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Exploring Family Relationships in the Context of Autism

by

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Thesis for the degree of Doctorate in Clinical Psychology

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Abstract

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The first chapter of this thesis contains a systematic review exploring the experiences of grandparents who have grandchildren diagnosed with autism. Following a systematic literature search eight studies were identified. A thematic synthesis was administered through which five themes were identified; 'Overarching Role of Grandparent', 'Unconditional Love and Appreciation', 'Challenges to Grandparent Role', 'Emotional Response to Diagnosis' and 'Importance of Support Systems'. Within this chapter the findings are discussed in relation to the existing literature exploring the experiences of parents and siblings of autistic children. The findings highlight some key areas for future research to consider, as well as implications for clinical practice.

The second chapter of this thesis includes a qualitative, Interpretative Phenomenological Analysis (IPA) empirical research study, exploring the parenting experiences of fathers diagnosed with autism. Semi-structured interviews were conducted with six autistic fathers. Through IPA four Group Experiential Themes were identified; 'The Meaning of Fatherhood', 'Impact of Autism on Parenting', 'Understanding of Diagnosis' and 'Importance of Coping Strategies and Support Systems'. This research highlights the importance of further research exploring the experiences of autistic fathers, given it is an under-researched area. Important clinical implications are also identified to improve the accessibility of services and support for autistic fathers.

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Research Thesis: Declaration of Authorship

Print name: Lucy Catherine Francis

Title of thesis: Exploring Family Relationships in the Context of Autism

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature: .... Date: 17/05/2023 ....

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Definitions and Abbreviations

ASD	Autism Spectrum Disorder
DSM	Diagnostic and Statistical Manual of Mental Disorders
APA	American Psychological Association
ICD	International Statistical Classification of Diseases and Related Health Problems
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-analyses’
PROSPERO	International Prospective Register of Systematic Reviews
PICo	Population, Phenomenon of Interest, & Context
CASP	Critical Appraisal Skills Programme Qualitative Checklist
ID	Intellectual Disability
NICE	National Institute of Health and Care Excellence
IPA	Interpretative Phenomenological Analysis
CORE-10	Clinical Outcomes in Routine Evaluation
HCPC	Health and Care Professions Council
ADHD	Attention Deficit Hyperactivity Disorder

Chapter 1 The experiences of grandparents of autistic grandchildren: A systematic review

This paper has been written in the format required for the *Review Journal of Autism and Developmental Disorders,* see Appendix A for submission guidelines. Whilst these have been followed, a few alterations have been made for the purposes of thesis submission (grey literature reference has been included in reference list, tables and figures included in the text). These will be changed when submitting to the journal.

1.1 Abstract

This systematic review aimed to synthesise the qualitative research exploring the experiences of grandparents of autistic grandchildren. Research has shown that grandparents play a key role in the lives of their grandchildren, in particular when the child has additional needs, due to the increased caring demands. Therefore, there is a need to explore the experiences of grandparents to understand their role as a carer. Eight studies were identified through a systematic search. A thematic synthesis identified five analytical themes; 'Overarching Role of Grandparent', 'Unconditional Love and Appreciation', 'Challenges to Grandparent Role', 'Emotional Response to Diagnosis' and 'Importance of Support Systems'. The findings highlight how grandparents saw their role as extensive, involving a range of responsibilities towards the care of their grandchild. Grandparents commented on the positives of their role, including the unconditional love they felt towards their grandchild, their appreciation for their grandchild's successes and their own personal growth. Grandparents reflected upon the experiences of their grandchild receiving their diagnosis and how they felt there was insufficient support available from professional systems. This research highlights the need for

improved accessibility of services and support for grandparents of autistic children, to offer them opportunities for learning around the diagnosis, as well as providing them with a space to access social support for their caring experiences.

