s (2017) study, the sample of carers were highly educated (undergraduate and postgraduate level) and their spouses were mainly medical professionals.

All the studies in this review were conducted in the last decade and highlight mainly negative experiences with special needs schools for ethnic carers. In 2014, the UK government published a code of practice for special education needs schools, which highlighted the need for schools to collaborate with parents and stated that ‘it is necessary to consider the young person within the context of their home, culture and community’ (Department for Education, 2014, pp. 61). It also highlighted that additional attention needed to be given for families whose first language was not English. However, from this review it seems that very few schools might be providing this support for families. This might be due to the high levels of burnout teachers and staff working in special education settings face (Brittle, 2020).

To cope with the diagnosis and multiple demands on their time, carers may use culture and religion. Cultural norms and religious attributions were factors that shaped perceptions of the child’s additional needs and appeared to be protective in the face of distress and stigma. This was also found by other reviews in the US (Emmanuel et al., 2022) and Africa (Mkabile et al., 2021). In contrast, in reviews focused on White carers, culture and religion was rarely discussed, either as a coping strategy or in the context of its influence on perceptions (Superdock et al., 2018). Thus, wider social constructs such as cultural norms, religion and stigma in the communities may heavily influence the experiences of ethnic minority carers. Immigration also impacted these differences between minority and White ethnic carers. For instance, in the current review, majority participants in the studies had emigrated from other countries into a foreign country and adjusting to new customs and ways of living underpinned how they perceived diagnoses, support from services, finding support in the community and adjusting to new school systems. Taken together, these could have implications for best practice in support provided by professionals, which are discussed in the next few paragraphs.

Limitations

Apart from the limitations of the researcher's insider perspective, there may have been limitations to the searching process. Although the search was done with some supervision from another researcher in line with the inclusion criteria, some studies may have been missed that used a diverse population but did not state what percentage of those were ethnic minority carers. Similarly, some studies may have mentioned caregiver stress in the form of opinions about medication, which were not included. However, such studies would not have provided rich data about caregiving experiences. Nevertheless, the systematic nature of the study selection allowed for a thorough search of the databases and literature.

Additionally, the review was limited by the small number of studies that met the eligibility criteria and therefore judgements about its transferability to other studies could not be made. The majority of ethnic minority groups were South Asian and it would be difficult to say if their interpretations of caregiving and their experiences would apply to other minorities. Nevertheless, there may be some connections between carers' experiences in general, as even previous research in majority of Caucasian carers found similar experiences of lack of support from services, difficulty accepting diagnosis and mental health difficulties (Corcoran et al., 2015).

Moreover, a lot of the experiences focused on the negatives and barriers to accessing support. Only one study mentioned significant themes around positive experiences (Habib et al., 2017) however that study consisted of carers who were more financially affluent and were spouses of healthcare workers, which could have influenced the number of positives they experienced. It was noted that all studies in the review had included participants based on purposeful selection of people who attended organizations and groups for carers of people with neurodevelopmental difficulties. This might also introduce some selection bias as only carers who face considerable difficulties might want to share their experiences and go to support groups. There may be many more positive experiences of caregiving however these may often be in the form of quantitative studies (Beighton & Wills, 2019), and thus would be excluded.

Another limitation was that it was not possible to include many researchers in the search, study selection and translation processes due to time constraints. This could have led to biases in the translation of studies and third order concepts. Nevertheless, care was taken by the researcher to preserve the context of the studies by paying attention to the gender, location and other socioeconomic factors mentioned in studies. However, some studies did not mention many contextual factors, which made it difficult at times to be mindful of the context.

Moreover, meta-ethnographies in general have been criticized for being less structured and without appropriate guidelines about their method (France et al., 2014). Although the eMERGE guidelines were used to guide reporting, these guidelines did not mention specific ways of conducting the meta-ethnography. There were no other articles that specified the methods. This lack of guidance could lead the process of translation and synthesis open to interpretation and risk further biases in the reporting of the results. This review consulted other papers such as Cahill et al. (2017) and Sattar et al. (2021) that provided some guidance on the method, however these were inconsistent, and it proved difficult to navigate.

Clinical Implications and Future Research

Based on the model of context explained earlier, there are several applications for how ethnic carers are viewed and understood. Particularly, professionals working with families and people with neurodevelopmental difficulties should be aware of the barriers that ethnic minority carers deal with when seeking help, especially language barriers, and should provide interpreters or people from the carers' community to help bridge the gap between understanding their specific difficulties and the cultural context. Understanding the wider contexts such as immigration and stigma might also help professionals empathize with caregivers, and provide safe spaces to discuss the impacts of these contexts. Understanding systemic factors influencing caregivers' needs can also help services spread awareness about them and help other professionals recognize them as well. Most carers reported not being involved in decision making and having difficulty reaching school staff when required. Making sure that staff are reachable and approachable and coordinating with caregivers at every step would help carers feel more supported.

Indeed, many policies outlined by the Challenging Behaviour Foundation (2019) and NICE guidance on assessment and interventions for young people with developmental disabilities (NICE, 2018) put an emphasis on working in collaboration with carers and service users. However, as evidenced by studies in this review, that has not always been possible. Nevertheless, this will need to change in the future if ethnic minority carers are to be offered more support. Services, schools and professionals could therefore collaborate with charity organisations, support groups and religious groups as well when working with ethnic minority carers to better understand and fulfil their needs.

Almost all studies reported barriers and distress experienced by caregivers, but only a few mentioned positive aspects of caregiving. There was also little focus on what might help foster resilience and coping strategies in carers. Thus, it was difficult to identify whether the limited coping strategies mentioned had an overall positive impact on their well-being. Future research should therefore concentrate on the positive aspects of caregiving for ethnic minority carers and how that might influence their overall well-being and resilience.

Conclusion

This meta-ethnography demonstrated the influence of contextual factors on carers' experiences of caregiving for a child with developmental difficulties. It also highlighted the lack of further research into ethnic carers' experiences, especially considering the additional challenges they may face in accessing support compared to White ethnic majority carers in the UK. Therefore, the evidence and factors mentioned in this review called for increased awareness and consideration of minority carers' unique experiences by services and others in the community in order to lessen the barriers they face and provide equal access for everyone.

1.6 References

Akbar, S., & Woods, K. (2019). The experiences of minority ethnic heritage parents having a child with SEND: a systematic literature review. *British Journal of Special Education*, *46*(3), 292-316. https://doi.org/10.1111/1467-8578.12272

Akbar, S., & Woods, K. (2020). Understanding Pakistani parents' experience of having a child with special educational needs and disability (SEND) in England. *European Journal of Special Needs Education*, *35*(5), 663–678. https://doi.org/10.1080/08856257.2020.1748428

Alsharaydeh, E. A., Alqudah, M., Lee, R. L. T., & Chan, S. W.-C. (2019). Challenges, Coping, and Resilience Among Immigrant Parents Caring for a Child With a Disability: An Integrative Review. *Journal of Nursing Scholarship*, *51*(6), 670– 679. https://doi.org/10.1111/jnu.12522

Atkins, S., Lewin, S., Smith, H., Engel, M., Fretheim, A., & Volmink, J. (2008). Conducting a meta-ethnography of qualitative literature: Lessons learnt. *BMC Medical Research Methodology*, *8*(1), 21. https://doi.org/10.1186/1471-2288-8-21

Azeem, M. W., Dogar, I. A., Shah, S., Cheema, M. A., Asmat, A., Akbar, M., Kousar, S., & Haider, I. I. (2013). Anxiety and Depression among Parents of Children with Intellectual Disability in Pakistan. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, *22*(4), 290–295.

Beighton, C., & Wills, J. (2019). How parents describe the positive aspects of parenting their child who has intellectual disabilities: A systematic review and narrative synthesis. *Journal of Applied Research in Intellectual Disabilities*, *32*(5), 1255- 1279. https://doi.org/10.1111/jar.12617

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Brittle, B. (2020). Coping strategies and burnout in staff working with students with special educational needs and disabilities. *Teaching and Teacher Education*, *87*, 102937. https://doi.org/10.1016/j.tate.2019.102937

Campbell, R., Pound, P., Morgan, M., Daker-White, G., Britten, N., Pill, R., Yardley, L., Pope, C., & Donovan, J. (2012). *Evaluating meta ethnography: Systematic analysis and synthesis of qualitative research*. https://doi.org/10.3310/hta15430

Carver, H., Ring, N., Miler, J., & Parkes, T. (2020). What constitutes effective problematic substance use treatment from the perspective of people who are homeless? A systematic review and meta-ethnography. *Harm reduction journal*, *17*(1), 1-22. https://doi.org/10.1186/s12954-020-0356-9

Challenging Behaviour Foundation. (2019). *Policy and best practice*. Challenging Behaviour Foundation. https://www.challengingbehaviour.org.uk/what-we-do/sharing-best-practice/policy-and-best-practice/

Chiarotti, F., & Venerosi, A. (2020). Epidemiology of Autism Spectrum Disorders: A Review of Worldwide Prevalence Estimates Since 2014. *Brain Sciences*, *10*(5), Article 5. https://doi.org/10.3390/brainsci10050274

Cooper, S., Schmidt, B. M., Sambala, E. Z., Swartz, A., Colvin, C. J., Leon, N., & Wiysonge, C. S. (2021). Factors that influence parents' and informal caregivers' views and practices regarding routine childhood vaccination: a qualitative evidence synthesis. *Cochrane Database of Systematic Reviews*, (10). https://doi.org/10.1002/14651858.cd013265.pub2

Corcoran, J., Berry, A., & Hill, S. (2015). The lived experience of US parents of children with autism spectrum disorders: A systematic review and meta-synthesis. *Journal of Intellectual Disabilities*, *19*(4), 356–366. https://doi.org/10.1177/1744629515577876

Croot, E., Grant, G., Mathers, N., & Cooper, C. (2012). Coping strategies used by Pakistani parents living in the United Kingdom and caring for a severely disabled child. *Disability and Rehabilitation*, *34*(18), 1540–1549. https://doi.org/10.3109/09638288.2011.650310

DeLambo, D., Chung, W., & Huang, W. (2011). Stress and age: A comparison of Asian American and non-Asian American parents of children with developmental disabilities. *Journal of Developmental and Physical Disabilities*, *23*(2), 129-141. https://doi.org/10.1007/s10882-010-9211-3

Department for Education. (2014, June 11). *SEND code of practice: 0 to 25 years*. GOV.UK. https://www.gov.uk/government/publications/send-code-of-practice-0-to-25

Durling, E., Chinn, D., & Scior, K. (2018). Family and community in the lives of UK Bangladeshi parents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *31*(6), 1133–1143. https://doi.org/10.1111/jar.12473

Ellen Selman, L., Fox, F., Aabe, N., Turner, K., Rai, D., & Redwood, S. (2018). 'You are labelled by your children's disability' – A community-based, participatory study of stigma among Somali parents of children with autism living in the United Kingdom. *Ethnicity & Health*, *23*(7), 781–796. https://doi.org/10.1080/13557858.2017.1294663

Elsabbagh, M., Divan, G., Koh, Y.-J., Kim, Y. S., Kauchali, S., Marcín, C., Montiel-Nava, C., Patel, V., Paula, C. S., Wang, C., Yasamy, M. T., & Fombonne, E. (2012). Global Prevalence of Autism and Other Pervasive Developmental Disorders. *Autism Research*, *5*(3), 160–179. https://doi.org/10.1002/aur.239

Emmanuel, C. J., Knafl, K. A., Hodges, E. A., Docherty, S. L., O'Shea, T. M., & Santos Jr., H. P. (2022). Family members' experience of well-being as racial/ethnic minorities raising a child with a neurodevelopmental disorder: A qualitative meta-synthesis. Research in Nursing &

Health, 45(3), 314–326. https://doi.org/10.1002/nur.22217

Estes, A., Olson, E., Sullivan, K., Greenson, J., Winter, J., Dawson, G., & Munson, J. (2013). Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. *Brain and Development*, *35*(2), 133–138. https://doi.org/10.1016/j.braindev.2012.10.004

Finfgeld-Connett, D., & Johnson, E. D. (2013). Literature search strategies for conducting knowledge-building and theory-generating qualitative systematic reviews. *Journal of Advanced Nursing*, *69*(1), 194–204. https://doi.org/10.1111/j.1365-2648.2012.06037.x

France, E. F., Ring, N., Thomas, R., Noyes, J., Maxwell, M., & Jepson, R. (2014). A methodological systematic review of what's wrong with meta-ethnography reporting. *BMC medical research methodology*, *14*(1), 1-16. https://doi.org/10.1186/1471-2288-14-119

France, E. F., Cunningham, M., Ring, N., Uny, I., Duncan, E. A., Jepson, R. G., ... & Noyes, J. (2019). Improving reporting of meta-ethnography: the eMERGe reporting guidance. *BMC medical research methodology*, *19*(1), 1-13. https://doi.org/10.1002/pon.4915

Gallagher, S., & Whiteley, J. (2013). The association between stress and physical health in parents caring for children with intellectual disabilities is moderated by children's challenging behaviours. *Journal of Health Psychology*, *18*(9), 1220–1231. https://doi.org/10.1177/1359105312464672

Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science & Medicine*, *64*(1), 150–163. https://doi.org/10.1016/j.socscimed.2006.08.025

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. https://doi.org/10.1111/jar.12073

Habib, S., Prendeville, P., Abdussabur, A., & Kinsella, W. (2017). Pakistani mothers' experiences of parenting a child with autism spectrum disorder (ASD) in Ireland. *Educational and Child Psychology*, *34*, 67–79. https://doi.org/10.53841/bpsecp.2017.34.2.67

Hatton, C., Emerson, E., Kirby, S., Kotwal, H., Baines, S., Hutchinson, C., Dobson, C., & Marks, B. (2010). Majority and Minority Ethnic Family Carers of Adults with Intellectual Disabilities: Perceptions of Challenging Behaviour and Family Impact. *Journal of Applied Research in Intellectual Disabilities*, *23*(1), 63–74. https://doi.org/10.1111/j.1468-3148.2009.00544.x

Heer, K., Larkin, M., & Rose, J. (2015). The experiences of British South Asian carers caring for a child with developmental disabilities in the UK. *Tizard Learning Disability Review*, *20*(4), 228–238. https://doi.org/10.1108/tldr-12-2014-0044

Huang, M., & Zhou, Z. (2022). Factors contributing to parental stress among Chinese families of children with autism: A qualitative study. *Psychology in the Schools*, 1– 18. https://doi.org/10.1002/pits.22837

Iadarola, S., Pérez-Ramos, J., Smith, T., & Dozier, A. (2019). Understanding stress in parents of children with autism spectrum disorder: A focus on under-represented families. *International Journal of Developmental Disabilities*, *65*(1), 20–30. https://doi.org/10.1080/20473869.2017.1347228

J. Marsh, A. (2019). Special education trends and variations from the United States and United Kingdom (England), 1984 to 2014. *International Journal of School & Educational Psychology*, *7*(4), 229-239. https://doi.org/10.1080/21683603.2018.1429335

Jegatheesan, B., Fowler, S., & Miller, P. J. (2010). From symptom recognition to services: How South Asian Muslim immigrant families navigate autism. *Disability & Society*, *25*(7), 797–

811. https://doi.org/10.1080/09687599.2010.520894

Lach, L. M., Kohen, D. E., Garner, R. E., Brehaut, J. C., Miller, A. R., Klassen, A. F., & Rosenbaum, P. L. (2009). The health and psychosocial functioning of caregivers of children with neurodevelopmental disorders. *Disability and Rehabilitation*, *31*(9), 741–752. https://doi.org/10.1080/08916930802354948

Lambrias, A., Ervin, J., Taouk, Y., & King, T. (2023). A systematic review comparing cardiovascular disease among informal carers and non-carers. *International Journal of Cardiology Cardiovascular Risk and Prevention*, *16*, 200174. https://doi.org/10.1016/j.ijcrp.2023.200174

Lyons, E., & Coyle, A. (2011). *Analysing Qualitative Data in Psychology*. SAGE Publications Ltd. Maridal, H. K., Bjørgaas, H. M., Hagen, K., Jonsbu, E., Mahat, P., Malakar, S., & Dørheim, S. (2021). Psychological Distress among Caregivers of Children with Neurodevelopmental Disorders in Nepal. *International Journal of Environmental Research and Public Health*, *18*(5), Article 5. https://doi.org/10.3390/ijerph18052460

Marku, B., Niolaki, G., Terzopoulos, A., & Wood, C. (2022). Eastern European parents’ experiences of parenting a child with SEN in England. *Educational Psychology in Practice*, *38*(3), 297–316. https://doi.org/10.1080/02667363.2022.2100320

Mbugua, M. N., Kuria, M. W., & Ndetei, D. M. (2011). The prevalence of depression among family caregivers of children with intellectual disability in a rural setting in Kenya. *International journal of family medicine*, 1-5. https://doi.org/10.1155/2011/534513

Mkabile, S., Garrun, K. L., Shelton, M., & Swartz, L. (2021). African families' and caregivers' experiences of raising a child with intellectual disability: A narrative synthesis of qualitative studies. *African Journal of Disability (Online)*, *10*, 1-10. https://doi.org/10.4102/ajod.v10i0.827

Munroe, K., Hammond, L., & Cole, S. (2016). The experiences of African immigrant mothers living in the United Kingdom with a child diagnosed with an autism spectrum disorder: An interpretive phenomenological analysis. *Disability & Society*, *31*(6), 798–819. https://doi.org/10.1080/09687599.2016.1200015

Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health and Development*, *33*(2), 180–187. https://doi.org/10.1111/j.1365-2214.2006.00644.x

NICE. (2012). Methods for the development of NICE public health guidance (third edition). *National Institute for Health and Care Excellence*.

NICE. (2018). Learning disabilities and behaviour that challenges: Service design and delivery. *Service Design and Delivery*.

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies* (Vol. 11). sage.