1.1.1 Keywords

Autism Spectrum, Autism, Grandparent, Systematic Review, Thematic Synthesis

1.2 Introduction

Autism Spectrum Disorder (ASD) is defined in the Diagnostic and Statistical Manual of Mental Disorders Fifth edition (DSM-5) as a neurodevelopmental condition that is characterised by persistent deficits in social communication and interaction and restricted, repetitive patterns of behaviour, interests, or activities (American Psychological Association APA, 2013). For this review the terms autism and autistic will be used, in order to follow the autistic preferred terminology (Monk et al., 2022). This will encompass corresponding diagnostic labels (e.g., Asperger's syndrome), that were previously used within the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV, APA, 1994), as well as those used within the International Statistical Classification of Diseases and Related Health Problems (ICD) versions 10 (WHO, 1993) and 11 (WHO, 2022).

The range of difficulties associated with autism can cause a significant impact on different areas of functioning, affecting individuals throughout their lifespan (Karst & Van Hecke, 2012). These difficulties have also been shown to impact the parents of autistic children (Karst & Van Hecke, 2012) due to the difficulties related to the condition adding additional complications to an already challenging role of being a parent (Rivard et al., 2014). This population of parents have also reported feeling unsupported by professionals (Falk et al., 2014). Furthermore, higher levels of stress (Baker- Ericzén et al., 2005, Kissel & Nelson, 2016), increased levels of anxiety and depression (Bitsika & Sharpley, 2004, Almansour et al., 2013) and poorer quality of life (Vasilopou & Nisbet, 2016) have been reported in parents of autistic children compared to parents of non-autistic children.

In order to manage the challenges associated with parenting autistic children, parents can rely on support from their wider systems, in particular grandparents (Margetts et al., 2006). This can be understood through the family life cycle theory which states that families go through a series of sequential stages, as they experience transitions (Medalie, 1979). The theory suggests that the cycle can be dependent on the individual life development of each family member (Medalie, 1979). Further to this, when a family experiences stresses, this can cause a disruption to the life cycle, whereby there may need to be an increased period of family closeness in order to cope (Newby, 1996). Therefore, in order to manage the difficulties associated with parenting an autistic child, the support of grandparents may be drawn upon by the family. Whilst the level of grandparent involvement towards the care of grandchildren can vary cross-culturally, research has suggested that grandparent involvement has been increasing globally (Pulgaron et al., 2016). The increase in grandparent involvement towards the care of their grandchildren is thought to be associated with the increase in life expectancy, meaning grandparents can play an important role in their grandchildren's lives throughout childhood and into adulthood (Dunifon, 2013). Further to this, with the increase in the number of children being raised by single parents and the increase in maternal employment, grandparents are more frequently supporting parents in caring for their grandchildren (Dunifon, 2013).

Grandparents play an important role in the life of their grandchildren through providing help, advice, and support (Nicholson & Zeece, 2008). It has also been suggested that grandparents can also play an indirect role in their grandchild's life, through providing emotional and instrumental support to parents, which consequently could have a positive effect on the grandchild (Dunifon, 2013). Whilst there is extensive research exploring the importance of secure attachments to parents for children's development, it has been identified that having attachments to various significant adults, particularly grandparents, is also highly important (Ochiltree, 2006) and grandparents play an important role, as an attachment figure, in a variety of cultures (van Ijzendoorn, 2005). Attachment theory also suggests that the way a caregiver responds and cares for their child during their early interactions, influences the way their child then conceptualises their own significant relationships as an adult (De Carli et al., 2018) With this in mind, this suggests there can be transgenerational transmission of attachment styles (De Carli et al., 2018) emphasising a further important role grandparents play in the lives of their grandchildren.

Whilst this is the case, it is also important to consider the multi-faceted role grandparents can play and how this may vary across cultures. For example, research comparing the role of grandparents across eleven European countries has shown that in Denmark between 50% and 60% of grandparents provide childcare to their grandchildren, compared to just 40% in southern European countries (Glaser, 2010). Additionally, the increasing diversity across family formation means the role of grandparents can also differ across families within countries (Berthoud, 2000). For example, research examining the involvement of grandparents across European countries suggested married grandparents are more than one and half times likely to provide care to their grandchildren, compared to grandparents who are never married, widowed or divorced (Glaser, 2010). The level of grandparent involvement is also influenced by individual factors that vary across each family system (Ochiltree, 2006). For example, grandparents' level of involvement may vary across factors such as the physical proximity, the relationship between grandparents and parents and individual life factors, such as employment, family stresses (Ochiltree, 2006).