Oh, H., & Lee, E. O. (2009). Caregiver Burden and Social Support among Mothers Raising Children with Developmental Disabilities in South Korea. *International Journal of Disability, Development and Education*, *56*(2), 149–167. https://doi.org/10.1080/10349120902868624

Ooi, K. L., Ong, Y. S., Jacob, S. A., & Khan, T. M. (2016). A meta-synthesis on parenting a child with autism. *Neuropsychiatric Disease and Treatment*, *12*, 745–762. https://doi.org/10.2147/ndt.s100634

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., ... & Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *Systematic reviews*, *10*(1), 1-11. https://doi.org/10.31222/osf.io/v7gm2

Rizvi, S. (2017). Exploring British Pakistani mothers' perception of their child with disability: Insights from a UK context. *Journal of Research in Special Educational Needs*, *17*(2), 87–97. https://doi.org/10.1111/1471-3802.12111

Sadiki, T. G., & Mashegoane, S. (2019). Caring for children with an intellectual disability: An exploratory qualitative study. *Journal of Psychology in Africa*, *29*(2), 191–194. https://doi.org/10.1080/14330237.2019.1603020

Sattar, R., Lawton, R., Panagioti, M., & Johnson, J. (2021). Meta-ethnography in healthcare research: A guide to using a meta-ethnographic approach for literature synthesis. *BMC Health Services Research*, *21*(1), 50. https://doi.org/10.1186/s12913-020-06049-w

Scherer, N., Verhey, I., & Kuper, H. (2019). Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta- analysis. *PLOS ONE*, *14*(7),e0219888. https://doi.org/10.1371/journal.pone.0219888

Shahat, A. R. S., & Greco, G. (2021). The Economic Costs of Childhood Disability: A Literature Review. *International Journal of Environmental Research and Public Health*, *18*(7), Article 7. https://doi.org/10.3390/ijerph18073531

Shorey, S., Ng, E. D., Haugan, G., & Law, E. (2020). The parenting experiences and needs of Asian primary caregivers of children with autism: A meta-synthesis. *Autism*, *24*(3), 591–604. https://doi.org/10.1177/1362361319886513

Superdock, A. K., Barfield, R. C., Brandon, D. H., & Docherty, S. L. (2018). Exploring the vagueness of Religion & Spirituality in complex pediatric decision-making: a qualitative study. *BMC Palliative Care*, *17*(1), 1-14. https://doi.org/10.1186/s12904-018-0360-y

Toye, F., & Barker, K. L. (2020). A meta-ethnography to understand the experience of living with urinary incontinence: ‘is it just part and parcel of life?’. *BMC urology*, *20*(1), 1-25. https://doi.org/10.1186/s12894-019-0555-4

Wang, J., Hu, Y., Wang, Y., Qin, X., Xia, W., Sun, C., ... & Wang, J. (2013). Parenting stress in Chinese mothers of children with autism spectrum disorders. *Social psychiatry and psychiatric epidemiology*, *48*(4), 575-582. https://doi.org/10.1007/s00127-012-0569-7

Woodcock, K. A., & Blackwell, S. (2020). Psychological treatment strategies for challenging behaviours in neurodevelopmental disorders: what lies beyond a purely behavioural approach?. *Current opinion in psychiatry*, *33*(2), 92-109. https://doi.org/10.1097/yco.0000000000000571

Young, S., Shakespeare-Finch, J., & Obst, P. (2020). Raising a child with a disability: A one-year qualitative investigation of parent distress and personal growth. *Disability & Society*, *35*(4), 629–653. https://doi.org/10.1080/09687599.2019.1649637

Chapter 2. Empirical Research Paper

Exploring the Experiences of Carers for Young People with Emotional Outbursts in the UK: Insights from and Before the COVID-19 Pandemic

2.1 Abstract

Emotional outbursts are common types of unpredictable challenging behaviour displayed by young people, which include temper tantrums and meltdowns. These can lead to increased stress levels and mental health difficulties in caregivers. However, there is little research on the mental health of carers for young people with emotional outbursts before and during the COVID-19 pandemic in the UK. This study aimed at filling this gap and understanding the influence of wider contextual factors on caregivers. Semi-structured interviews were conducted via remote methods with nine carers of young people aged 5-20 years from the UK. Interviews were transcribed and analyzed with reflexive thematic analysis to identify patterns in the data. Three main themes (challenges with childcare and services: context-dependent; everything and everyone for the young person; surviving the good and bad) introduced the multiple challenges carers faced before and during the pandemic. This study highlighted that the pandemic had a big impact on carers' experiences and mental health and added to pre-existing problems. However, carers' experiences were also dependent on the contexts they were in and their own perceptions. Nevertheless, the findings have many implications for how policies and services can be improved to accommodate these experiences in the future.

2.2 Introduction

Background and Rationale

Challenging behaviours (CB) can be defined as injurious behaviours that affect the individuals themselves or others, such as hitting others, self-harm in the form of head-banging, eye-poking, etc., destruction of property, eating inedible objects, and are usually displayed by people with diagnoses of learning disabilities (LD) or autism spectrum disorder (ASD) (CB Foundation, 2022). Emotional outbursts (or temper outbursts) are one of the most common types of CBs. These refer to “highly emotional, explosive episodes” (Chung et al., 2022) characterized by patterns of CB. Chung et al. (2022) found that emotional outbursts (EO) in children may differ based on perceived safety of the setting and may be related to distinctions in sensory processes.

These EOs can often come on suddenly due to unforeseen triggers and be uncontrollable (Lipsky, 2011). They can also be of varying intensities, which can lead to carers being hyper aware of triggers in the environment and constantly preparing and pre-empting to avoid EOs. For instance, O’Nions et al. (2018) reported that carers had to apply preventative measures when managing EOs, such as continually monitoring and modifying the environment to maintain safety, trying to manage the child’s anxieties, and planning and analysing strategies. Thus, the unpredictability of EOs require large amounts of time and energy from carers, which can leave them exhausted and anxious. Interestingly, when the effect of EOs was accounted for, one study found that other symptoms of developmental difficulties such as cognitive delay did not add to parental stress (Baker et al., 2002). Nevertheless, another study reported that both severity of developmental disabilities and of

EOs contributed to parenting stress (Argumedes et al., 2018). This indicates that the amount of caregiving strain may be moderated by parents' perceptions of the severity of EOs and diagnosis.

Some studies have demonstrated that caring for a child with EOs and developmental difficulties can lead to increased stress levels and worse mental health outcomes than caring for typically developing children. Cadman et al. (2012) found that caregivers of children with ASD faced a larger strain due to the child's anxiety, inappropriate behaviour and multiple meltdowns, social relationships, and other mental health issues. In another study, parents were asked to track meltdowns and record their experiences. They reported that the unpredictable nature of meltdowns lead to immense anxiety, fear and helplessness in managing them (Montaque et al., 2018). It often left them feeling drained, especially while being hyper-vigilant of future meltdowns. These meltdowns were experienced as especially stigmatising in outdoor settings, with parents feeling judged and criticised, leading to self-doubt and self-criticism (Montaque et al., 2018). Thus, EOs and the child's mental health seemed to affect parental mental health more than just the severity of the child's developmental difficulties. However, little research has studied the specific effect of EOs on carers and further studies are required due to EOs' unpredictable and highly volatile nature that can leave carers with undue distress. For instance, there has been no research on the influence of EOs on carers in the COVID-19 pandemic and little research around how carers may cope with EOs.

Apart from EOs, wider systemic factors also can affect how caregivers experience distress. For instance, greater marital quality mediated parental stress and led to fewer depression symptoms among caregivers (Kersh et al., 2006). This might be facilitated through the availability of more support from the spouse and the shared burden of caregiving. Consequently, single mothers may face lower levels of social and family support (Bromley et al., 2004). Nevertheless, one main factor affecting carers has been access to services. Caregivers faced negative experiences in accessing support from professionals for their child and themselves (Jackson et al., 2020). This was also found by foster carers caring for children with CB, who reported wider systemic problems such as reduced access to and quality of services, poor communication with systems and professionals and lack of adequate financial support (Bergsund et al., 2020). Moreover, families caring for children with additional needs are often more financially disadvantaged than those without, which can put an additional economic strain on caregiving and increase carer stress. Poverty and stressful life events are also associated with greater caregiver mental health problems (Emerson, 2003).

Stressful life events, such as a pandemic could greatly impact the above-mentioned factors and thus indirectly influence caregiver mental health. In 2020, the COVID-19 pandemic was a significant event that had a negative effect on carers. The pandemic started in early 2020 and led to a series of lockdowns all over the world, which lasted till the middle of 2022. In these lockdowns there was little to no access to the outdoors and face-to-face interaction with others. A survey in the UK found that increases in psychological distress measured by the General Health Questionnaire were highest for carers for young people with additional needs continued to increase as the pandemic went on. In general, unpaid carers looking after young children were highly distressed however these increases were more marked in carers for people with disabilities who provided more hours of continuous care (Whitley et al., 2023). Similarly, another questionnaire study found that compared to carers of children without CB, carers of children and adults with it had higher levels of anxiety and depression.

However, these carers received less social support from friends, family and relatives, especially as CB increased (Willner et al., 2020).

Decrease in opportunities for self-care in the pandemic also led to increased caregiver burden (Iovino et al., 2021). Some qualitative studies investigated a more in-depth impact of the pandemic, highlighting themes such as feeling unappreciated, reduction in formal and informal support and emotional impact of the pandemic. For instance, Patel et al. (2021) found that carers caring for adults with additional needs experienced lack of control and powerlessness, along with hopelessness, confusion about guidelines and lack of support from services in the UK. Carers from the UK and Ireland experienced a lack of trust in services, fear of COVID-19, isolation and exhaustion related to caring (Linden et al., 2022).
They faced pressures such as feeling abandoned by others and fear of the pandemic, but also experienced positive outcomes such as less time pressures and resilience in coping (Rogers et al., 2021). Thus, the impact of the pandemic was multifaceted for carers—increase in psychological distress due to CBs and decrease in support from schools and services they would have had before the pandemic.

As mentioned earlier, although there was a reported increase in outbursts and meltdowns, only one qualitative study in the UK reported the impact of CBs in general in the pandemic (Rogers et al., 2021). However, while CBs included predictable reactions to triggers such as disruption of routines, this differed from the unpredictable and highly emotional states of emotional outbursts. Moreover, Rogers et al. (2021) did not specifically include questions about CB or EOs in their study and it was not their main aim. No other qualitative studies in the pandemic specifically focused on carers whose children had experienced EOs. Thus, the current qualitative study builds upon existing research by exploring the mental health of carers for young people with emotional outbursts before and in the context of the pandemic. It also adds depth to the quantitative research conducted in the pandemic by looking at carers' experiences in much more detail and by closely examining different contexts that might influence these experiences.

Research question and aims

What were the experiences of carers for young people with emotional outbursts before and during the COVID-19 pandemic?

Aims:

1. To explore the lived experiences of carers for young people with emotional outbursts.
2. To understand the influences of wider contextual factors (such as the pandemic) and different circumstances on the experiences of carers.

2.3 Methods

Participants

Nine carers of young people with emotional outbursts were interviewed between May and August 2022. These participants were recruited via purposive and snowball sampling and were above 18 years of age. More demographic information is presented in Table 2.1. Information about the child's diagnosis was not formally obtained as it was not vastly relevant to the aim of the study, however some parents chose to disclose this information in the interviews, which has been recorded with the demographic information. Inclusion criteria were defined according to research aims and sent out to organisations in the form of poster advertisements. These criteria stipulated that participants had to (1) be the primary (full-time) carer for a young person aged between 5-20 and (2) care for people who experienced emotional outbursts at least once a month. Those who volunteered for the study were asked if they knew of others who met the inclusion criteria and would be interested in participating.

Table 2.1

Demographic information

Participant ID	**Gender**	**Ethnicity**	**Child's difficulties**	**Child's gender**	**Relationship to child**	**Marital status**
Rowena	F	White British	ASD	M	Adoptive mother	Married
Mary	F	White British	ASD	M	Mother	Single
Julie	F	White British	Developmental trauma/ attachment difficulties	M	Adoptive parent	Single
Andrea	F	White British	ASD and ADHD	M	Foster carer	Married

Jane	F	White British	Attachment difficulties	M	Adoptive parent	Partnered
Hannah	F	White British	Unknown	M	Mother	Married
Tim	M	White British	ASD and LD	M	Father	Married
Ginny	F	White British	Unknown	F	Adoptive parent	Single
Cecelia	F	White British	LD	M	Foster carer	Single

Design

The qualitative study took place retrospectively as lockdowns were almost at an end at the time of the interviews. Semi-structured interviews were conducted via an online platform such as Zoom or Microsoft Teams or via telephone calls by the primary researcher between May and August 2022, depending on the participants' availability and convenience. The interviews lasted between 60-90 minutes and were conducted remotely for the convenience of the carers who were juggling multiple responsibilities and lived in various locations across the UK.

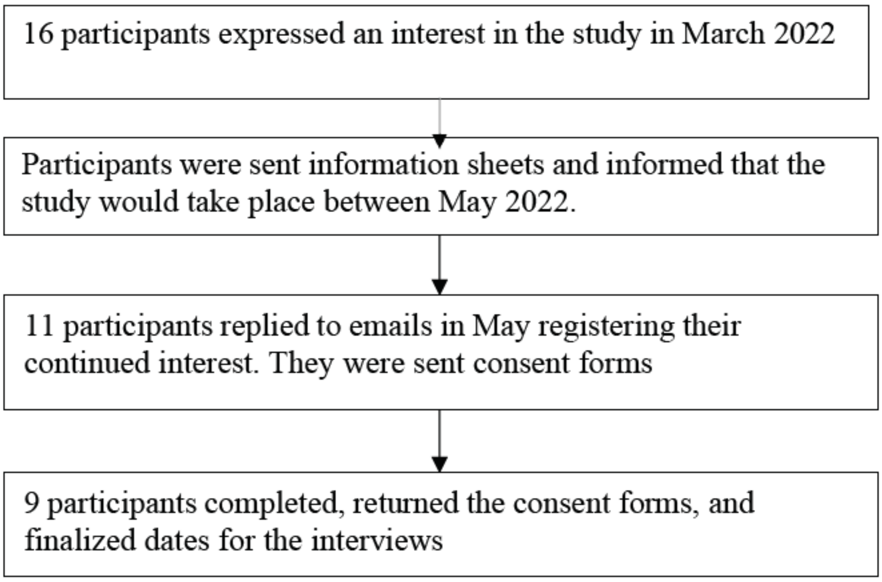
Procedure

Prior to gaining ethical approval, an interview schedule (Appendix F) was designed. This was adapted from Rogers et al.'s (2021) study and included questions around what it had been like to care for the child before the pandemic, challenges, increase in outbursts and any positives they found. The schedule was discussed with research assistants in the team to ensure coherence and well-roundedness of the questions.

After ethical approval was gained, charity organizations and support groups such as the Challenging Behaviour Foundation, National Autistic Society, Parenting Additional Needs were contacted via email and telephone, along with local schools known by the primary and secondary researchers on this project. Out of thirty organisations contacted, ten replied to ask for more information about the research, upon which the ethical approval letter (Appendix G) and research poster (Appendix H) were sent. The organisations then distributed the information amongst their members and support groups, from which participants could contact the researchers to volunteer for the project. Upon email contact with prospective participants, they were asked about the nature and frequency of EOs, and if their children were in the age range for this study to confirm agreement with inclusion criteria. A full breakdown of the number of participants who initially volunteered, and the final number of participants is presented in Figure 2.1.

Figure 2.1

Breakdown of participant recruitment



16 participants expressed an interest in the study in March 2022

Participants were sent information sheets and informed that the study would take place between May 2022.

11 participants replied to emails in May registering their continued interest. They were sent consent forms

9 participants completed, returned the consent forms, and finalized dates for the interviews

After dates and choice of audio platform were finalized with the participants, the interview schedule was practiced with research assistants to ensure that the questions targeted the research question accurately. Participant pseudonyms were also assigned to ensure anonymity. Four interviews were conducted via video platforms and five were conducted over the telephone, according to participant preferences. At the end of the interviews, each participant was sent a debrief form (Appendix I) and a £10 Amazon voucher to express gratitude for their participation. All the interviews were transcribed by the primary researcher into Word documents for analysis, without the use of any external software. Microsoft Word's audio to text dictation feature was used to transcribe parts of the interviews, after which interviews were run through again and the transcription was edited to ensure its accuracy.

Ethics

Ethical approval was obtained from the University of Birmingham Science, Technology, Engineering and Mathematics Ethical Review Committee prior to contacting organizations and participants. Consent forms (Appendix J) and information sheets (Appendix K) were sent out to participants via email before interviews were conducted, and debrief sheets were sent out after the interviews. Before the interviews, verbal consent was also taken to ensure participants were content with audio recordings. Participants were given opportunities to clarify any concerns before and after the interviews, and care was taken to ensure that ample breaks were given if required. During the interviews if participants encountered distress while recounting their experiences, the interview was paused and only started again once participants gave verbal consent to continue. It was also ensured that they were content with the nature of the questions and that these situations were handled with empathy and understanding. Lastly, all recordings and transcripts were stored on a secure University data storage facility that could be accessed by the researcher. These were transferred as soon as each interview was completed and erased from the password-protected laptop on which they were recorded.

Analysis

Braun and Clarke's (2019) reflexive thematic analysis (RTA) was used to analyse the interview transcripts. Within this approach, meaning making can be inductive (driven by the content of the data) or deductive (driven by existing theories and research separate from the data), or a mix of both. It can also be semantic (surface-level, where the data is taken at face value) or latent (deeper meanings not explicit in the data) (Vossler & Moller, 2014). The researcher's role is thus to be reflexive in the production of knowledge and themes. In this approach, themes can be seen as ideas underpinned by a shared concept or meaning, whereas codes capture a single part of the overarching idea (Braun & Clarke, 2021). RTA in this study involved the following stages (Lyons & Coyle, 2021). At each stage in this study (Table 2.2), the primary researcher and her supervisor conferred together on the development of codes, themes and ideas to ensure a degree of validity. Examples of the process are show in Figure 2.2.

Table 2.2

Stages of analysis

No.	Stage	Processes involved in this study
1	Familiarisation with the data	This stage involved reading and re-reading the transcripts to get immersed in and familiarized with the data. This process also included thinking about how the data answers the research question and looking for patterns and assumptions (Vossler & Moller, 2014). The transcripts were read three times and notes were made that highlighted interesting quotes or lines that stood out, along with context they were situated in. The research question and aims were kept in mind as to not lose focus while reading the transcripts. At this early stage in the study, mainly inductive and semantic approaches were used to preserve meaning in the data. In some transcripts carers had talked about being single parents, foster carers or adoptive parents. These contexts were considered while coding their caregiving and placement experiences in relation to others who did not have those experiences.
2	Coding the data	This stage involved assigning distinct labels (brief phrases) or codes to data in the transcripts by systematically going through each transcript. It included deeper interpretations of the data (latent) as well as summaries or surface meanings (semantic). Codes captured any patterns across data in the form of short phrases that could be understood without reading the data. The notes made during the familiarization phase were considered while assigning labels to the data. Codes were also recoded, if necessary, upon discussion with the researcher's supervisor. These were done manually by hand in an Excel and no external coding software was used to ensure better familiarization with the data.
3	Initial theme generation	This phase required the researcher to view larger, overarching patterns in the data by grouping together codes that might relate to bigger ideas or concepts. The researcher in this study viewed and generated initial broad ideas based on patterns observed in the codes. These were recorded in an Excel sheet with references to quotes and researcher interpretations from the transcripts to ensure no loss of context or meaning in the process. At this initial stage, it was imperative to keep close in meaning to the codes.

4	Developing and reviewing themes	The main aim was to integrate the initial themes without losing meaning and ensuring the broader themes still addressed the research question. The initial themes were further broadened into larger themes while preserving the meaning and context in the Excel document. Themes from phase 3 were colour coded and grouped together to make secondary themes. Similarly, secondary themes were grouped together and broadened to make tertiary themes. The final themes were developed by grouping tertiary themes, with reference to the wider contexts which they sat in. An example of this is given in Figure 2.2. At this stage, several different interpretations of the data and themes were often encountered, which has been experienced by other researchers as well (Byrne, 2022). However, after thorough contemplation and discussion with a supervisor, the chosen interpretations and themes were seen as the best fit for the data and research question.
5	Refining, defining and naming themes	This last stage involved defining the themes and ensuring that the names and descriptions told a story or alluded to a deeper meaning. This involved going over the final themes and refining the names to ensure they included contextual references. It also involved writing up descriptions of the themes and making references to quotes from the transcripts. Subthemes were also refined from the tertiary themes and appropriate descriptions were written in the Excel document.

Researcher Position

Another important step in the analysis was to be aware of the researcher's position relative to the transcripts and research. This included both the epistemological position and the researcher's position as an insider or outside. The epistemological position of contextualism assumed that people made sense of their own reality but also acknowledged the wider effects of socio-political contexts and environments in shaping those realities (Braun & Clarke, 2006). Therefore, this position was adopted by the researcher as it aligned with the aims of this study and helped the researcher examine wider systemic contexts such as the pandemic, marital status and financial conditions that influenced caregivers' experiences. It was also used by the researcher to be aware of how carers perceived their own reality while being situated in these wider contexts. This position was maintained throughout the analysis of data and while developing the conclusions of this study.

The other position adopted by the researcher was that of an outsider at three points.
Firstly, all participants were parents or carers while the researcher was not. Secondly, all participants had experienced and dealt with regular outbursts from their children, which the researcher had not. Moreover, the researcher was from an ethnic minority South Asian background while all the carers were from White British backgrounds, which could have added to differences in perceptions of the world, cultures and societies. Therefore, the researcher was positioned as an outsider merely opening a window into the carers' experiences. Nevertheless, the researcher's supervisor was from a White British background and had more than twenty years' experience in working with families affected by EOs. This lent a sense of rigor to the analysis as it was done in conjunction with the supervisor. In line with the principles of RTA, this reflexivity was maintained while interpreting the data and making sense of the carers' experiences. Any potential biases were also noted and reflected upon in a reflexive diary. An example of a reflective note on the interview process is given below:

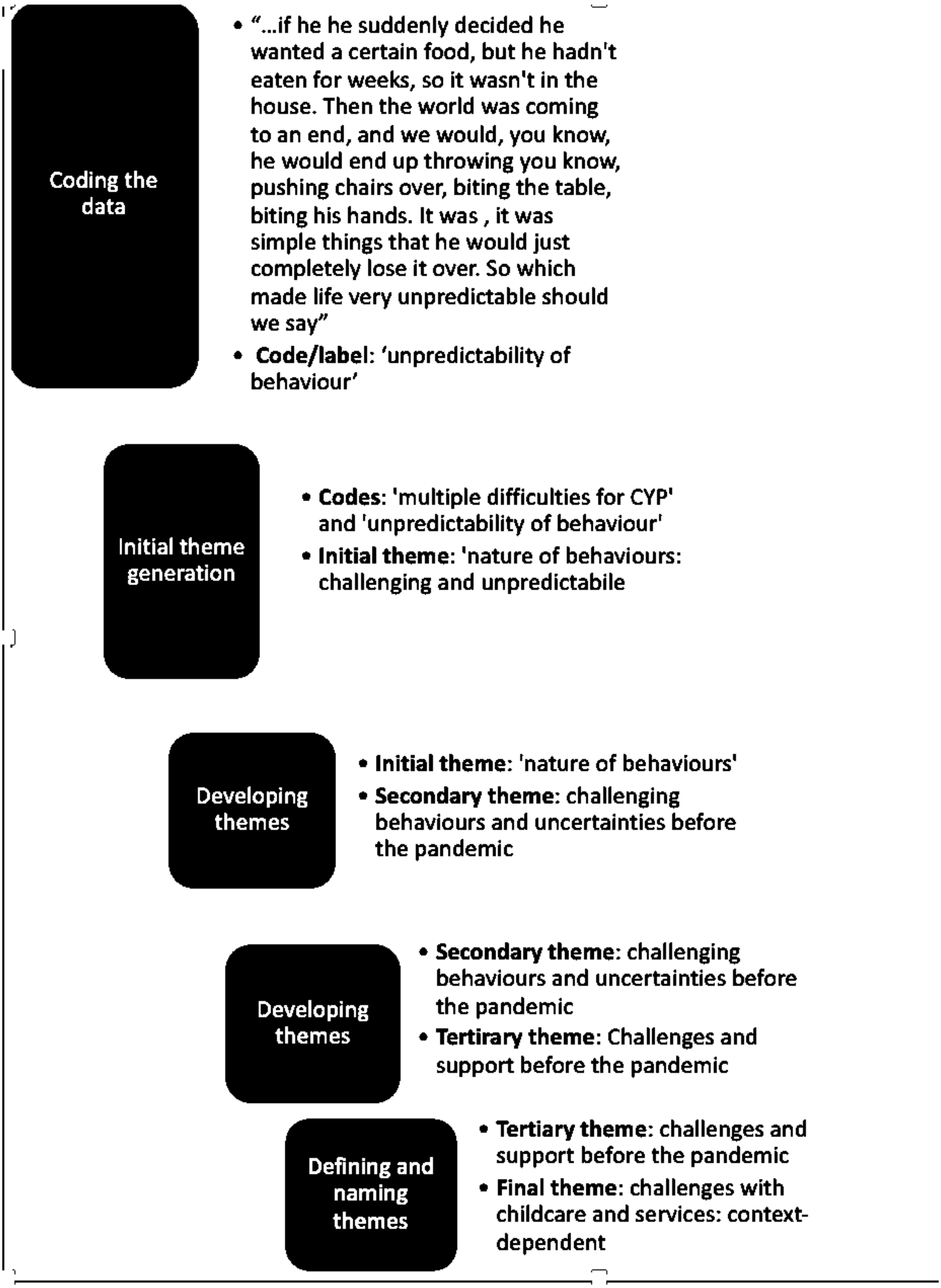
"As I was going through the transcription for the first interview, I noticed that at times I had missed out on asking follow-up questions relating to specific experiences mentioned by the carer. For example, she talked about the context of adopting a child with additional needs in addition to having children of her own. What was the reaction of the non-adoptive sibling? How did the family deal with that transition before the pandemic and did the mother notice any differences in the way she felt towards both children in the pandemic? These were some

of the questions crossing my mind as I transcribed the interview.

However, I also wondered if these questions arose from my own biases and perhaps the mother did not feel any differently towards her adoptive child. This got me thinking about the perception of adoption in my culture and that there was still a stigma attached to it. Though, in Western societies, adoption may be seen as a more common and normalized process. Nevertheless, I wondered if the process of adoption and finding out the child had additional needs had added to the mother's distress even before the pandemic."

Figure 2.2

Example of development of themes



- "...if he he suddenly decided he wanted a certain food, but he hadn't eaten for weeks, so it wasn't in the house. Then the world was coming to an end, and we would, you know, he would end up throwing you know, pushing chairs over, biting the table, biting his hands. It was , it was simple things that he would just completely lose it over. So which made life very unpredictable should we say"
- **Code/label**: 'unpredictability of behaviour'

- **Codes**: 'multiple difficulties for CYP' and 'unpredictability of behaviour'
- **Initial theme**: 'nature of behaviours: challenging and unpredictabile

- **Initial theme**: 'nature of behaviours'
- **Secondary theme**: challenging behaviours and uncertainties before the pandemic

- **Secondary theme**: challenging behaviours and uncertainties before the pandemic
- **Tertirary theme**: Challenges and support before the pandemic

- **Tertiary theme**: challenges and support before the pandemic
- **Final theme**: challenges with childcare and services: context-dependent

2.4 Findings

Three main themes were generated from the data: (1) Challenges with childcare and service: context-dependent; (2) Surviving the good and bad; and (3) Everything and everyone for the young person. The first two themes had three subthemes each and the third had two subthemes (in Table 2.3).

Table 2.3

Themes, subthemes and participants who contributed to each

Themes	**Subthemes**	**Participants who contributed to the themes and subthemes**
Challenges with childcare and services: context-dependent	Challenges and support before the pandemic	Rowena, Mary, Julie, Andrea, Jane, Hannah, Tim, Ginny
	Difficulties with services	Rowena, Mary, Julie, Andrea, Jane, Hannah, Tim, Ginny, Cecelia
	Struggles of single, adoptive and foster parents	Rowena, Mary, Julie, Andrea, Jane, Ginny, Cecelia
Everything and everyone for the young person	Balancing multiple roles and worries	Rowena, Mary, Julie, Andrea, Jane, Hannah, Ginny, Cecelia
	Sacrifices, empathy and resilience for the child	Rowena, Mary, Julie, Andrea, Jane, Hannah, Tim, Ginny, Cecelia
Surviving the good and bad	Coping strategies: preparing, resources and perspectives	Rowena, Mary, Andrea, Jane, Hannah, Tim, Cecelia
	Impact on relationships, personal time and support	Rowena, Mary, Julie, Andrea, Jane, Hannah, Tim, Ginny, Cecelia
	Positives in the pandemic	Mary, Andrea, Jane, Hannah, Tim, Ginny, Cecelia

Theme 1- Challenges with childcare and services: context-dependent

This theme signifies the number of challenges carers faced with services and caring for the child before and during the pandemic. Some carers who were foster, adoptive or single parents faced additional pressures due to services closing down in the pandemic.

1. *Challenges and support before the pandemic*

Caring for the young had always had its *peaks and troughs* (Julie). The multiple difficulties that the young people faced left carers *very exhausted* (Mary). Each child had a facet of emotional and behavioural problems, which required constant attention, appointments with professionals and kept carers very busy before the pandemic:

> "So simply his age and physical size makes violent outbursts…more significant than they would have been a few years ago…so life before the pandemic, you know there were various adjustments compared to dealing with a normal autistic child." (Tim)

> "I had to seek out all the support myself, I'm the one who had to keep hounding the GP and connecting all the professionals up...Really tiring, really, really hard work…dealing with a child that was getting frustrated as well so he would sort of throw himself on the floor, he would hit out, so a lot of outbursts that way." (Mary)

However, for most, the challenges in taking care of the child were offset by some face-to-face support. Before the pandemic, most carers had support and respite in the form of schools, therapeutic services, and respite care, which eased some of the pressure of the child's multiple care needs. Carers did not have to play the role of every professional:

> "Uh, so before the pandemic there were things like access to in person services. So having like a speech therapist come to my house and I was able to go to an occupational therapy clinic in person…And my child was going to nursery regularly…in some ways was respite for me but also gave me some direct support... So that was obviously really good." (Hannah)

Moreover, for some, having set routines and respite in place before the pandemic has made them accustomed to dealing with challenges on a daily basis. Thus, there was a sense among some carers of things moving along in a status quo and getting through one day at a time:

> "So, it was difficult before the pandemic hit. We had a lot of respite in place and we have good set routines. So for every minute of everyday he was occupied doing something, whether it be with us, with school or with respite. And that seemed to work…we had lots of respite and we were coping day to day." (Rowena)

Additionally, some carers had informal support in the form of friends, family members and spouses, which helped buffer the amount of stress they faced:

> "And like my husband's family were quite close, living quite close and helping, like, have my, my eldest, you know, every now and again of an evening or something like that. So yeah, you know, there was support available, definitely." (Hannah)

For others, however, both sources of formal and informal support were very limited, which led to a great deal of distress and left carers having to cope with multiple demands on their time and emotional wellbeing. This was situated in a wider context of pre-existing difficulties with staff shortages and pressure on schools and services to meet demands more than the supplies:

> "I had a social worker, but very sporadic contact and completely underresourced. She worked two days a week and she had a caseload of 28 families. So, contact was very few and far between despite there being ongoing issues in in school, so much so that you know school have said that they can no longer meet his needs." (Julie)

This then could lead to feelings of guilt, failure and self-doubt, which often left the carers being very hard on themselves for not being able to get the support their child needed:

> "There weren't many support groups out there like there are now um, you know, it was really sort of clinging for support. I found that really, really hard…and felt like am I failing him because I can't, I don't understand where to go to get the

> support…Really hard, really, exhausting hard." (Mary)

2. *Difficulties with services*

While there were difficulties with services before the pandemic, this increased tenfold at the start of and during the pandemic, especially in the initial stages. Carers were suddenly cut off from all support as services shut down with very little or no warning and no chance of support returning any time soon. There was thus a deep sense of frustration and feelings of abandonment among all carers:

> "…his whole structure and routine disappeared overnight with very little explanation so school didn't happen, respite care didn't happen and…we were abandoned because the idea that working parents could simultaneously homeschool their children with additional needs…very quickly led to a deterioration in his behaviour. So violent outbursts, repetitive behaviour, that sort of thing." (Tim)

Others had difficulties accessing services due to the prioritization of NHS frontline workers, which led to a lot of confusion and frustration. This was also situated in the context of the child's need for routine and need for advanced notice. So, when services closed with very little notice, it triggered the child's emotional outbursts and thus put a lot more strain on the caregiver:

> "…the schools closed on the Friday with no warning…And then by the Monday

> morning, I had a text from the child carer to say she can't work because she had to prioritise NHS kids…and then his main respite carer said she's not gonna work through the pandemic…So it was absolutely horrendous. He was kicking off, obviously because he didn't understand his routine." (Rowena)

Therefore, when asked about changes they would like to see post pandemic, most carers said they would like services to be more responsive and adaptive, possibly by checking in more regularly and understanding the needs of young people with additional needs. This was fueled by feelings of abandonment and the emotional strain of being left to deal with the aftermath of outbursts and disruption of routines on their own:

> "You've suddenly got a lot of systems shutting doors on everyone and…I don't know, like a weekly check in or something for those families…I'm guessing maybe from the health services, if your child's, you know, got a disability, or maybe from another service if you're in a different scenario…right from the beginning rather than just to make sure that you know, everything's okay." (Hannah)

3. *Struggles of single, adoptive and foster parents*

Adoptive, foster and single parents often faced more pressure due to undergoing unique circumstances and it was therefore important to highlight their experiences. For instance, single carers often expressed that they found the living situations with their children "really hard" (Ginny) even before the pandemic. There were considerable challenges in raising a child with additional needs on their own, with little help from friends and family members. Thus, many found themselves having to rely on support groups for physical, practical support and emotional. However, this was disrupted in the pandemic, which caused a lot of distress for the carers:

> "I mean it was just more challenging than usual because as a single parent you have no choice. You have to rely on a wider network for, I don't know, if you're running late from a meeting you get on WhatsApp to the mums, 'Can somebody pick up my son?' type of thing…of course that goes out of the window in the pandemic. So, it's just the loss of that kind of support network." (Julie)

Some single carers also had difficulties accessing childcare when not being able to draw upon the help of family members during the pandemic, which then led to challenges in finding time for themselves or for work and feelings of low mood and frustration:

> "I was feeling very down, frustrated that I couldn't work because she was home for such a long period. And then I tried to get back to work and couldn't get childcare for her…I was very, very restricted. And family had always been supportive but couldn't help anymore, because of the level of the behaviour it was hard for anyone else to deal with her at that time." (Ginny)

Such instances led to self-comparisons with other families and parents with neurotypical children and partners. This was in the context of having little support, handling caregiving alone, feeling isolated and emotionally exhausted. Therefore, the carers wished for a family unit or someone to share the burden:

> "I felt a little bit angry as well, knowing that other families had more support. They had a partner…I've had no siblings help out with that, so I felt really, really angry about that actually thinking God, no one really understands." (Mary)

The context of being a single parent also had a vast effect on how carers saw the pandemic and their fear of the virus. For some single carers, the pandemic brought out fears about their mortality and who would take care of their child should anything happen to them. This fear could have manifested due to having little childcare support outside of themselves:

> "Yeah, just paranoid about following the rules and kind of hand washing and getting him to take that seriously and…you have to confront your own mortality as well and oh God, you know, how on Earth would I cope if I if I, you know, if I was laid low or you know, or seriously ill." (Julie)

Some adoptive parents had similar concerns about how they "could easily be on that list" (Andrea). The context surrounding this was that some parents had started getting to know their adopted children and to realise the extent of their difficulties and emotional outbursts that meant they needed additional attention and care:

> "So a few months before the pandemic started, he was gradually having speech problems, but he always wanted us to play with him. And we started to have an expectation that we would be able to do some housework…And then discovered that it doesn't work." (Jane)

Adoptive and foster parents also had additional challenges with accessing services, adoption or foster support and contact with foster agencies in the pandemic, which increased the emotional impact of caregiving. For instance, one adoptive parent talked about how they had to reach crisis point before the adoption agency and services intervened:

> "Support only stepped up really when we hit sort of crisis point kind of halfway through the pandemic and the instance of violence and outbursts and and self-harm got to such degree that…I remember, being on phones just crying to social services, saying you've just gotta take him cause I can't cope anymore, you know?" (Julie)

Another foster carer talked about the little respite received from services and not being able to take leave while she was being paid to care for a child in the pandemic. This instilled a sense of frustration about not having any personal time to themselves and feeling trapped:

> "There was no point asking for anything cuz we were told there wouldn't be any

> opportunity. We got paid for the leave we didn't have but…I'm not a foster carer for money because they couldn't afford to pay me for the hours that I worked, you know what I mean?" (Cecelia)

Consequently, some foster and adoptive carers also felt unheard and unappreciated, especially compared to NHS frontline workers. This was in the context of caring for children that weren't their own by birth and not feeling understood or valued by others in their caring role:

> "You feel that you're taking on a lot of risk you are frontline and yet you weren't being acknowledged like the nurses and police officers and all this." (Andrea)

However, foster carers also demonstrated a lot of resilience in the face of all these challenges. There was a sense of pushing through tough times and putting on a brave face, at the heart of which was a need to protect the young person from emotional distress. However, this meant that carers often had to stomach their own emotional distress:

> "The thing about the children I look after…I was worried and if you're not 100% for those children in your care, they get in a panic because they've come from a household where the adults have let them down. So then when you're not ok it's really important that you show that you're ok because they can't really deal with another rejection." (Cecelia)

Moreover, some foster carers also saw their caring role as rewarding, especially when hearing positive feedback from others or the children in their care, getting to know and understand the young people and finding a sense of contentment at contributing to shaping them:

> "I get such joy out of when they actually tell me things or it's to say that they've enjoyed something that we've done, or I meet them a few years later and they're proudly introducing me to the girlfriend or whoever and they say 'this was my foster carer, she was great, we did this, we did that'…so I feel happy when I get some positive feedback" (Cecelia)

Theme 2- Everything and everyone for the young person

This theme relates to the idea that carers had to take on multiple caring roles in the pandemic, be multiple people for the young person and make many sacrifices on their time and work. This took an emotional toll on the carers, however, they were very empathetic towards the young person and understanding of their difficulties. As a result, carers developed a great sense of resilience and ability to get through tough times.

1. *Balancing multiple roles and worries*

In the pandemic, resources and services were sparse, with schools, therapeutic spaces and play areas closing as the lockdown set in. Thus, carers had to adopt multiple roles for their child—become professionals, social workers, teachers and parents to support their child while having little support themselves. This often led to a lot of anxiety and mental health issues due to juggling these roles with little to no help, which the young people picked up on. This often led to a cycle of trying to help the child, feeling exhausted and the young person reacting with their own anxieties:

> "…he was picking up on my anxieties, and seeing that mum was busy all the time…and kind of, you know, I was teacher, shopper, cook, worker…Yeah, his behaviour was probably largely picking up on knowing that my cap was empty, broken, or overflowing and him reacting against that." (Julie)

There was also a sense of helplessness that all the responsibilities would fall on the primary caregiver, most often the mother, who had no one else to ask for support and nowhere to get respite:

> "What it felt like is that ultimately, it all falls on your head as the as mum…You know you've got family, but my parents are too old so they can't cope with him…Ultimately, it's all on your head...Everybody else can take a step away. But you as a parent obviously can't." (Rowena)

On top of playing multiple roles for the child, carers also struggled to find time for other responsibilities such as their own work. This meant most were forced to work at night and had little time for themselves overall:

> "I knew that if I was on my own with him for 12 hours in the day, there was two points in the day that you were like oh I can either get some quiet time or I can actually do my work...So I was working from 7:00 o'clock at night onwards, once he'd gone to bed." (Rowena)

Some carers had to juggle these responsibilities with their own physical health needs, thus leaving them little time to take care of themselves. There was a sense of having to move forward no matter what and keep things together even at the cost of their own health. Underlying this was a sense of having no other options and having to put the child's needs above their own:

> "Yeah, so I kept everything together…'cause if something else, like a curveball came into it, that's where everything else had to be really, really organized…So I needed everything running as smoothly as possible, but yeah, I have my fibromyalgia, so I get very exhausted all the time." (Mary)

In addition to balancing many roles, most carers had to deal with the emotional strain of increases in outbursts in the pandemic while carrying out different caregiving roles. Along with the added pressure of emotional outbursts, there was a sense of helplessness about not knowing what to do:

> "She started to get hostile towards me, so I thought of ways to try and make it interesting and, you know, with a bit of structure and just try and make it enjoyable…But she was very resistant to anything... She might start screaming, banging the table, kicking chairs, storming off to a room, slamming doors." (Ginny)

Some carers felt like they did not have anyone to confide in and that they could not tell others that they were struggling, like Jane and her partner who were "*not really telling people what the meltdowns were like and weren't really telling people that we were struggling*". This might have been partly due to wanting to protect others like elderly parents and partly not wanting others to think they were struggling. During this period, some carers were also taking care of elderly parents and relatives, which added to their caregiving pressures and to how stretched they already were. However, many were also not able to physically meet their parents and it made them feel very isolated and helpless, especially while worrying about their parents catching the virus. Therefore, their worries doubled and tripled in the pandemic:

> "My father is on his own as well and 'cause he was, he was in in the high risk group, trying and keeping in touch with him on the phone and organising the shopping and everything and as well as keeping my son as regulated as possible, really, it was, yeah, just awful, awful frightening time that I hope I don't ever have to repeat." (Julie)

Moreover, many carers were also worrying about practical matters such as food and procuring necessities, especially when there were food shortages during lockdowns. This was more so in the context of caring for a child with additional needs who had specific dietary and sensory requirements and most times, if the desired foods were unavailable, the carers would have to face emotional outbursts and additional emotional strain:

> “During the pandemic, we were fighting for food shortages especially when you have autism special dietary requirements…And if he he wasn’t happy, we would suffer because he would scream the house down.” (Andrea)

2. *Sacrifices, empathy and resilience for the child*

All carers had a deep sense of empathy and understanding of the child’s difficulties.