When a child has additional needs, the demands of parenting increase and consequently drawing upon the support of wider family, particularly grandparents, can become increasingly important (Sullivan et al., 2012). In particular, grandparents may support with the financial cost of the additional services required, transportation to healthcare appointments and with managing behaviours (Sullivan et al., 2012). A review exploring the experiences of grandparents of children with developmental disabilities concluded that grandparents play an important role in supporting families of children with disabilities through emotional, instrumental, and financial support (Novak-Pavlic et al., 2022). However, this review did not differentiate the experiences depending on the grandchildren's diagnosis, and instead summarised the literature across a range of disabilities. With this in mind, it is evident there has been less focus on exploring the experiences of grandparents of children specifically diagnosed with autism (Sullivan et al., 2012). Through a quantitative, online survey, Hillman et al., (2015), highlighted how 70% of grandparents were actively engaged in autism-related treatment decisions for their grandchild. This highlights, the significant contribution grandparents can have to the lives of their autistic grandchildren and the importance of exploring the experiences of this population group further.

The use of a systematic review helps to synthesise the evidence relating to a specific research question, which can then help to draw conclusions to inform interventions or policies (Boland et al., 2017). Qualitative research allows for participants to share their lived experiences from their own perspectives (Prosek & Gibson, 2021). Whilst there have been systematic reviews carried out that have synthesised the research exploring the lived experiences of both parents (Corcoran et al., 2015) and of siblings (Watson et al., 2021) of autistic children, to date, and to the author's knowledge, there is no published systematic review synthesising the research exploring the first-hand experiences of grandparents of autistic grandchildren. This systematic review aims to synthesise research, using a thematic synthesis approach, to explore the first-hand experiences of grandparents of children diagnosed with autism with the hope to increase insight into their lived experiences. This can help highlight potential areas of support that would be beneficial for this population, as well as identify what further research can be carried out to explore the needs of this population group further.

1.3 Methods

This systematic review was administered and reported using the guidance of the 'Preferred Reporting Items for Systematic Reviews and Meta-analyses' (PRISMA, Page et al., 2021). In accordance with PRISMA guidelines, the protocol for this systematic review was registered with the 'International Prospective Register of Systematic Reviews' (PROSPERO) (Registration number: CRD42023369168).

1.3.1 Search strategy

The adapted 'PICo' tool (Population, Phenomenon of Interest, & Context) for qualitative systematic reviews was used when devising the review question and search strategy (Boland et al., 2017) (Table I). This tool was chosen as it has been recommended for qualitative systematic reviews, allowing for search filtering without increasing the risk of excluding studies that fit the research question (Boland et al., 2017).

Table I

'PICo' Tool

PICo tool	Key words
P- Population	Grandparent
I-Phenomenon of Interest	Autism
Co- Context	Experiences

The electronic databases PsycINFO, MEDLINE, Web of Science and CINAHL were searched in January 2023 to retrieve published and unpublished literature between 1980 and 2023. These databases were chosen as they were relevant to the topic searched. The screening process was rerun in March 2023 to check for any additional research papers, but none were identified. It was decided to filter the dates searched to start from 1980, as in 1980 'infantile autism' was listed in the DSM-III as distinct from 'childhood schizophrenia' (Volkmar et al., 1986, Lashewicz et al., 2019).

'Grey' literature was also searched for, as this is recommended to help minimise publication bias within a systematic review, as well as help to enable a more comprehensive review of the literature (Mahood et al., 2014). The following databases were searched; E-Theses, Pro-Quest and Open Grey. Hand-searching was also used as a further method of literature searching. This involved identifying key journals that were noted during the screening phase as commonly fitting the inclusion criteria were searched (e.g., Journal of Autism and Developmental Disorders). The citation list of research papers that were full-text screened were also checked to determine whether there was any further literature of relevance that may not have been captured by database searches.