They tried to make sense of why the young person might be experiencing emotional outbursts, including incidents that had taken place in the past, such as early life experiences, triggers or in the context of the pandemic. This increased the carers’ worries and concerns for the young person, but also helped them keep these things in mind and cope when caregiving seemed challenging:

> “You know, you just want to take the pain away, you want to take the anxiety away,

> you just want him to be happy and seeing him not happy then again, adds to your own anxiety…He struggles with so many things in life, you really don't need anything else throwing extra curveballs in…You were just extremely anxious and worried." (Rowena)

To be the best caregiver they could be and due to the young person's complex needs, many carers also had to make certain sacrifices. For some, this meant giving up their careers or jobs to meet their childrens' needs, which had a big impact on their lives. Although carers did not express regret over their choices, there was a sense of sadness at giving up something they had enjoyed in the past:

> "…I was a teacher for 27 years and I enjoyed it very much, but I had to give up to to be at home for my daughter and all the appointments and the times that she was at school." (Ginny)

In putting the child's needs above their own, carers at times disregarded their self-care needs and habits. Some carers did not know how to engage in self-care activities or what it was supposed to be. This was indicative of how carers had kept going even before the pandemic and had less opportunities for self-care, which was further amplified in the pandemic due to the lack of any respite:

> "I remember having a conversation with a parent partner on the phone and she was

> trying to teach us all about self-care and I said what is self-care?And in hindsight, that felt such a like a massive red flag." (Jane)

However, constantly dealing with tough times and struggles with services also left some carers with a lot of resilience. There was a sense of pushing through challenging periods with a positive attitude and trying their best for the young person. This was also facilitated by empathy for the young person's circumstances and, for some foster carers, the knowledge that the child would have nowhere else to go if they gave up:

> "One of my sons, he wasn't medicated. We didn't have any respite. Nobody would look after him... But you know, we're also the type of people that won't give in because we feel that if we give up and my son being 4-5 his only option would have been a care home." (Andrea)

Theme 3- Surviving the good and bad

This theme shows how carers handled the ups and downs, and the balance of negative and positives in the pandemic. While resilience allowed carers to push through tough times, they also employed other coping strategies in the pandemic, especially as there were little opportunities to access respite or personal time. There was also little access to support and caring responsibilities led to strains in relationships with family and friends. However, this theme also highlights the positives that some carers found in the pandemic.

1. Impact on relationships, personal time and support

Isolation was one of the main feelings carers experienced during the pandemic. Many had been separated from friends and family, with their social lives being disrupted and no chance to get some respite from constant caregiving demands. Due to the pandemic, friends and family were often cautious to meet and the duration of the pandemic led to an eventual decrease in virtual socialising opportunities. This left carers struggling to speak to people, which led to a feeling of helplessness:

> "All my social activities went by the wayside...some of my friends are older than me so they were a bit more cautious than other people and didn't want to meet up. My sister was shielding because she's got several autoimmune conditions, so we couldn't meet up at all...So that was really, really hard." (Ginny)

For some, even before the pandemic, caregiving responsibilities and the extent of the young person's needs and behaviours led to a breakdown in personal relationships. For instance, Ginny described that "the family did break down completely because of the girls' difficulties and me and my ex-husband are divorced." Family members also alienated the carers at times because they found it hard to deal with the young person. Thus, dealing with the aftermath of that and being a single parent in the pandemic caused a great deal of emotional strain:

> “So, I’ve known my partner for 9 years but I had a very difficult young man, and he used to be very jealous of my partner and he would wreck the house and tell lies and say that I’ve had men in and it’s just really nasty you know to start with. So, it was easier to see my partner outside the house.” (Cecelia)

Apart from relationships, carers’ work and careers were affected as well. One carer talked about having a promotion withdrawn due to the amount of time and effort it took to manage child’s difficulties. There was a sense of resignment and having to choose between the promotion and their own mental health:

> “In lockdown, I chose mental health above career. Because of this particular situation I had with this promotion, for 2020, I was trying to keep the thing under review with the hope that when my child went back to school we might be able to pick up where we left off… it became clear both that my child was not recovering and that the promotion was not willing to wait any longer.” (Tim)

Thus, as with work, there was also little time for carers to do anything for themselves.

Between juggling multiple roles and responsibilities in the pandemic, working and keeping up with the young person’s needs, some carers had to find ways of keeping the child occupied to squeeze in some time for chores or other activities. When they did find time for themselves, they might have to deal with more outbursts from the young person. This often left carers exhausted and unable to cope:

> “I just thought I was losing my mind. I used to run a little bit…But if I go out for an hour, then my husband’s going to be with him on his own and when I get home, then there’s more stuff to sort out cause my husband and my son, they would have fallen out. So it was almost like, is it worth having a bit of me time because you have more hassle to sort out when you get home” (Rowena)

Therefore, some carers also experienced guilt when taking time out for themselves. They experienced a lot of anxiety around not doing something for their child when they had some free time. This was also related to the theme of doing everything for the child and sacrificing their own time and mental health. As carers become so used to doing everything for the child, they felt guilty when they had even limited time for themselves even before the pandemic:

> “So I went to some classes...Couple of hours on a Monday morning and then I felt guilty for that, you know, because that’s the time that I could have been using to do a phone call or, you know, writing an email or chasing this up. There’s a lot of guilt that comes in with carers, with parents if they make time for themselves.” (Mary)

2. *Coping strategies: preparing, resources and perspectives*

Even before the pandemic, some carers had a habit of pre-empting and preparing things for the young person to remain equipped in the face of last-minute changes or surprises. This was also underpinned by a sense of anxiety about dealing with any emotional outbursts the young person might have if things did not go according to plan. Thus, it also led to a lot of emotional and physical strain for the carers:

> "It was um, quite draining sort of emotionally and also physically but you pre-empt all the time and you're always having strategies up your sleeve for things that could not work…you're going to bed thinking, right, have I prepared him enough for this? And that is really exhausting in itself." (Mary)

In the pandemic, some carers used these preparations and "being organised" (Mary) as coping strategies. Being practical about what the child could do and where he could go, helped carers plan for uncertainties and be prepared in worst-case scenarios:

> "…we got really practical and we were trying to deal with how scary it felt by finding things that we could do and that were within our power and focusing on practical plans." (Jane)

As their regular routines went out the window, some carers started creating new routines. They also started getting creative with the activities they could do, games they could play and other things they could do to keep the young person and themselves occupied. For some, it was an attempt to help the young person and themselves unwind in the pandemic:

> "So we were cooking and that was quite nice to do and then we would sit down and watch films together. So I could relax when they were relaxed. And then we did party games and I would let them do dancing…so that was good for me as well I could get, um, some of my frustration out just physically by jumping up and down." (Cecelia)

For others, it was an attempt to help their partner work while the young person was kept busy, and to avoid another emotional outburst. It also helped the child keep a semblance of the routine they had before the pandemic, especially when playgroups and schools closed suddenly:

> "What we did was we recreated the routine, we invented this thing called fake playgroup…and I would have had activities lined up for him and my partner would go up to the room…that was a way of saying there are special things for you down here and you're not being left." (Jane)

Some carers had training experiences prior to the pandemic that they used in the pandemic to teach the young person new skills and help them cope with distress. In turn, it also helped carers cope with the strain of the pandemic, especially while therapeutic resources and staff were few:

> "So I kind of drew on all my training and I taught myself and the children how to breathe properly…and they quite enjoyed that but it did help them to calm down. But I was doing it for my benefit to start with." (Cecelia)

During the pandemic, although outdoor activities were limited, some carers used allotted outdoor times to pursue hobbies, create some personal time for themselves and take a break from caregiving. This helped them cope with the pressures of the pandemic and get away from their main identity as a ‘carer’ to explore what they liked doing outside of caring:

> “After a few weeks, I started going back to work at one of my gardens and that gave me a space to get out of the house…and it is a therapeutic space for my son. But it gave me a sense of ah look at this creative place where I’m doing stuff…I gave myself a narrative that I had agency, I guess in the chaos that was happening or everything was happening.” (Jane)

Some other carers also used other strategies to cope. For instance, some carers put on a brave face and “had to be strong” (Ginny) for their families, while others turned to their GPs for support. The lack of formal and informal support left the carers dealing with all the responsibilities on their and even less personal time or respite. Thus, they experienced increased feelings of guilt, anxiety and low mood. Many carers decided to seek medication as it was the only personal support they could access in the pandemic:

> “I contacted the GP and I was really exhausted and tearful, I wasn’t sleeping. My tolerance and patience levels of dealing with my son just melting down multiple times a day everyday was low…I got put on antidepressants. Because of course, there’s no counselling services or anything like that.” (Julie)

A few carers also used positivity to cope with the challenges of caregiving during the pandemic. Some also had a good support network and spouses working as a team that facilitated the positivity and changed the carer's perspectives:

> "…you've got the wrong people because we're very happy people. But it's good to say that, emotionally, we were very high spirited. We had some challenges as no doubt about children, particularly because of their disabilities. But we're a pretty good team I think." (Andrea)

One carer tried to avoid the news to avoid the constant negativity and exhaustion associated with watching COVID-19 briefings. She also used humour to "look for a funny side when things are quite bad" (Cecelia).

3. *Positives in the pandemic*

Due to the emotional impact of caregiving and the pandemic, some carers found it difficult to think of any positive experiences. Even if they had positive times in the pandemic, it was often overshadowed by the negative experiences, which signified the amount of strain carers were under:

> "I'm struggling to, even if we'd have a lovely, you know, cuddly afternoon with blankie and snacks, watching a film together…and then it would be time for the telly

> to go off and then whoosh the violence and the aggression and the trashing would start…You were just bracing yourself for the next blow constantly." (Julie)

On the other hand, some carers were able to think of many positives in the pandemic. For some, this was related to having less pressures of work and time schedules in the day, to be able to relax a little bit and not have to worry about deadlines:

> "And when we came to the lockdown, my husband and I, it was almost like, oh, we've got some time off, you know, like there's some holidays. You don't have to be in that strict regime regime. No meetings…all the pressure of work actually relieved a lot." (Andrea)

Consequently, this also created more time for carers to spend with their families or with the young person. Moreover, the ease of routines and pressures also reduced the strain on young people, which had a positive effect on the amount of enjoyment carers could get out of family time. They were able to do recreational activities together, which helped them bond and teach the young person some life skills:

> "It was positive that I did have a lot more time to spend with [child's name]…because we spent so much time together, he did learn quite a lot of just household needs, life skills, kind of things to do…we're still doing that now so that's good." (Cecelia)

Some carers learnt more about letting the small things go to better their mental health and reduce anxiety:

> "…somethings don't matter as long as your health is OK and your you've got time for your child and keeping them happy. That you kind of really realised that was the most important thing…and that was the positive that came out of that as well." (Mary)

With more time away from strict routines and work pressures, carers were also able to utilize outdoor spaces and make the most of the sunny weather in the first lockdown. When the government increased the time they could spend outdoors, carers took advantage of this to spend time with the young person, especially when play areas were less crowded:

> "So another good thing that did come out of the lockdowns or sort of happening when things were opening up again was that you had to do lots of booking online and you have to do lots of pre booking and stuff…for my child, that was actually really good because it meant there was no waiting for queuing to pay or like waiting or knowing it would be really busy inside" (Hannah)

Another positive that came out of the pandemic for some was the strengthening of some relationships, particularly sibling relationships. One carer talked about how the pandemic allowed for her daughter to understand and appreciate her son's additional needs, which then led to her helping to calm him down and consequently help the carer:

> “Yeah there was one positive that came out of all of it. My daughter and my son’s relationship is leagues better. She is amazing with him…she understood why I would do certain things to try to distract him, to try to calm him down.” (Rowena)

2.5 Discussion

This qualitative study aimed to explore the experiences of carers for young people with emotional outbursts outside and within the context of the pandemic. Other contextual factors such as marital and carer status that affected caregiving experiences were also considered. Semi-structured interviews were conducted, and RTA was used to identify three main themes: ‘challenges with childcare and services: context-dependent’, ‘everything and everyone for the young person’ and ‘surviving the good and bad’. The first and last themes contained three subthemes and the second theme had two subthemes (Table 2.3), which all revealed important aspects of the caregivers’ experiences. The findings suggest that the pandemic had a profound impact on caregiving stress, in addition to pre-existing challenges. Moreover, single, adoptive, and foster carers faced unique factors that affected their experiences of caregiving and their mental health.

Associations to existing research

In the following paragraphs, the findings and themes will be discussed as they appeared in the results. First, the findings around frustrations with services before and during the pandemic and the lack of informal and formal support will be linked to existing research. This will be connected to the isolation and abandonment carers experienced due to these frustrations. Next, the toll of increased EOs on increased anxiety, guilt and the increased challenges faced by single, adoptive, and foster parents will be discussed, all related to the theme ‘challenges with childcare and services: context-dependent’. The next theme ‘everything and everyone for the young person’ will be reviewed with respect to the carers’ mental health problems associated with balancing multiple responsibilities and making sacrifices for the child. Lastly, the theme ‘surviving the good and bad’ will highlight how carers coped with the positives and negatives in the pandemic, with reference to previous literature.

All carers in the current study were often very disappointed with how services had been responding when further formal support was required from them. For most carers, challenges with services existed even before the pandemic, with some receiving little to no professional help. This was also found by McGill et al. (2006), who reported that almost half the carers in their questionnaire study either did not receive formal support or received support that was not helpful. Several studies have also reported that many times, carers had to hit crisis point for services to offer help (James, 2013; McGill et al., 2010; Wodehouse & McGill, 2009), which supported the current findings. On the other hand, one study found that practical help, mental health care and counselling were received frequently by carers of young people with behavioural problems (Weiss & Lunsky, 2010). Taken together, these findings represented the current study’s themes around some carers receiving support before the pandemic, but that overall, all carers were unhappy with the amount and type of support received.

In the pandemic, however, there was no in-person support provided, regardless of the number of behavioural problems experienced by the child. This was also found by Rogers et al. (2021), who reported that when support was suddenly taken away, many carers felt isolated and left to fend for themselves. However, this may be dependent on context. For instance, a study in the UK and Ireland found that although carers felt abandoned by government-run services, they received support from charity and independent organisations and built good relationships with them (Power, 2009). In the current study, some carers talked about receiving online support from non-governmental organisations, and although it was praised for a fast switch to online platforms, it was perceived as insufficient. This could be in the context of the amount of isolation felt by carers, especially when all services had withdrawn suddenly at the start of the pandemic, which left carers feeling deserted and distressed.

In the present study, due to services and schools closing without warning, there was a drastic increase in the number of EOs displayed by the children and consequently, an increase in reported carer stress and anxiety levels. This was supported by Gillespie-Smith et al.'s (2023) study, which found that higher severity of EOs was associated with higher parental stress. Although carers in the present study reported other benefits of the lockdowns, all mentioned that EOs had increased and that it had a negative impact on their mental health. For foster carers in this study, at times it also led to feelings of helplessness, giving up and sending the child back to services. However, other carers in the current study did not have that option and had to wait for their child to reach a certain age to be sent to a care home.

Carers in the current study also reported that as EOs increased, they felt guilty for taking time out for themselves and excluding the young person from family activities. This coincided with reports of feeling like they were not doing enough for their child in the context of caregiving in the pandemic. This could mean that there might have been a connection between increase in EOs and increase in feelings of guilt and self-blame for carers. Indeed, a previous study found that when dealing with EOs and CB in general, staff and professionals also reported feelings of guilt, self-blame and self-doubt, but that these were related to their self-perceptions and perceptions of their roles in society (Butrimaviciute & Grieve, 2014). Possibly, this could mean that carers' perceptions of the world and themselves influenced how they perceived their caregiving roles and responsibilities.

Indeed, two foster carers in the current study reported that their positive attitudes towards life and pushing through challenging times had gotten them through tough intervals in the pandemic. Perhaps it was these outlooks that functioned as coping strategies as well. Nevertheless, foster carers faced other challenges as well, such as feeling disrespected and undervalued by services and raising children who weren't their own in the pandemic. Feeling unsupported by fostering agencies and facing regular allegations from social workers was also highlighted by a survey conducted in the pandemic (Blackburn & Matchett, 2022). However, these were enduring, not short-term problems, and emerged in addition to dealing with EOs and funding issues. Therefore, foster carers may have been under much more strain than carers who did not foster children.

In the present study, some foster and adoptive carers were also unmarried or unpartnered, which added to their pressures. Single carers in general in this study highlighted challenges such as increased isolation, feeling trapped in the house with a young person with EOs, fear of the virus and mortality and wishing for a family unit to ease caregiving strain. Some single carers also talked about giving up their careers to care for the child or only working at night when the child was asleep. These current findings supported Brewer's (2018) findings as well, that even before the pandemic mothers caring for children with additional needs and EOs found it necessary to reduce their work hours. However, single and low socio-economic status carers experienced greater income insecurity due to the financial burdens of caregiving without another source of income to mitigate it (Brewer, 2018). Although the UK has a benefits scheme for unemployed and low-income households, in the current study, being a single carer and balancing a career with the child's medical appointments and additional needs meant that they had to make many sacrifices and compromises for the child. This led to further strains, stressors, and isolation, above and beyond what partnered carers faced, as single carers were cut off from all the practical and emotional support they had from friends and family before the pandemic.

Christie et al.'s (2022) study also highlighted that carers were taking on multiple roles and becoming teachers and mental health professionals for their children while also balancing other caring and daily responsibilities. This was supported by the current findings and often left them with no time for themselves, which had an adverse effect on their mental health. An investigation found that any little personal time carers had was taken up by trying to procure essentials and special dietary food for their child, which left them feeling exhausted (Dickinson & Yates, 2020). This scarcity of personal time and balancing multiple roles also may have affected mothers more than fathers of children with additional needs, as mothers had to sacrifice their careers while fathers may be protected by work outside the home (Rowbotham et al., 2011). Similar to the findings of the present study, Patel et al. (2021) also found that carers had been used to making sacrifices for their children and putting them first even before the pandemic. Their participants also consisted mainly of mothers and one father. However, the only father in the current study spoke about having to give up a promotion due to caring responsibilities. Nevertheless, he had also mentioned that his wife was the main carer for their child and did not work. Thus, although mothers may be disproportionally affected by multiple responsibilities and sacrifices they make for the child, fathers may also be affected but may be less willing to speak about it.