1.3.2 Search terms

Search terms were devised in collaboration with a librarian through consulting the systematic review question and were amended as appropriate across databases. The search terms used in PsycINFO are shown in the table below (Table II). Subject terms were also used in each database to expand the search further, for example within PsycINFO, the subject term 'Autism Spectrum Disorders' and 'Grandparents' were added to the search strategy. Equivalent subject terms were used across the different databases. Due to the scarcity of research exploring grandparent's experiences, it was decided to keep the searches broad in each database, by not narrowing down the search by the 'Context' to gather a more extensive search of initial results. However, the 'Context' element of PICo tool was still applied when screening papers.

Table II

Search Terms Used in PsycINFO Database

Key concept relating to inclusion criteria	Search terms
Population	grandparent* OR grandmother* OR grandfather* OR "grand mother*" OR "grand father*" OR "grand parent*" OR grandmaternal OR grandparental OR "grand maternal" OR "grand parental" OR grandma* OR grandpa* OR grandad* OR grandparenthood
	AND
Phenomenon of interest	Autis* OR ASD OR "autism spectrum disorder*" OR ASC OR "autism spectrum condition*" OR "autistic disorder*" OR asperger* OR "asperger* syndrome" OR "pervasive developmental disorder*" OR PDD

Note. *= truncation

1.3.3 Inclusion and exclusion criteria

The following inclusion and exclusion criteria were used when selecting papers (Table III).

Table III

Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
• Participants, of any age, who are grandparents to an individual/s diagnosed with autism (or any equivalent diagnosis e.g., Asperger's syndrome), of any age. No restrictions were made as to whether the grandchildren have to be biologically related to their grandparents. • Grandparents who have a grandchild/grandchildren diagnosed with autism and co-occurring conditions will be included as long as the prominent focus is on the autism diagnosis. • Research design is qualitative or mixed methods (focus only on qualitative analysis). • Research includes qualitative analysis where themes have been identified. • Research explores the first-hand experiences of grandparents who have a grandchild/grandchildren diagnosed with autism. • Published research and grey literature. • Research is published in English.	• Participants do not have a grandchild who is diagnosed with autism (or any equivalent diagnosis e.g., Asperger's syndrome). • Grandparents have a grandchild diagnosed with autism and co-occurring conditions where the prominent focus is not on the diagnosis of autism. • The research refers to experience of grandparents who have grandchildren with a "disability" without indicating which themes are specific to grandchildren diagnosed with autism. • The research focuses on the experiences of different family members (including grandparents) however there is no indication as to which themes apply to grandparents. • Research is not first-hand grandparent's experiences. • Research is focused on grandparents' experiences of an intervention, rather than their experiences of grandparenting. • Audio files, book, and conference proceedings. • Secondary data reviews. • No English version available.