Contrary to Dickinson & Yates's (2020) findings, although carers in the present study expressed the strain of multiple responsibilities, they also reported finding some quality time for themselves and their families due to ease of routines. This was supported by Neece et al. (2020) and Rogers et al.'s (2021) studies, which conveyed that majority carers experienced benefits of spending more time with their families, cognitive gains made by the child and more time spent outdoors. Nevertheless, while increased outdoor and personal time was also reported in the current study, some carers struggled to find any positives at all. Possibly, similar to conclusions drawn by Butrimaviciute & Grieve (2014), differences in how carers experienced positives and negatives in the pandemic in the current study were influenced by individual perceptions of their situations and roles. In the present findings, carers who reported positive attitudes and resilience also reported using coping strategies such as preparing, using humour and creating new routines to keep their child occupied. Indeed, Tokatly Latzer et al. (2021) also reported that parents of children with additional needs who actively created some routines reported more positive experiences than those who passively accepted the lack of routines. Thus, carers who tried to actively modify their perceptions or creatively manage their time in the pandemic may have experienced more positives.

Clinical Implications

This study highlighted the role of services, support and carers' perceptions and coping strategies in shaping their experiences in the pandemic. Specifically, consistent with other studies (Neece et al., 2021; Patel et al., 2021; Rogers et al., 2021; Tokatly Latzer et al., 2021), the current study also highlighted the frustrations and stressful times carers experienced with services. Thus, one of the recommendations for services would be to have better plans in place for future emergencies such as the lockdown, perhaps in the form of care plans for all the children, with additional plans for contingencies. This could include offering more online support, in the form of support groups or therapeutic groups to help the carer deal with the increase in emotional outbursts along with advice about managing the restricted spaces and practicalities. Key workers could also be allocated to each family who can coordinate access to support and provide daily check-ins to ensure carers needs are being met. Better access to respite services should be provided at least once a week even in unpredictable situations like the pandemic. Moreover, Psychological therapies such as cognitive behaviour therapy (CBT) or Acceptance and Commitment Therapy (ACT) could be offered to help carers deal with anxiety, low mood and guilt arising due to their children's care needs. Interventions for the children that include therapy or counselling services for carers would therefore be the most beneficial. Policies on CB such as the ones by the National Institute for Health and Care Excellence (NICE) propose support groups and individual support for carers (NICE, 2018), which can be provided in person or online.

The Challenging Behaviour Foundation provides information on many existing policies and recommendations for working in partnership with carers and involving more service users in decision-making (Challenging Behaviour Foundation, 2019). However, this was limited in the pandemic due to its unprecedented nature. A report published by the UK government highlighted the challenges faced by social care workers in and after the pandemic, including reduced workforce and increasing referral rates (Gov.UK, 2022). Thus, better policies and national strategies are required to support primary and secondary services, with increased funding and recruitment plans for staff.

Another recommendation to come out of this study would be for greater therapeutic support to be provided for single, adoptive and foster carers. As found in this study, these carers may face additional challenges when caring for children with special needs and may be more likely to feel isolated, lost, and low. They could be provided with buddy programs to link them with carers in their area who can provide social and practical support and understand their unique circumstances. Like other carers, single carers should be offered person-centered therapeutic support, offered to them regardless of whether their child is known to mental health services already. This can either be offered either through their GP surgery or along with the offer of the buddy program. Respite services should also make sure that mandatory respite is provided at least twice a week to help ease some of time pressure of caregiving and allow single carers to enjoy some recreational activities.

Strengths and Limitations

This research added to investigations into the mental health of carers of young people, specifically the limited knowledge about their experiences during the pandemic. The findings provided insight into how carers from various backgrounds dealt with caregiving stress and emotional outbursts in the UK. Such insights could be used to enhance future interventions and response from services and ultimately help better the mental health of carers.

Another strength was the reflective nature of the analysis. For instance, the researcher noted her similarities and differences to the participants and how this might affect her interview skills. The researcher noted how she was an outsider to the interviews due to belonging to a different ethnicity and an insider due to being a Psychologist in training and providing therapeutic help to carers whose children had experienced EOs. This led to more questions about how the carers were feeling and noting down subtle references they made to issues such as sacrificing their career or balancing multiple responsibilities. However, this may also have led to some biases from the researcher as concentrating on certain aspects of caregiving meant other aspects may have been left out or given less attention.

Moreover, all carers were of White British ethnicity and mainly female. This could affect transferability to other populations, especially in the context of additional financial strains and health disparities for ethnic minority carers (Christie et al., 2022; Smitherman et al., 2021). Perhaps if efforts had been made to contact organisations specific to ethnic minority carers such as religious associations or schools with a majority of minority carers, more diversity could have been introduced into the sample.

Future research

The findings of this study highlighted the lack of research into the experiences of single and foster carers in the pandemic. For single carers, there is little research available even before the pandemic. Future research should thus explore their unique circumstances to better understand their needs and build on their care planning. This is especially important as single and foster carers had additional factors such as lesser social support and fears of mortality in the pandemic that made it a more stressful time.

This study also shed light on the scarce literature on the experiences of ethnic minority carers. Although they experience worse health disparities than White ethnic carers, there have been few studies on their experiences in the pandemic, especially in the context of caring for a child with additional needs. As explored earlier, ethnic carers may also be more likely to experience financial difficulties, which could have been made worse by the pandemic. Thus, future research should investigate the pressures of the pandemic and lockdowns on the mental health of ethnic minority carers.

Conclusion

The current findings not only pointed to the varied experiences of carers but also demonstrated that carers were affected by a multitude of worries and frustrations in the pandemic, which consequently affected their mental health. This not only has implications for how services could respond in the future but also how policies could be modified to better accommodate for contingencies and unprecedented events. However, the amount of resilience and types of perspectives carers had on caregiving also influenced their coping strategies and how they experienced caregiving in the pandemic.

2.6 References

Argumedes, M., Lanovaz, M. J., & Larivée, S. (2018). Brief Report: Impact of Challenging Behavior on Parenting Stress in Mothers and Fathers of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *48*(7), 2585–2589. https://doi.org/10.1007/s10803-018-3513-1

Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior Problems and Parenting Stress in Families of Three-Year-Old Children With and Without Developmental Delays. *American Journal on Mental Retardation*, *107*(6), 433–444. https://doi.org/10.1352/0895-8017(2002)107<0433:BPAPSI>2.0.CO;2

Bergsund, H. B., Wentzel-Larsen, T., & Jacobsen, H. (2020). Parenting stress in long-term foster carers: A longitudinal study. *Child & Family Social Work*, *25*(S1), 53–62. https://doi.org/10.1111/cfs.12713

Blackburn, C., & Matchett, E. (2022). 'A little piece of my heart goes with each of them': Foster carer reflections on current fostering practice. *Adoption & Fostering*, *46*(4), 383–396. https://doi.org/10.1177/03085759221135203

Blythe, S. L., Wilkes, L., & Halcomb, E. J. (2014). The foster carer's experience: An integrative review. *Collegian*, *21*(1), 21–32. https://doi.org/10.1016/j.colegn.2012.12.001

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597. https://doi.org/10.1080/2159676x.2019.1628806

Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, *18*(3), 328–352. https://doi.org/10.1080/14780887.2020.1769238

Brewer, A. (2018). “We were on our own”: Mothers’ experiences navigating the fragmented system of professional care for autism. *Social Science & Medicine*, *215*, 61–68. https://doi.org/10.1016/j.socscimed.2018.08.039

Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism*, *8*(4), 409–423. https://doi.org/10.1177/1362361304047224

Butrimaviciute, R., & Grieve, A. (2014). Carers’ experiences of being exposed to challenging behaviour in services for autism spectrum disorders. *Autism*, *18*(8), 882–890. https://doi.org/10.1177/1362361313508022

Byrne, D. (2022). A worked example of Braun and Clarke’s approach to reflexive thematic analysis. *Quality & Quantity*, *56*(3), 1391–1412. https://doi.org/10.1007/s11135-021-01182-y

Cadman, T., Eklund, H., Howley, D., Hayward, H., Clarke, H., Findon, J., Xenitidis, K., Murphy, D., Asherson, P., & Glaser, K. (2012). Caregiver Burden as People With Autism Spectrum Disorder and Attention-Deficit/Hyperactivity Disorder Transition into Adolescence and Adulthood in the United Kingdom. *Journal of the American Academy of Child & Adolescent Psychiatry*, *51*(9), 879–888. https://doi.org/10.1016/j.jaac.2012.06.017

Challenging Behaviour Foundation. (2022). *What is challenging behaviour?* Challenging Behaviour Foundation. https://www.challengingbehaviour.org.uk/understanding-challenging-behaviour/what-is-challenging-behaviour/

Chung, J. C. Y., Mevorach, C., & Woodcock, K. A. (2022). Establishing the transdiagnostic contextual pathways of emotional outbursts. *Scientific Reports*, *12*(1), Article 1. https://doi.org/10.1038/s41598-022-11474-4

Christie, H., Hiscox, L. V., Halligan, S. L., & Creswell, C. (2022). Examining harmful impacts of the COVID-19 pandemic and school closures on parents and carers in the United Kingdom:

A rapid review. *JCPP Advances*, *2*(3), e12095. https://doi.org/10.1002/jcv2.12095

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. https://doi.org/10.1111/j.1365-2788.2010.01258.x

Dickinson, H., & Yates, S. (2020). *More than isolated: The experience of children and young people with disability and their families during the COVID-19 pandemic* [Report]. Children and Young People with Disability Australia. https://apo.org.au/node/305856

Dillenburger, K., & McKerr, L. (2011). 'How long are we able to go on?' Issues faced by older family caregivers of adults with disabilities. *British Journal of Learning Disabilities*, *39*(1), 29–38. https://doi.org/10.1111/j.1468-3156.2010.00613.x

Dyches, T. T., Christensen, R., Harper, J. M., Mandleco, B., & Roper, S. O. (2016). Respite Care for Single Mothers of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *46*(3), 812–824. https://doi.org/10.1007/s10803-015-2618-z

Emerson, E. (2003). Mothers of children and adolescents with intellectual disability: Social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research*, *47*(4–5), 385–399. https://doi.org/10.1046/j.1365-2788.2003.00498.x

Faust, H., & Scior, K. (2008). Mental Health Problems in Young People with Intellectual Disabilities: The Impact on Parents. *Journal of Applied Research in Intellectual Disabilities*, *21*(5), 414–424. https://doi.org/10.1111/j.1468-3148.2007.00411.x

Follan, M., & McNamara, M. (2014). A fragile bond: Adoptive parents' experiences of caring for children with a diagnosis of reactive attachment disorder. *Journal of Clinical Nursing*, *23*(7–8), 1076–1085. https://doi.org/10.1111/jocn.12341

Geiger, J. M., Hayes, M. J., & Lietz, C. A. (2013). Should I stay or should I go? A mixed methods study examining the factors influencing foster parents' decisions to continue or discontinue providing foster care. *Children and Youth Services Review*, *35*(9), 1356–1365. https://doi.org/10.1016/j.childyouth.2013.05.003

Gillespie-Smith, K., McConachie, D., Ballantyne, C., Auyeung, B., & Goodall, K. (2023). The Impact of COVID-19 Restrictions on Psychological Distress in Family Caregivers of Children with Neurodevelopmental Disability in the UK. *Journal of Autism and Developmental Disorders*, *53*(4), 1573–1587. https://doi.org/10.1007/s10803-021-05132-3

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. https://doi.org/10.1046/j.1365-2788.2003.00485.x

Iovino, E. A., Caemmerer, J., & Chafouleas, S. M. (2021). Psychological distress and burden among family caregivers of children with and without developmental disabilities six months into the COVID-19 pandemic. *Research in Developmental Disabilities*, *114*, 103983. https://doi.org/10.1016/j.ridd.2021.103983

Jackson, L., Keville, S., & Ludlow, A. K. (2020). Mothers' Experiences of Accessing Mental Health Care for their Child with an Autism Spectrum Disorder. *Journal of Child and Family Studies*, *29*(2), 534–545. https://doi.org/10.1007/s10826-019-01662-8

Kersh, J., Hedvat, T. t., Hauser-Cram, P., & Warfield, M. E. (2006). The contribution of marital quality to the well-being of parents of children with developmental disabilities. *Journal of Intellectual Disability Research*, *50*(12), 883–893. https://doi.org/10.1111/j.1365-2788.2006.00906.x

Kouroupa, A., Allard, A., Gray, K. M., Hastings, R. P., Heyne, D., Melvin, G. A., Tonge, B. J., & Totsika, V. (2022). Home schooling during the COVID-19 pandemic in the United Kingdom: The experience of families of children with neurodevelopmental conditions. *Frontiers in Education*, *7*. https://doi.org/10.3389/feduc.2022.974558

Linden, M. A., Forbes, T., Brown, M., Marsh, L., Truesdale, M., McCann, E., Todd, S., &

Hughes, N. (2022). Impact of the COVID-19 pandemic on family carers of those with profound and multiple intellectual disabilities: Perspectives from UK and Irish Non-Governmental Organisations. *BMC Public Health*, *22*(1), 2095. https://doi.org/10.1186/s12889-022-14560-4

Lipsky, D. (2011). *From Anxiety to Meltdown: How Individuals on the Autism Spectrum Deal with Anxiety, Experience Meltdowns, Manifest Tantrums, and How You Can Intervene Effectively*. Jessica Kingsley Publishers.

Lyons, E., & Coyle, A. (2021). Doing thematic analysis. *Analysing qualitative data in psychology* (3rd ed., pp 104-118). SAGE.

McCarthy, J., Hemmings, C., Kravariti, E., Dworzynski, K., Holt, G., Bouras, N., & Tsakanikos, E. (2010). Challenging behavior and co-morbid psychopathology in adults with intellectual disability and autism spectrum disorders. *Research in Developmental Disabilities*, *31*(2), 362–366. https://doi.org/10.1016/j.ridd.2009.10.009

McGill, P., Papachristoforou, E., & Cooper, V. (2006). Support for family carers of children and young people with developmental disabilities and challenging behaviour. *Child: Care, Health and Development*, *32*(2), 159–165. https://doi.org/10.1111/j.1365-2214.2006.00600.x

McGill, P., Cooper, V., & Honeyman, G. (2010). Developing better commissioning for individuals with behaviour that challenges services – a scoping exercise.

Montaque, I., Dallos, R., & McKenzie, B. (2018). "It feels like something difficult is coming back to haunt me": An exploration of 'meltdowns' associated with autistic spectrum disorder from a parental perspective. *Clinical Child Psychology and Psychiatry*, *23*(1), 125–139. https://doi.org/10.1177/1359104517730114

Morgan, K., & Baron, R. (2011). Challenging Behaviour in Looked after Young People, Feelings of Parental Self-Efficacy and Psychological Well-Being in Foster Carers. *Adoption & Fostering*, *35*(1), 18–32. https://doi.org/10.1177/030857591103500104

Murphy, G. H., Beadle-Brown, J., Wing, L., Gould, J., Shah, A., & Holmes, N. (2005). Chronicity of Challenging Behaviours in People with Severe Intellectual Disabilities and/or Autism: A Total Population Sample. *Journal of Autism and Developmental Disorders*, *35*(4), 405–418. https://doi.org/10.1007/s10803-005-5030-2

Neece, C., McIntyre, L. L., & Fenning, R. (2020). Examining the impact of COVID-19 in ethnically diverse families with young children with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, *64*(10), 739–749. https://doi.org/10.1111/jir.12769

Octoman, O., & McLean, S. (2014). Challenging behaviour in foster care: What supports do foster carers want? *Adoption & Fostering*, *38*(2), 149-158. https://doi.org/10.1177/0308575914532404

Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, *45*(6), 535–543. https://doi.org/10.1046/j.1365-2788.2001.00372.x

O'Nions, E., Happé, F., Evers, K., Boonen, H., & Noens, I. (2018). How do Parents Manage Irritability, Challenging Behaviour, Non-Compliance and Anxiety in Children with Autism Spectrum Disorders? A Meta-Synthesis. *Journal of Autism and Developmental Disorders*, *48*(4), 1272–1286. https://doi.org/10.1007/s10803-017-3361-4

Patel, V., Perez-Olivas, G., Kroese, B. S., Rogers, G., Rose, J., Murphy, G., Cooper, V., Langdon,P. E., Hiles, S., Clifford, C., & Willner, P. (2021). The Experiences of Carers of Adults WithIntellectual Disabilities During the First COVID-19 Lockdown Period. *Journal of Policy and Practice in Intellectual Disabilities*, *18*(4), 254–262. https://doi.org/10.1111/jppi.12382

Power, A. (2009). 'It's the system working for the system': Carers' experiences of learning disability services in Ireland. *Health & Social Care in the Community*, *17*(1), 92–98.

https://doi.org/10.1111/j.1365-2524.2008.00807.x

Regan, D. (2020). How the challenging behaviour of a traumatised child tells their trauma story and is a vital part of their recovery. *Journal of Social Work Practice*, *34*(1), 113–118. https://doi.org/10.1080/02650533.2019.1572081

Robinson, S., & Weiss, J. A. (2020). Examining the relationship between social support and stress for parents of individuals with autism. *Research in Autism Spectrum Disorders*, *74*, 101557. https://doi.org/10.1016/j.rasd.2020.101557

Rogers, G., Perez-Olivas, G., Stenfert Kroese, B., Patel, V., Murphy, G., Rose, J., Cooper, V., Langdon, P. E., Hiles, S., Clifford, C., & Willner, P. (2021). The experiences of mothers of children and young people with intellectual disabilities during the first COVID-19 lockdown period. *Journal of Applied Research in Intellectual Disabilities*, *34*(6), 1421–1430. https://doi.org/10.1111/jar.12884

Rowbotham, M., Carroll, A., & Cuskelly, M. (2011). Mothers' and Fathers' Roles in Caring for an Adult Child with an Intellectual Disability. *International Journal of Disability, Development and Education*, *58*(3), 223–240. https://doi.org/10.1080/1034912X.2011.598396

Rzepecka, H., McKenzie, K., McClure, I., & Murphy, S. (2011). Sleep, anxiety and challenging behaviour in children with intellectual disability and/or autism spectrum disorder. *Research in Developmental Disabilities*, *32*(6), 2758–2766. https://doi.org/10.1016/j.ridd.2011.05.034

Saunders, B. S., Tilford, J. M., Fussell, J. J., Schulz, E. G., Casey, P. H., & Kuo, D. Z. (2015). Financial and employment impact of intellectual disability on families of children with autism. *Families, Systems, & Health*, *33*, 36–45. https://doi.org/10.1037/fsh0000102

Seymour, M., Allen, S., Giallo, R., & Wood, C. E. (2022). 'Dads kind of get forgotten': The mental health support needs of fathers raising a child with Autism Spectrum Disorder. *Journal of Family Studies*, *28*(4), 1199– 1216.

https://doi.org/10.1080/13229400.2020.1809491

Sharda, E. (2022). Parenting Stress and Well-Being Among Foster Parents: The Moderating Effect of Social Support. *Child and Adolescent Social Work Journal*, *39*(5), 547–559. https://doi.org/10.1007/s10560-022-00836-6

Smith, L. E., Greenberg, J. S., & Seltzer, M. M. (2012). Social Support and Well-being at Mid-Life Among Mothers of Adolescents and Adults with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *42*(9), 1818–1826. https://doi.org/10.1007/s10803-011-1420-9

Smitherman, L. C., Golden, W. C., & Walton, J. R. (2021). Health Disparities and Their Effects on Children and Their Caregivers During the Coronavirus Disease 2019 Pandemic. *Pediatric Clinics*, *68*(5), 1133–1145. https://doi.org/10.1016/j.pcl.2021.05.013

Tokatly Latzer, I., Leitner, Y., & Karnieli-Miller, O. (2021). Core experiences of parents of children with autism during the COVID-19 pandemic lockdown. *Autism*, *25*(4), 1047–1059. https://doi.org/10.1177/1362361320984317

Vossler, A., & Moller, N. (2014). How to use thematic analysis with interview data. *The counselling and psychotherapy research handbook* (1st ed., pp 173-184). SAGE Publications, Limited.

Weiss, J., & Lunsky, Y. (2010). Service Utilization Patterns in Parents of Youth and Adults With Intellectual Disability Who Experienced Behavioral Crisis. *Journal of Mental Health Research in Intellectual Disabilities*, *3*(3), 145–163. https://doi.org/10.1080/19315864.2010.490617

White, N., & Hastings, R. P. (2004). Social and Professional Support for Parents of Adolescents with Severe Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, *17*(3), 181–190. https://doi.org/10.1111/j.14683148.2004.00197.x

Whitley, E., Reeve, K., & Benzeval, M. (2023). Tracking the mental health of home-carers during the first COVID-19 national lockdown: Evidence from a nationally representative UK survey. *Psychological Medicine*, *53*(3), 1096–1105. https://doi.org/10.1101/2021.01.25.21250437

Whitt-Woosley, A., Sprang, G., & Eslinger, J. (2022). Foster care during the COVID-19 pandemic: A qualitative analysis of caregiver and professional experiences. *Child Abuse & Neglect*, *124*, 105444. https://doi.org/10.1016/j.chiabu.2021.105444

Willner, P., Rose, J., Stenfert Kroese, B., Murphy, G. H., Langdon, P. E., Clifford, C., Hutchings, H., Watkins, A., Hiles, S., & Cooper, V. (2020). Effect of the COVID-19 pandemic on the mental health of carers of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *33*(6), 1523–1533. https://doi.org/10.1111/jar.12811

Wodehouse, G., & McGill, P. (2009). Support for family carers of children and young people with developmental disabilities and challenging behaviour: What stops it being helpful? *Journal of Intellectual Disability Research*, *53*(7), 644–653. https://doi.org/10.1111/j.1365-2788.2009.01163.x

Chapter 3. Press Release: Literature Review

‘I thought my son will be going to Oxford University, not to a special school’: Voices of ethnic minority carers in the UK

10% of carers in the UK care for children with developmental difficulties, of which 7% are from ethnic minority backgrounds (Roman-Urrestarazu et al., 2021). Yet, ethnic carers’ experiences are often ignored, with little appreciation of their unique circumstances. Difficulties with finances, lack of support from services and respite care can influence minority carers’ experiences, more than those of White British carers (DeLambo et al., 2011). Ethnic minority carers also face more stigma and discrimination, not only from others but many times from their own families (Alsharaydeh et al., 2019). This can lead to increases in mental health problems such as anxiety and depression. Despite these difficulties, there has been very little research into the needs and experiences of ethnic minority carers in the UK, and even less research into their own insights.

Therefore, to explore the experiences of minority carers in the UK, principal researcher Snigdha Mukerji, University of Birmingham, reviewed studies on carers’ personal accounts. With assistance from other researchers at the School of Psychology, all relevant studies in the last ten years were screened for quality, reviewed, synthesized and compared for similarities and differences. This resulted in the generation of four main factors that surrounded carers’ experiences: understanding the diagnosis and its social and cultural implications; lack of support from professionals, family members and own community; barriers to advocacy; cultural coping, all of which were underpinned by wider factors such as immigration and social and cultural norms present in the communities.

Most carers had difficulties accepting the diagnosis, as in some cultures the concept of disabilities did not exist or was associated with a lot of stigma and bad omens. In turn, some carers may resort to self-blame, shame and grief over the loss of a 'normal' child, while others may reject their community's norms and judgements. One carer expressed disappointment and surprise over the diagnosis and said, '*Oh, my god, (deep breath) that was very difficult . . . Yes! . . . when I came to the UK, I thought my son will be going to Oxford University, not to a special school. That was very difficult to tell people*' (Marku, 2022)

Many carers also had to battle with services to receive any support and often felt unheard. Thus, they had difficulties advocating for their child, with the main barrier being language and communication constraints, especially for carers who had recently migrated from another country. As a result, they felt lost and frustrated regarding the care they should be giving their child and strategies they should be applying: '*Nobody has told mum what to do or how to improve her [daughter with disabilities'] behaviour, explained it to her in mum's language and helped her understand. There are lots of things they could do which haven't been done*' (Hatton et al., 2010).

On the flip side, however, some carers also had positive experiences of interactions with services and communities, where they started to build meaningful relationships and support networks. Once they saw that schools were responsive and '*they let (the child) learn at her own pace*' (Rizvi 2017), they started to accept that their child would be going to a special school. However, factors such as living in a more financially well-off area and having a partner who works in the healthcare sector might influence how some carers have more positive experiences than those living in socially and financially deprived areas.

Religion and cultural coping methods seemed to be very important to carers, with most of them expressing that it's '*all the will of Allah*' (Durling et al., 2018) and attributing the presence of the 'special' child in their lives to a test from God. This helped them cope in tough times and built a sense of resilience. However, under societal pressure, many carers also searched for 'cures' in the form of religious leaders or methods of removing the curse from their child.

These experiences highlighted some important implications for future services, support and policies. Firstly, there is a need for more awareness of diagnoses such as autism and other developmental disabilities for ethnic minority communities. Formal services should also offer more culturally sensitive meetings with carers and provide translators where necessary to avoid carers feeling left out. Without these changes, ethnic carers may continue to face additional pressures from communities, distress when dealing with services and feelings of grief and shame.

3.1 References

Alsharaydeh, E. A., Alqudah, M., Lee, R. L. T., & Chan, S. W.-C. (2019). Challenges, Coping, and Resilience Among Immigrant Parents Caring for a Child With a Disability: An Integrative Review. *Journal of Nursing Scholarship*, *51*(6), 670– 679. https://doi.org/10.1111/jnu.12522

DeLambo, D., Chung, W., & Huang, W. (2011). Stress and age: A comparison of Asian American and non-Asian American parents of children with developmental disabilities. *Journal of Developmental and Physical Disabilities*, *23*(2), 129-141. https://doi.org/10.1007/s10882-010-9211-3

Durling, E., Chinn, D., & Scior, K. (2018). Family and community in the lives of UK Bangladeshi parents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *31*(6), 1133–1143. https://doi.org/10.1111/jar.12473

Marku, B., Niolaki, G., Terzopoulos, A., & Wood, C. (2022). Eastern European parents' experiences of parenting a child with SEN in England. *Educational Psychology in Practice*, *38*(3), 297–316. https://doi.org/10.1080/02667363.2022.2100320

Rizvi, S. (2017). Exploring British Pakistani mothers' perception of their child with disability: Insights from a UK context. *Journal of Research in Special Educational Needs*, *17*(2), 87–97. https://doi.org/10.1111/1471-3802.12111

Roman-Urrestarazu, A., van Kessel, R., Allison, C., Matthews, F. E., Brayne, C., & Baron- Cohen, S. (2021). Association of Race/Ethnicity and Social Disadvantage With Autism Prevalence in 7 Million School Children in England. *JAMA Pediatrics*, *175*(6), e210054. https://doi.org/10.1001/jamapediatrics.2021.0054

Chapter 4. Press Release: Empirical Research Paper

Permanently locked down: What it meant to be a carer for young people with emotional outbursts in and before the COVID-19 pandemic

Challenging behaviour, such as screaming, throwing objects, self-harm and hitting out at others is often observed in young people and adults with developmental disabilities like autism and learning disabilities (Challenging Behaviour Foundation, 2022). One aspect of challenging behaviours involves emotional outbursts, which are highly emotional episodes of tantrums (vocal aggression) or meltdowns (physical forms of aggression). Unsurprisingly, emotional outbursts can have a negative impact on caregiver mental health.

The unpredictable nature of emotional outbursts can push carers to constantly prepare and pre-empt to avoid triggering them and lead to higher levels of anxiety, fear and exhaustion for carers (Montaque et al., 2018). Moreover, factors such as marital status, financial status, education level and access to services can influence carer mental health in different contexts. Many studies explored the personal experiences of carers for young people with autism or learning disabilities, however, none of the studies specifically investigated the experiences of carers who faced emotional outbursts regularly in the UK.

Therefore, primary researcher Snigdha Mukerji at the University of Birmingham, explored the personal experiences of carers of young people (aged between five and twenty years) with emotional outbursts before and during the pandemic in the UK. Interviews were conducted and analysed with the help of Dr Kate Woodcock, senior lecturer at the University of Birmingham, to identify shared patterns around carers' experiences.

The findings highlighted the profound impact of the pandemic on carers' experiences. While some carers had access to services and face-to-face support before the pandemic, this stopped suddenly in the pandemic. With no sources of support, carers were left to play multiple roles for the child and balance multiple responsibilities, which led to immense frustration with services, exhaustion, hopelessness, guilt and self-doubt. One carer shared, "*…it was really sort of clinging for support. I found that really, really hard…and felt like am I failing him because I can't, I don't understand where to go to get the support?"*

Many carers also talked about the increase in emotional outbursts in the pandemic, which left them feeling anxious, fearful and tired. They lived in constant fear of the outbursts they would deal with when they did pursue their hobbies, as one carer expressed, "*I go out for an hour, then my husband's going to be with him on his own and then there's more stuff to sort out cause my husband and my son, they would have fallen out. So it was almost like, is it worth going out, having a bit of me time because you have more hassle to sort out when you get home."* Sacrifices also came in the form of carers giving up their careers and relationships to attend multiple appointments and give their full attention to the child's needs.

Single, adoptive and foster carers had additional pressures such as not having any support at home, increased isolation, challenges with foster and adoption agencies and fear of mortality from the virus, especially in the context of caring for children who would be left alone or put back into care homes if the carer passed away. Some foster carers also shared feeling undervalued compared to frontline workers: *"it was challenging, when you've got no one to depend on and you've got three children that technically aren't yours. You feel that you're taking on a lot of risk you are frontline and yet you weren't being acknowledged like* *the nurses and police officers and all this."*

Nevertheless, some carers also reported positive experiences of spending more time with families and ease of routines. They employed coping strategies such as preparing, creating new routines, using resilience to push through tough times and keeping a positive mindset. Although it was difficult to carve out some personal time, some found outdoor activities relaxing and achieved a sense of "*agency*".

These findings support previous research and theories and have several implications for policymakers and services. Lead researcher Snigdha Mukerji says "given that the pandemic was an unprecedented event, future policies and services could learn from it and include contingency plans to support carers." In the era of the internet, more online support and weekly calls could be scheduled for carers, with specific strategies for dealing with emotional outbursts.

4.1 References

Challenging Behaviour Foundation. (2022). *What is challenging behaviour?* Challenging Behaviour Foundation. https://www.challengingbehaviour.org.uk/understanding-challenging-behaviour/what-is-challenging-behaviour/

Montaque, I., Dallos, R., & McKenzie, B. (2018). "It feels like something difficult is coming back to haunt me": An exploration of 'meltdowns' associated with autistic spectrum disorder from a parental perspective. *Clinical Child Psychology and Psychiatry*, *23*(1), 125–139. https://doi.org/10.1177/1359104517730114

Appendix A

NICE Quality Checklist for Qualitative Research

Checklist

Study identification: Include author, title, reference, year of publication		
Guidance topic:	**Key research question/aim:**	
Checklist completed by:		
Theoretical approach		
Is a qualitative approach appropriate? For example: Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? Could a quantitative approach better have addressed the research question?	Appropriate Inappropriate Not sure	Comments:
Is the study clear in what it seeks to do? For example: Is the purpose of the study discussed – aims/objectives/research question/s? Is there adequate/appropriate reference to the literature? Are underpinning values/assumptions/theory discussed?	Clear Unclear Mixed	Comments:
Study design		

3. How defensible/rigorous is the research design/methodology? For example: Is the design appropriate to the research question?	Defensible Indefensible	Comments:

Is a rationale given for using a qualitative approach? Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? Is the selection of cases/sampling strategy theoretically justified?	Not sure	
Data collection		
How well was the data collection carried out? For example: Are the data collection methods clearly described? Were the appropriate data collected to address the research question? Was the data collection and record keeping systematic?	Appropriately Inappropriately Not sure/inadequately reported	Comments:
Trustworthiness		
Is the role of the researcher clearly described? For example: Has the relationship between the researcher and the participants been adequately considered? Does the paper describe how the research was explained and presented to the participants?	Clearly described Unclear Not described	Comments:

Is the context clearly described? For example: Are the characteristics of the participants and settings clearly defined? Were observations made in a sufficient variety of circumstances Was context bias considered	Clear Unclear Not sure	Comments:
7. Were the methods reliable? For example: Was data collected by more than 1 method? Is there justification for triangulation, or for not triangulating? Do the methods investigate what they claim to?	Reliable Unreliable Not sure	Comments:
Analysis		
Is the data analysis sufficiently rigorous? For example: Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results? How systematic is the analysis, is the procedure reliable/dependable? Is it clear how the themes and concepts were derived from the data?	Rigorous Not rigorous Not sure/not reported	Comments:

Is the data 'rich'? For example: How well are the contexts of the data described? Has the diversity of perspective and content been explored? How well has the detail and depth been demonstrated? Are responses compared and contrasted across groups/sites?	Rich Poor Not sure/not reported	Comments:
Is the analysis reliable? For example: Did more than 1 researcher theme and code transcripts/data? If so, how were differences resolved? Did participants feedback on the transcripts/data if possible and relevant? Were negative/discrepant results addressed or ignored?	Reliable Unreliable Not sure/not reported	Comments:

Are the findings convincing? For example: Are the findings clearly presented? Are the findings internally coherent? Are extracts from the original data included? Are the data appropriately referenced? Is the reporting clear and coherent?	Convincing Not convincing Not sure	Comments:

12. Are the findings relevant to the aims of the study?	Relevant Irrelevant Partially relevant	Comments:
Conclusions For example: How clear are the links between data, interpretation and conclusions? Are the conclusions plausible and coherent? Have alternative explanations been explored and discounted? Does this enhance understanding of the research topic? Are the implications of the research clearly defined? **Is there adequate discussion of any limitations encountered?**	Adequate Inadequate Not sure	Comments:
Ethics		
14. How clear and coherent is the reporting of ethics? For example: Have ethical issues been taken into consideration? Are they adequately discussed e.g. do they address consent and anonymity? Have the consequences of the research been considered i.e. raising expectations, changing behaviour? Was the study approved by an ethics committee?	Appropriate Inappropriate Not sure/not reported	Comments:
Overall assessment		

As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)	++ + –	Comments:

Note. Checklist taken from NICE (2012) guidance.

Appendix B

Quality Appraisal Outcomes Table

Study Title	Appropriateness of study	Clearness of study	Study Design	Data Collection	Role of researcher	Clear context	Reliable methods
Eastern European parents' experiences of parenting a child with SEN in England (Marku, 2022)	Met: research questions would not have been better answered by quantitative methods	Met: adequate and appropriate reference to previous literature and Bronfenbrenner's ecological systems theory	Met: clearly stated the design and appropriateness to research question, rationale regarding use of purposive sampling and inclusion criteria	Met: methods described clearly and appropriate to research question, including where, how, when and how long interviews lasted	Partially-met: some statements about the researchers' own epistemological position but limited discussion about it and no mention of how research was presented to participants	Met: clear description of participants and setting and discussion of how some contextual characteristics might give different results in different studies	Met: data collected through one source (interviews) but appropriate and checked through a pilot first and some triangulation (interviewing a couple)
Understanding Pakistani parents' experience of having a child with special educational needs and disability (SEND) in England (Akbar & Woods, 2020)	Met: research questions would not have been better answered by quantitative methods	Met: adequate and appropriate reference to previous literature and Bronfenbrenner's ecological systems theory	Met: clearly stated the design and appropriateness to research question, rationale regarding use of purposive sampling and inclusion criteria	Met: methods described clearly and appropriate to research question, including where, how, when and how long interviews	Met: adequate discussion about researcher's own insider/outside perspective and factors such as age, ethnicity, gender	Met: clear description of participants and setting and discussion of how some contextual characteristics might give different results in different studies	Met: data collected through one source (interviews) but appropriate and checked through a pilot first and some triangulation (interviewing fathers and a

				lasted			sibling)
Family and community in the lives of UK Bangladeshi parents with intellectual disabilities (Durling et al., 2018)	Met: aim would not have been better answered by quantitative methods	Partially-met: adequate and appropriate reference to previous literature and although aims were set out, no research questions were mentioned	Met: clearly stated the design and appropriateness to research question, rationale regarding inclusion criteria	Met: methods described clearly and appropriate to research question, including where, how, when and how long interviews lasted	Met: adequate discussion about researcher's own insider/outside perspective and factors such as age, ethnicity, gender and reflexivity	Met: clear description of participants and setting and discussion of how some contextual characteristics might give different results in different studies	Met: data collected through one source (interviews) but appropriate and checked through a pilot first and some triangulation (interviewing fathers, siblings, and community members)
'You are labelled by your children's disability' - A community-based, participatory study of stigma among Somali parents of children with autism living in the United Kingdom (Ellen Selman et al., 2018)	Met: aim would not have been better answered by quantitative methods	Met: adequate and appropriate reference to previous literature and stigma theory	Met: clearly stated the design and appropriateness to research question, rationale regarding use of purposive sampling and inclusion criteria	Met: methods described clearly and appropriate to research question, including where, how, when and how long interviews lasted	Unmet: no mention of researcher characteristics or role and/or reflection on how this could have impacted data collection and interpretation	Met: clear description of participants and setting and discussion of how some contextual characteristics might give different results in different studies	Met: data collected through one source (interviews) but appropriate and some triangulation (interviewing fathers as well as mothers)
Pakistani mothers' experiences of parenting a child with autism	Met: aim would not have been better answered by quantitative	Partially-met: adequate and appropriate reference to	Met: clearly stated the design and appropriateness	Met: methods described clearly and	Met: adequate discussion about researcher's own insider/outside	Partially-met: clear description of participants	Met: data collected through one source

spectrum disorder (ASD) in Ireland (Habib et al., 2017)	methods	previous literature although aims and research questions were not clearly set out	to research question, rationale regarding use of purposive sampling and inclusion criteria	appropriate to aim, including where, how, when and how long interviews lasted	perspective and factors such as age, ethnicity, gender and position	but very limited description of context of interviews and no discussion of potential context bias	(interviews) but appropriate and no triangulation as it did not relate to aim
Exploring British Pakistani mothers' perception of their child with disability: insights from a UK context (Rizvi, 2017)	Met: aim would not have been better answered by quantitative methods	Met: adequate and appropriate reference to previous literature the framework that the study sits in	Met: clearly stated the design and appropriateness to research question, rationale regarding inclusion criteria	Partially-met: no description of where or how long interviews were conducted for	Unmet: no mention of researcher characteristics or role and/or reflection on how this could have impacted data collection and interpretation	Partially-met: clear description of participants but very limited description of context of interviews and no discussion of potential context bias	Met: data collected through one source (interviews) but appropriate and no triangulation as it did not relate to aim
The experiences of African immigrant mothers living in the United Kingdom with a child diagnosed with an autism spectrum disorder: an interpretive phenomenological analysis (Munroe et al., 2016)	Met: research questions would not have been better answered by quantitative methods	Met: adequate and appropriate reference to previous literature the framework that the study sits in	Met: clearly stated the design and appropriateness to research question, rationale regarding use of purposive sampling and inclusion criteria	Met: methods described clearly and appropriate to research question, including where, how, when and how long interviews lasted	Met: adequate discussion about researcher's own insider/outside perspective and factors such as age, ethnicity, gender and reflexivity	Met: clear description of participants and setting and discussion of how some contextual characteristics might give different results in different studies	Met: data collected through one source (interviews) but appropriate as checked by pilot and no triangulation as it did not relate to aim

The experiences of British South Asian carers caring for a child with developmental disabilities in the UK (Heer et al., 2015)	Met: aim would not have been better answered by quantitative methods	Met: adequate and appropriate reference to previous literature the framework that the study sits in	Met: clearly stated the design and appropriateness to research question, rationale regarding inclusion criteria	Met: methods described clearly and appropriate to aim, including where, how, when and how long interviews lasted	Partially-met: some statements about the researchers' own epistemological position but limited discussion about it	Met: clear description of participants and setting and discussion of how some contextual characteristics might give different results in different studies	Met: data collected through one source (interviews) but appropriate and checked through a pilot first and some triangulation
Coping strategies used by Pakistani parents living in the United Kingdom and caring for a severely disabled child (Croot et al., 2012)	Met: aim would not have been better answered by quantitative methods	Met: adequate and appropriate reference to previous literature the framework that the study sits in	Met: clearly stated the design and appropriateness to research question, rationale regarding use of purposive sampling and inclusion criteria	Met: methods described clearly and appropriate to aim, including where, how, when and how long interviews lasted	Unmet: no mention of researcher characteristics or role and/or reflection on how this could have impacted data collection and interpretation	Met: clear description of participants and setting and discussion of how some contextual characteristics might give different results in different studies	Met: data collected through one source (interviews) but appropriate and checked through a pilot first and some triangulation (interviewing fathers, and grandparents)
Majority and Minority Ethnic Family Carers of Adults with Intellectual Disabilities: Perceptions of Challenging	Met: aim would not have been better answered by quantitative methods	Met: adequate and appropriate reference to previous literature the framework that the study sits in	Met: clearly stated the design and appropriateness to research question, rationale regarding use of	Met: methods described clearly and appropriate to aim, including where,	Partially-met: some statements about the researchers' own epistemological position but limited discussion about	Met: clear description of participants and setting and discussion of how some contextual characteristics	Met: data collected through one source (interviews) but appropriate and checked

Behaviour and Family Impact (Hatton et al., 2010)			purposive sampling and inclusion criteria	how, when and how long interviews lasted	it	might give different results in different studies	through a pilot first and some triangulation (interviewing fathers, and siblings)

Study Title	**Rigorous data analysis**	**Richness of data**	**Reliable analysis**	**Convincing findings**	**Findings relevant to aims**	**Conclusions and limitations**	**Ethics**	**Overall assessment**
Eastern European parents' experiences of parenting a child with SEN in England (Marku, 2022)	Partially-met: Braun and Clarke's process summarized and clear but although there was mention of reflexivity being used, no mention of how or what contribution it had to the data analysis	Met: detail and depth of interviews, comparing and contrasting responses	Unmet: no mention of another researcher coding themes and no discussion of negative/discrepant results	Met: clear and consistent data reporting, extracts from original data included, appropriately referenced	Met: findings answer the research questions and aims	Met: clear and appropriate links between data and interpretation and discussion of implications, along with appropriate considerations for a range of limitations	Met: approved by ethics and some discussion of how participants were anonymised and how confidentiality was ensured	+' (Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter.)
Understanding Pakistani parents' experience of having a child with special educational needs and disability (SEND) in	Met: clear description of coding and analysis and how codes were derived	Met: detail and depth of interviews, comparing and contrasting responses	Met: coding undertaken by another researcher and inter-rater reliability calculated, along with any translations double	Met: clear and consistent data reporting, extracts from original data included,	Met: findings answer the research questions and aims	Met: clear and appropriate links between data and interpretation and discussion of implications,	Met: approved by ethics and some discussion of how participants were anonymised	++' (All or most of the checklist criteria have been fulfilled, where they have not

England (Akbar & Woods, 2020)			checked by a Psychologist of the same background	appropriately referenced		along with appropriate considerations for a range of limitations	and how confidentiality was ensured	been fulfilled the conclusions are very unlikely to alter)
Family and community in the lives of UK Bangladeshi parents with intellectual disabilities (Durling et al., 2018)	Met: clear description of coding and analysis and how codes were derived	Met: detail and depth of interviews, comparing and contrasting responses	Met: coding undertaken by another researcher along with any translations double checked by another translator of the same background	Met: clear and consistent data reporting, extracts from original data included, appropriately referenced	Met: findings answer the research questions and aims	Met: clear and appropriate links between data and interpretation and discussion of implications, along with appropriate considerations for a range of limitations	Met: approved by ethics and some discussion of how participants were anonymised and how confidentiality was ensured	++' (All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter)
'You are labelled by your children's disability' - A community-based, participatory study of stigma among Somali parents of children with autism living in the United Kingdom (Ellen Selman et al., 2018)	Met: clear description of coding and analysis and how codes were derived	Met: detail and depth of interviews, comparing and contrasting responses	Met: coding undertaken by co-researcher along with any translations double checked by co-researcher	Met: clear and consistent data reporting, extracts from original data included, appropriately referenced	Met: findings answer the research questions and aims	Met: clear and appropriate links between data and interpretation and discussion of implications, along with appropriate considerations for a range of limitations	Met: approved by ethics and some discussion of how participants were anonymised and how confidentiality was ensured	++' (All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter)
Pakistani mothers'	Met: clear	Met: detail	Partially-met:	Met: clear	Met:	Met: clear and	Met: approved	+' (Some of

experiences of parenting a child with autism spectrum disorder (ASD) in Ireland (Habib et al., 2017)	description of coding and analysis and how codes were derived	and depth of interviews, comparing and contrasting responses	although there was a discussion of negative/discrepant themes, there was no mention of another researcher double-coding the themes	and consistent data reporting, extracts from original data included, appropriately referenced	findings answer the research questions and aims	appropriate links between data and interpretation and discussion of implications, along with appropriate considerations for a range of limitations	by ethics and some discussion of how participants were anonymised and how confidentiality was ensured	the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter.)
Exploring British Pakistani mothers' perception of their child with disability: insights from a UK context (Rizvi, 2017)	Met: clear description of coding and analysis and how codes were derived	Met: detail and depth of interviews, comparing and contrasting responses	Partially-met: although there was a discussion of negative/discrepant themes, there was no mention of another researcher double-coding the themes	Met: clear and consistent data reporting, extracts from original data included, appropriately referenced	Met: findings answer the research questions and aims	Met: clear and appropriate links between data and interpretation and discussion of implications, along with appropriate considerations for a range of limitations	Met: approved by ethics and some discussion of how participants were anonymised and how confidentiality was ensured	+' (Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter.)
The experiences of African immigrant	Met: clear description	Met: detail and depth	Met: coding undertaken by	Met: clear and	Met: findings	Met: clear and appropriate	Met: approved by ethics and	++' (All or most of the

mothers living in the United Kingdom with a child diagnosed with an autism spectrum disorder: an interpretive phenomenological analysis (Munroe et al., 2016)	of coding and analysis and how codes were derived	of interviews, comparing and contrasting responses	another researcher along with any translations double checked by another translator of the same background	consistent data reporting, extracts from original data included, appropriately referenced	answer the research questions and aims	links between data and interpretation and discussion of implications, along with appropriate considerations for a range of limitations	some discussion of how participants were anonymised and how confidentiality was ensured	checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter)
The experiences of British South Asian carers caring for a child with developmental disabilities in the UK (Heer et al., 2015)	Met: clear description of coding and analysis and how codes were derived	Met: detail and depth of interviews, comparing and contrasting responses	Met: coding undertaken by another researcher along with any translations double checked by another translator of the same background	Met: clear and consistent data reporting, extracts from original data included, appropriately referenced	Met: findings answer the research questions and aims	Met: clear and appropriate links between data and interpretation and discussion of implications, along with appropriate considerations for a range of limitations	Met: approved by ethics and some discussion of how participants were anonymised and how confidentiality was ensured	++' (All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter)
Coping strategies used by Pakistani parents living in the United Kingdom and caring for a severely disabled child (Croot et al., 2012)	Met: clear description of coding and analysis and how codes were derived	Met: detail and depth of interviews, comparing and contrasting responses	Met: coding undertaken by another researcher along with any translations double checked by another translator of the same background	Met: clear and consistent data reporting, extracts from original data included, appropriately	Met: findings answer the research questions and aims	Met: clear and appropriate links between data and interpretation and discussion of implications, along with	Met: approved by ethics and some discussion of how participants were anonymised and how	++' (All or most of the checklist criteria have been fulfilled, where they have not been

				referenced		appropriate considerations for a range of limitations	confidentiality was ensured	fulfilled the conclusions are very unlikely to alter)
Majority and Minority Ethnic Family Carers of Adults with Intellectual Disabilities: Perceptions of Challenging Behaviour and Family Impact (Hatton et al., 2010)	Met: clear description of coding and analysis and how codes were derived	Met: detail and depth of interviews, comparing and contrasting responses	Met: coding undertaken by another researcher along with any translations double checked by another translator of the same background	Met: clear and consistent data reporting, extracts from original data included, appropriately referenced	Met: findings answer the research questions and aims	Met: clear and appropriate links between data and interpretation and discussion of implications, along with appropriate considerations for a range of limitations	Met: approved by ethics and some discussion of how participants were anonymised and how confidentiality was ensured	++' (All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter)

Note. The quality checklist is split into two tables to accommodate all items

Appendix C

Study Characteristics Table

Year	Author	Title	Location	Sample				Method of data collection	Analysis method
				Age	Gender	Ethnicity	Number		
2022	B. Marku, G. Niolaki, A. Terzopoulos and C. Wood	Eastern European parents' experiences of parenting a child with SEN in England	England	Not given	7 female, 1 male	a parent from an A8 country that joined European Union (EU) in 2004; namely, Poland, Czech Republic, Slovenia, Slovakia, Lithuania, Estonia, Hungary and Latvia	Six mothers and one couple approached the researcher; three participants made contact by phone and five via email.	To investigate the A8 parents' lived experiences, a phenomenological lifeworld approach with in-depth semi-structured interviews and thematic analysis (TA), was chosen.	thematic analysis
2020	S. Akbar and K. Woods	Understanding Pakistani parents' experience of having a child with special educational needs and disability (SEND) in England	England	21-55	8 female, 2 male	Pakistani Muslim ethnic minority	10	semi-structured interviews	thematic analysis
2018	E. Durling, D. Chinn and K. Scior	Family and community in the lives of UK Bangladeshi parents with intellectual disabilities	England	21-50	5 female, 5 male	Bangladeshi	4 family members and 6 community members, 4 parents with ID	semi-structured interviews	thematic analysis

2018	L. Ellen Selman, F. Fox, N. Aabe, K. Turner, D. Rai and S. Redwood	'You are labelled by your children's disability' - A community-based, participatory study of stigma among Somali parents of children with autism living in the United Kingdom	England	28-56	12 female, 3 male	Somali	14 parents	semi-structured interviews	thematic analysis
2017	S. Habib, P. Prendeville, A. Abdussabur and W. Kinsella	Pakistani mothers' experiences of parenting a child with autism spectrum disorder (ASD) in Ireland	Ireland	Not given	Female	Pakistani Muslim ethnic minority	7	semi-structured interviews	thematic analysis
2017	S. Rizvi	Exploring British Pakistani mothers' perception of their child with disability: insights from a UK context	England	36-42	Female	Pakistani Muslim ethnic minority	5	semi-structured interviews	did not name the analysis but described how they formed the codes
2016	K. Munroe, L. Hammond and S. Cole	The experiences of African immigrant mothers living in the United Kingdom with a child diagnosed	England	30-45	Female	African	6	semi-structured interviews	IPA

		with an autism spectrum disorder: an interpretive phenomenological analysis							
2015	K. Heer, M. Larkin and J. Rose	The experiences of British South Asian carers caring for a child with developmental disabilities in the UK	England	27-42	5 female, 2 male	South Asian	7	semi-structured interviews	IPA
2012	E. Croot, G. Grant, N. Mathers and C. Cooper	Coping strategies used by Pakistani parents living in the United Kingdom and caring for a severely disabled child	England	Not given	7 female, 3 male	Pakistani Muslim ethnic minority	9	semi-structured interviews	constant comparative coding
2010	C. Hatton, E. Emerson, S. Kirby, H. Kotwal, S. Baines, C. Hutchinson, et al.	Majority and Minority Ethnic Family Carers of Adults with Intellectual Disabilities: Perceptions of Challenging Behaviour and Family Impact	England	33-70	Not given	7 ethnic minority and 7 majority	14	semi-structured interviews	IPA

Appendix D

Example of Data Extraction Table

Marku et al., 2022

Themes/ Metaphors	First Order	Third Order notes
making sense of SEN	‘Back home, autistic children do not always go to school . . . A friend of mine has a girl with autism . . . she hits, bites people, screams all the time and throws things. My son is not like that’ (Lena). As Lena talked about children with autism in her own country and SEN in the UK, she highlights the culture and educational provision differences between her country and the UK. Due to these differences, she also communicates a sense of fear that a label might deny her son the right to education (Manzoni & Rolfe, 2019). ‘ . . . everything is SEN here (UK), lots of children learn to talk late . . . girls are shy and get upset easily, that is normal. She can walk, she can talk . . . ’ (Anna). ‘ ... it was all about convincing me that my son has SEN ... In the end I agreed with the school . . . I think that was the best thing I did . . . the focus shifted to talk about what can be done to support my son rather than play the convincing game’ (Beata). Other parents disclosed that they felt pressured by professionals to agree to SEN referrals, particularly by the early years’ educators. Whilst many parents revealed that they accepted the advice given and went ahead with the referrals, some parents recalled waiting before pursuing an assessment. One parent communicated a sense of regret for delaying the	In the context of immigration and adapting to a new culture. Struggle between what parents and professionals thought was right. Reluctance and fear about getting a referral for an assessment- might highlight reluctance to accept that the child has additional needs and the stress that comes along with it, of not knowing how to help them, sense of tiredness and hopelessness (as reflected by primary author's interpretation) Idea that the struggles in accepting and going through the process of diagnosis is not unique to ethnic minorities or immigrants. Note also the common idea of loss and grief mentioned but balanced with some sense of understanding and relief. Balancing resistance to accept diagnosis with wanting an answer, a solution Fear of unknown and distress associated with navigating differences in each country

	assessment. ' . . . he loved numbers and I think because he likes numbers . . . they (the nursery staff) said "oh he is special, need to have him assessed" . . . If they talked to him about numbers, I think he would have showed interest in talking and interacting' (Lena). This can suggest that Lena felt that the professionals were more concerned with labelling her son than offering strategies to help him. 'I just keep stressing and worrying about how to help my daughter . . . It breaks my heart when I see her sad and do not know what to do' (Anna). 'I just do not know what to do, I have tried everything . . . the rewards and things . . . it is impossible to keep up' (Paulina). As parents try to make sense of their children's SEN, in the absence of support, different emotions have left some parents physically and emotionally drained and feelings of helplessness overwhelm them	
unpredicted destination	'I am worried that my son will not do well . . . if I cannot help him, I feel that I have failed in life . . . I have given up everything, I was a secondary teacher back home and I came here, and I work in a shop' (Dora). Most parents emphasised that the plans and the life they envisaged when they left their country for a better life in the UK were altered when they discovered their children's SEN. Dora's quote serves to illustrate this experience 'Oh, my god, (deep breath) that was very difficult . . . Yes! . . . when I came to the UK, I thought my son will be going to	Highlights participants feeling like they sacrificed a lot to provide the best for their child, to move to the UK. And have to leave behind expectations they had for their child as well. Due to this sacrifice, feeling like if they cannot help their child now, they will have failed. Difficulty disclosing and coming to terms with the diagnosis especially in front of others (family, friends, community) and what that means for their child. A sense of taking on their child's diagnosis as personal embarrassment or failure. And the importance of being included in the community--even if

	Oxford University, not to a special school. That was very difficult to tell people' (Daniela). ' . . . it was so embarrassing to hear that my child is not listening to the teacher . . . I told him (son) that if he cannot behave, we will have to go home . . . I could not say my child is naughty . . . now at least we know he is not naughty' (Rick) The fear of being perceived as a failure was echoed in other parents. Some parents talked about the broader pressure and the difficulty to tell friends and family in their home country about their children's needs. Rick communicates a sense of relief in under- standing that his son's behaviour is governed by his difficulties and not a discipline issue. 'My mum reminds me of how lucky my boy is to have such a good school ... it is the best place for my son but is far from the real world, and that still hurts'.(Daniela) Though many parents saw the transformation of the life they had previously envisaged in a less favourable light, some saw it as an opportunity for their children as they would not have had the same level of support in their home country. Although Daniela accepts that the special school is the 'best place' to meet her son's needs, the fear of separation from the 'real world', her child being segregated and not included in society still troubles her.	special schools might be good for the child, parents might feel fearful of rejection for their child
language barriers	'I was still learning English . . . I did not know what they were saying, what they wanted me to do. He was in school, and I was at home. I used to say to school to call my husband' (Paulina). Reflecting on their first encounters with education settings in the UK, parents recall that the language barriers were a challenge for most of them. Although two participants said	Stress associated with wanting to support their child but having to redirect people to others in the family who could speak English. Most times a challenge for more elderly people who had not learnt English and carers might feel a responsibility to act as a translator while trying to manage their own lives. This marks

	that translation services were provided over the phone, others relied heavily on family support. 'The nursery would call my mother in law and say, "Come and pick him up". I would be on the phone with the nursery and my mother in law because she did not understand much English. It was very difficult for her' (Lena). Most of the parents in this study communicated that challenges related to the English language impacted their elders and their children more than them as individuals. The support that Lena's mother- in-law could provide was very restricted due to the language barriers Whilst research acknowledges that feeling overwhelmed is a process that all parents experience, it is vital to recognise the multiple socio-economic and socio-cultural challenges that immigrant parents may experience could exacerbate these feelings. A critical example of these challenges felt by most parents in this study was the language barrier.	parents/carers from immigrant/ethnic minorities apart from the universal struggle of caring for a child with additional needs. Added pressure of supporting themselves and other family members- trying to multi-task with caring for their child and learning a foreign language and communicate with professionals. Not only very difficult for family members but added work for carers to act as interpreters
	" . . . the nursery was saying 'speak English, speak English, speak English' and speech and language therapist told me to speak our language " (Lena). 'When you are a young parent, you think the doctors and teachers know best, but now I think mums know a lot' (Anna). 'They (schoolteachers) have told me to keep reading stories in my language and in English . . . and talk and talk to her so that she can learn more words'. Most parents recalled that educators advised them to talk to their children in English, only to be given conflicting advice when they sought support from other professionals. Some parents recalled that education psychologists and speech and	Confusion between speaking English and their native language-sense of looking to professionals for advice regarding what to teach their children possibly due to carers feeling less confident in that area. Inconsistent advice and support by professionals and lack of communication between professionals-decrease in trust in professionals and dissatisfaction with how things were dealt with at school. Some recognition of the support provided by the teachers and social workers--very much focused on things to do for the

	language therapists discussed linguistic choices and advised parents not to mix languages in one sentence. ‘I do not remember the teacher, or the SENCO talk about what language to use when doing the activities’ (Dora). Indeed, linguistic or other support and guidance these EAL learners and families received depended greatly on the type of settings and individual professionals ‘A few times they (pre-school) called me to go and change his nappy . . . now when my son is at school; the school does everything for him . . . They are amazing’ (Daniela). Although educational settings have a legislative duty (Children & Families Act, 2014 & Equality Act, 2010) to support children who have health needs, Daniela’s quote highlights discrepancies amongst settings. In this case, the benefits of home language have not been embraced (Suárez-Orozco et al., 2011) and the opportunities to continue developing children’s home language seem to have been missed (Howard et al., 2021). These missed opportunities can impact children’s learning as research has found that supporting children’s home language is beneficial for acquiring an additional language, critical thinking, literacy skills and cultural identity (Howard et al., 2021; Suárez-Orozco et al., 2011). ‘One teacher told me that they are trying to separate my son and his friend because all they do is chat (in-home language) . . . The key worker was good; she kept sending me things for me to do at home’ (Dora). A8 parents recalled the advice given regarding their children’s linguistic choices; they highlighted inconsistency in the advice	child, not so much on listening to parents. Perhaps the concept of good support for carers meant actions for the child, indirect support for carers

	offered by educators and other professionals. this study highlights the discrepancy in partnership working and the shortcomings in advice and support provided to parents.	
	‘I have been so blessed to have had my mother-in-law with me; otherwise, I don’t know what I would do . . . she does everything for my children’ (Lena). those who had grandparents’ support had high regard and appreciation for their influence and involvement ‘My mother is very encouraging . . . she looks after my nephews back home . . . If she was with me, she would help look after him; I would spend more time at work’ (Dora). ‘I did not know that many people, and it is not like I can call my mum, or my sister to go and get him. They were back home’ (Daniela). Many parents expressed that they missed the support and access from their elders and wider family. At times, the challenges accessing the needed support leave some parents feeling helpless and defeated (Soriano et al., 2009). Such feelings can cause substantial distress and have a massive impact on their quality of life and the quality of their children’s upbringing (Kwan-Tat, 2018). In spite of this, as the journey continued, many participants gained a better understanding of their children’s needs. They started to accept a new normal, and as a result, they felt more empowered to help their children.	Mainly female relatives thought about for help. Cultural connotations? Frustration and sense of loss of support from relatives, maybe loss of own life where support was not available. But also about going through that struggle alone to make them more independent and confident in caring for the child. Also, sense of community support, not just the mum alone trying to care for the child, looking to elders Support from family networks might be a mediating factor in shame and personal failure

Appendix E

Colour Coded Themes Table

Marku, 2022	**Akbar and Woods, 2020**	**Durling et al (2018)**	**Ellen Selman et al (2018)**	**Habib et al (2017)**	**Rizvi (2017)**	**Munroe et al (2016)**	**Heer et al (2015)**	**Croot et al (2012)**	**Hatton et al (2010)**
making sense of SEN	Hidden disabilities more difficult to understand, explain and seek services for	Learning disability is an “alien concept”	Labelling and stereotyping: ‘you are labelled by your children’s disability’	Positive experiences of education	Understanding and perceptions of disability	All consuming	An uncertain future	Sharing care with others in the immediate family	Difficulties of the adult with intellectual disabilities
unpredicted destination	Confusion around the label	Everyone joins the cycle of life	Separation: ‘you always meet a lot of difficulties out there’	Positive impact of parenting a child with ASD	School placement decisions and maternal experiences with professionals	Maintaining privacy versus seeking support	Concurrent losses	Accepting support from the extended family	Relationships to local community
language barriers	Difficulty accepting diagnosis	A spouse may leave	Emotional responses, discrimination and power: ‘they don’t say it, but I feel it’	Access to services	Role of religion within parenting and supporting a disabled child	Loss	Fears about vulnerability of child	Use of external support	Relationships to services
professional support and guidance	Easier to hide the disability.	Understanding what marriage entails	Coping and resistance	Challenges in education		Others’ judgements	Managing multiple responsibilities	Taking a proactive approach	Relationship between person with intellectual disabilities and family carer
family and	Access to	Parenting is a	The power of	Life in the		Impact on	“Everything	Avoiding	

support networks	services/support delayed or refused by some families.	shared task	language: 'he's different, yes. He is delayed, yes, but he's the same as the other children'	wider community		maternal identity	was delayed"	difficult situations	
	Strained marital relationships.	Restricting the parenting role	Faith as a resource: 'it's what Allah already wrote'	Life within the family		Diagnosis	Struggling to understand the diagnosis	Reframing disability	
	Religious understanding of disability	Sharing the parenting tasks requires shared values	Learning, peer-support and community relationships: 'I start to explain autism'	Cultural factors – being a Muslim in a Western world		Religious beliefs	"They just don't understand it"	Inner conviction	
	Faith as a protective factor.			Perception of autism in Pakistan		Cultural beliefs	"There's a stigma attached to things like disability"	Recognition and enjoyment of care giving rewards	
	Seeking cures.					Shifting cultural allegiances	"They have their own beliefs"	Maintaining interests outside the home	
	Experience within educational settings					Impact on cultural identity	Coming to terms with life as a caregiver		
	Language barriers						Adapting to a new culture		
	Non-inclusive ethos.								

	Lack of support groups.								
	Power differentials.								
	Experience of the process for a statutory SEND plan (EHCP)								
	Lack of knowledge of statutory processes.								
	Slow paced.								
	Parental voice missing								
	The will of Allah.								

Appendix F

Interview Schedule

Introduction

(Explain background information about the study from the information sheet, along with purpose, consent, confidentiality, withdrawal, etc.)

Before we continue, I know that you completed the consent form and returned it to us, but I just wanted to check that you are happy with everything. The key things I wanted to check are that you remember that if you change your mind at any time, you can stop taking part. You can also ask for the data to be removed from the study up to one month after the interview. For the study, I would need to audio-record the interview. As with all the other information, this will be kept confidential, only my supervisor and I will listen to the recordings. Do I have your consent to record?

I also wanted to remind you about confidentiality. We can keep most things confidential. The only exception to this is if you tell us about something that suggests that a child is at risk. If this happens, we have a duty to inform the people in our University responsible for child safeguarding and they will follow their safeguarding procedures.

1. Is there anything you would like clarified from what has just been explained?

   (Build rapport and define emotional outbursts)

   In this study on carer mental wellbeing, we are specifically looking at understanding the experience of carers for young people with emotional outbursts in the COVID-19 pandemic and the impact of this on their mental health. Emotional outbursts (sometimes referred to as ‘temper tantrums’ or 'meltdowns') involve sudden, intense, often apparently out-of-proportion emotional episodes, which include at least one of a number of behaviours, such as crying, shouting, hitting, biting.

2. Would you prefer to use any other term instead of emotional outbursts for this interview?

   Pre-pandemic

3. Could you tell me what it is normally like to care for (child’s name)?

a. Prompts:

i. Challenges?
ii. Positives?
iii. Services normally received?
iv. Support you normally get?
v. How did you feel? How was your wellbeing?

   Impact

4. Can you tell me about the first day of lockdown for you?

5. Can you tell me about the first outburst your child had during the lockdown? What else was going on for you that day? (if not the same as question 4)
6. What has the experience of caring for (child's name) been like in the pandemic?

a. Prompts:

i. Any changes in outbursts? (frequency, intensity, etc.). How have you felt seeing them go through any changes?

ii. What things have changed?

- Has anything stopped?
- How has daily life changed?
- What have you found most challenging? Examples?
- How has that affected your mental wellbeing?
- How does it affect the person you are for and the people in your family?
- How have you coped? Has that helped?

iii. Any positive changes?

- How do you feel about those?

iv. Have you felt understood by others regarding your caring situation?

7. How has your mental health been in the lockdown and throughout the pandemic? Did you seek any support for yourself?

Support

8. What support have you received in the pandemic?
9. Can you tell me about a time during lockdown when you felt unsupported?

a. Prompts:

i. From professionals and mental health services?

ii. From your family,friends, etc.?

iii. From other organisations in the community (charities, support groups, religious organisations, etc.)?

iv. Anyone else to contact if you need help?

v. If little support was received, what were the barriers?

10. How have you felt about any support received?

a. Prompts:

i. Any positives?

ii. Any negatives?

iii. What would you have liked more support with?

iv. How has it affected your mental health?

Role and Expectations

11. How do you feel about your role as a carer?

a. what were the changes to the expectations of your roles in the pandemic? How did you feel about it?

12. Is there anything that you don't have at the moment that would help you manage things better?

a. Prompts:

i. Would there be anything to change with the system or with society?

ii. What would you want to remain the same?

iii. Any changes to level of support?

iv. What are your main concerns right now?

v. Ideas for how things could change?

Closing

13. Are there any other factors you would like to talk about that have affected your mental health in the pandemic?

14. How has it felt talking about this?
15. Is there anything you'd like to ask before we finish?

Take some feedback about the questions and process

Appendix G

Ethical Approval Letter

20th December 2021

Dear Dr Woodcock

Re: "Impact of the COVID-19 Pandemic on the Mental Health of Carers for Young People with Emotional Outbursts"
Ethics application ERN_19-1520AP15 Programme Lead: Dr Kate Woodcock

Thank you for the above application to use Programme of Work ERN_19-1520P. This has now been considered by the Science, Technology, Engineering and Mathematics Ethical Review Committee.

On behalf of the Committee, I can confirm a favourable ethical opinion for this application.

I would like to remind you that any substantive changes to the nature of the study as described in the Application for Ethical Review, and/or any adverse events occurring during the study should be promptly brought to the Committee's attention by the Principal Investigator and may necessitate further ethical review.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University's guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University's

H&S Unit at healthandsafety@contacts.bham.ac.uk.

If you require a hard copy of this correspondence, please let me know.

Kind regards

Mrs Susan Cottam

Research Ethics Manager

Research Support Group

University of Birmingham

Appendix H Research Poster

Your Mental Health Matters

We are looking for volunteers to participate in our study on the mental health of carers for young people with emotional outbursts

Introduction

This study on the mental wellbeing of carers focuses on understanding how carers of young people with emotional outbursts have coped during the pandemic and the impact of that on their daily lives and access to support. We are hoping to spread more awareness about carers mental health and to help us think about how we can improve services support in the future, especially in isolating circumstances like pandemics.

Who are we looking for?

We are specifically looking for families/ carers of young people aged between 5-20 years old, who have emotional outbursts at least once a month.

What will the study involve?

It will involve interviews of around an hour via either video call or telephone. The interviews will include questions about how you felt before the pandemic and what changes you experienced during it. A 10 pound Amazon voucher will be provided to thank you for your participation.

Who are we?

We are researchers from the Kate Woodcock Research Group, at the School of Psychology, University of Birmingham. Ms Snigdha Mukerji, the principal investigator, is a trainee Clinical Psychologist and Dr Kate Woodcock is a senior lecturer at the University of Birmingham

Contact Us To Participate

Snigdha Mukerji: sxm1636@student.bham.ac.uk

Kate Woodcock: k.a.woodcock@bham.ac.uk

Appendix I

Debrief Form for Carers

Thank you for taking part in the study on the mental wellbeing of carers.

Emotional outbursts (sometimes referred to as ‘temper tantrums’ or 'meltdowns') involve sudden, intense, often apparently out-of-proportion emotional episodes, which include at least one of a number of behaviours, such as crying, shouting, hitting, biting. These outbursts can usually be seen in children with special needs such as those with learning/intellectual disabilities, genetic syndromes and traumatic childhoods. For caregivers, these outbursts can cause stress and affect their mental health, especially due to low support or other needs not being met.

Carers’ mental wellbeing may have been impacted even more during the COVID-19 due to lesser availability of support, no access to schools and isolation. However, there is little research on the experience of carers in the pandemic or other adverse events, and even less research on the impact of emotional outbursts. Therefore, this study aimed at investigating the mental health of carers for young people with emotional outbursts before and during the pandemic. It is hoped that this study will inform any improvements in support provided to carers in the future.

By completing this interview study, you have helped us understand your perspective and lend a voice to carers going through the same things.

After we have interviewed all the carers, we will look for key ideas that carers tell us about.

We will group what was said during the interviews into these key ‘themes’, which will help us present the main points of the interviews. Based on the findings, recommendations will be made for future studies and services.

If you feel that additional emotional or behavioural support may be beneficial for you or your child, please get in touch with the Challenging Behaviour Foundation.

Website:	www.challengingbehaviour.org.uk
Email:	support@thecbf.org.uk
Telephone:	0300 666 0126

If you would like further help and guidance in identifying other forms of support that may be available to you, please get in touch with Snigdha or Kate.

Additionally, you can request that we destroy their research data up to 1 month from when we collect it.

If you have any further questions, please contact Snigdha Mukerji at [redacted] or Kate Woodcock on [redacted] or at [redacted]

If you would like to discuss a specific concern in relation to how the study was conducted please contact the Research Governance Team on researchgovernance@contacts.bham.ac.uk

Appendix J

Consent Form for Carers

Study Director: Dr Kate Woodcock

[redacted]

[redacted]

[redacted] initial box to indicate your agreement with the following statements.

1	I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2	I understand that my participation is voluntary and that I am free to stop completing the assessments at any time, without my or that of my child's medical care or legal rights being affected.	
3	I understand that if I do withdraw, I can request that information collected, other than that specified in item 3, is destroyed. I have up to 1 month from when this information is collected to request that it is destroyed.	
4	I understand that all data will be kept confidential throughout the study.	
5	I understand that following the end of the study, data may be shared with other researchers in anonymous form (so it cannot be linked back to me or my child).	
6	I agree to take part in this research.	

Please only sign this form after you have initialled all of the boxes to indicate that you agree with the statements on the previous page

Name (please print):

Address:

Telephone number (landline):

Mobile telephone number:

Email address:

Relationship to child I care for:

Signature:

Date:

At the end of the information sheet, we explained that you can provide your consent for us to keep your contact details after the end of the study to let you know about future research.

Are you willing for us to keep your contact details after the end of the study? (please circle)

YES **NO**

Signature of behalf of researchers:

Alternatively, the following e-mail may be sent to parents to obtain consent:

Dear [name of parent],

Thank you for your interest in this research project with the University of Birmingham
For more information about the project and what that would entail for you and your child, please read the caregiver information sheet and consent form attached. Please don't hesitate to contact us if you have any questions about the study.

If you would like to provide your consent to take part, but you would prefer to do this via email instead of signing the form and returning it to us, please copy and paste the email consent statement below:

"I confirm I have read the information sheet and consent form about this research and I consent to take part".

Finally, please tell us whether you would be willing for us to keep your contact details after the end of the study using the following statement (deleting as appropriate):

"I would/ would not be willing for you to keep my contact details after the end of the study."

When we receive a response to this email with these statements, we can use this as your official consent and your child's assent to take part in the study.

Again, if you have any questions, please get in touch.

We look forward to hearing from you in due course.

Kind regards,

[redacted]

Snigdha Mukerji

Trainee Clinical Psychologist

[redacted]

[redacted]

Dr Kate Woodcock

Reader

Director of KWRG

[redacted]

[redacted]

Appendix K
Information Sheet for Carers

We would like to invite you to participate in the study on carer mental wellbeing at the University of Birmingham, School of Psychology. The research is led by Snigdha Mukerji and Dr Kate Woodcock, Senior Lecturer at the University's Psychology department.

Should you have any questions or require further information, please contact Snigdha Mukerji at [redacted] or Kate Woodcock at [redacted] or via email at [redacted].

Aims:

All of the work at KWRG aims to better understand some of the problems faced by young people and their caregivers. We aim to use the knowledge we create, and test strategies and tools designed to reduce these problems. To make the strategies and tools as useful as possible it is extremely important for us to work closely with the communities that we are developing them for.

In this study on carer mental wellbeing, we are specifically looking at understanding the experience of carers for people with emotional outbursts in the COVID-19 pandemic and the impact of this on their mental health. Emotional outbursts (sometimes referred to as 'temper tantrums' or 'meltdowns') involve sudden, intense, often apparently out-of-proportion emotional episodes, which include at least one of a number of behaviours, such as crying, shouting, hitting, biting.

We would like to know how caring for a young person with emotional outbursts has affected carers in the pandemic, as well as what support was available. We hope that this will help us directly inform practice and the support available for carers as well as future research.

Where will the research take place?

The research will take place remotely via telephone or video calls.

Who will be involved in collecting the data?

Ms Snigdha Mukerji and members of the research team at the University of Birmingham.

What will we ask you to do during the study?

Your participation is entirely voluntary. We will ask you to participate in one or more of the following activities.

> **Individual interviews**: We will talk to you about your experiences during the pandemic, either by telephone or Skype. This will not take longer than 1 hour.

What kinds of information will be recorded and what will we do with it?

1. Your name and contact details

We will keep your name and contact details until the end of the study in September 2023. After this time, we will destroy this information unless you ask us not to.

When you enter the study, we will give you a unique participant number. We will use this number to identify all of the information we collect from you. The only link between this number and your name will be stored securely at the University of Birmingham. This means that after the study has ended we can make sure that most of the information we have collected from you is made anonymous.

We will also keep your name and contact details on the written consent you will be asked to provide us with. We will keep an electronic copy of this securely for 10 years.

2. Sound recordings

Some research activities will be recorded. These recordings will not be linked to the other information we collect from you. We will keep these securely at the University until we have transcribed them. The University of Birmingham will hold the copyright for these recordings.

3. Other information

All other information we collect will only be linked to you by the unique participant number. We will use this information to publish reports and present at conferences. However, it will be published in an anonymous way and it will not be possible for anyone to trace this information to you.

All of the information we collect will be stored in line with the Data Protection Act 2018.

Are there any risks that individuals taking part in the study might experience?

Some of the issues discussed may cause you to experience some uneasiness or negativity. It is important that you only take part in the activities that you feel are appropriate for you and would not cause too much upset.

Throughout the interview(s), we will check in with you to ensure that you are happy to continue. If you feel uncomfortable at any time, we will ensure to take a break and check in with you about how you are feeling and if you would like to continue to participate.

What are the potential benefits for participants for taking part?

There are no direct beneficial effects for participants of this research. However, research activities are designed in bring about reflective discussion of adaptive coping mechanisms to maintain good mental health.

Ultimately, we hope that the outcomes of this research will lead to improved assessment and intervention tools that benefit carers from a wide variety of backgrounds.

If you decide to participate, what will happen after that participation?

We expect to have finished with our data collection procedure by June 2023. Thereafter, you will receive a report detailing outcomes of this research. If we pursue further steps with developed assessment/intervention materials, you can request that we keep you updated about further research activities.

Confidentiality

The information we collect will only be linked to you with your unique number, so it will be confidential.

It is important to note a possible exception to confidentiality in line with the University’s Child Protection Procedures. If researchers have any concerns about the welfare of children they have a duty to disclose this to the University’s Child Protection Officer. Confidentiality may be broken to ensure children’s safety.

Consent

If you wish to receive any further information about this research before deciding upon your participation, please contact a member of the research team. We will be happy to discuss the information provided in this sheet or answer any further questions.

If you decide that you will participate in this research, you will be asked to provide your consent in writing.

Withdrawal

You can withdraw from the programme at any point, without being asked to provide any information why you wish to do so. Even after providing consent, you can decide to stop participating at any time (just stop).

For individual interviews you can ask us to destroy this up to 1 month after it was collected. Later than that, it will no longer be possible to erase your data, as we will have started using your data for our analyses.

What are the consequences of withdrawing?

If you decide to withdraw, there are no consequences for you or your child. This will not affect your eligibility for any treatment or education programme.

Compensation

A 10 pound Amazon voucher will be provided as a gesture to thank you for your participation.

What if there is a problem?

Should you encounter any difficulties, or have further questions, please contact Snigdha Mukerji at [redacted] or Kate Woodcock at [redacted] or [redacted], or the Research Governance Team on researchgovernance@contacts.bham.ac.uk for assistance.

Review

The programme of work has been approved by the Research Ethics Committee at the University of Birmingham.

Further information

Please contact Snigdha Mukerji at [redacted] or Kate Woodcock at [redacted] or [redacted] for further information.

If you have any concerns, please contact Susan Cottam, Research Ethics Manager, University of Birmingham on [redacted], or at [redacted]

Ongoing research participation database

If you have no interest in hearing about future research we are doing, there is no need to read any further.

If you are interested in hearing about future research we are doing that we think might be relevant for you, you can provide your consent for us to keep your contact details after the end of the study. We would only use these details to contact you about other research that we do in future, which we think may be relevant for you. Every time we contact you we would check that you are still happy for us to keep your contact details, and if you are not happy with this we would destroy them. You could also contact us at any time any ask us to destroy your contact details. We would keep your contact details securely at the University of Birmingham.