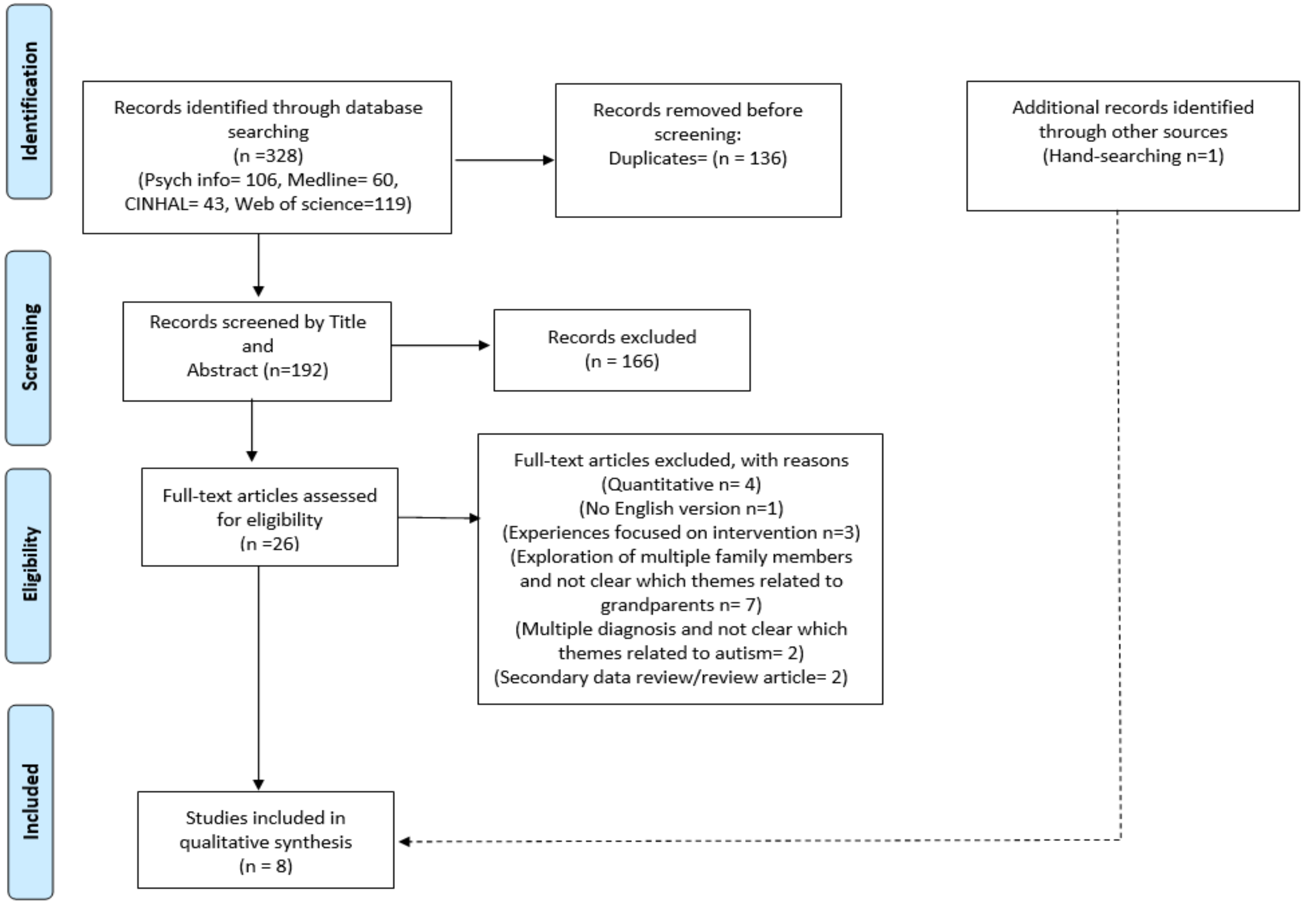
1.3.4 Screening process

A PRISMA (Page et al., 2021) flowchart (Figure I) illustrates the screening process followed within this review. Initially, 328 research papers were identified through database searches. Duplicates were then removed, which left 192 research papers that were screened using the title and abstract. Through the process of title and abstract screening 166 papers were excluded. 26 papers were then full-text screened from which 19 were excluded. Considering the importance of using multiple raters during the screening process to account for possible differences in coding behaviour (Belur et al., 2021), screening was completed independently by the first researcher and a research assistant, to check for inter-rater reliability. The Kappa statistic (Cohen, 1960) was used in order measure the interrater reliability between the two raters. The Kappa statistic for these checks was 0.95 showing there was almost perfect agreement between raters (McHugh, 2012). The two discrepancies were checked by the rest of the research team following which it was decided the research papers were eligible to go forward to full- text screening. For full-text screening the Kappa statistic for interrater reliability was 1, indicating perfect agreement.

One additional paper was also sourced during the hand-searching process. In total eight research papers were included in the final synthesis. A PRISMA flowchart (Figure I) illustrates the screening process followed within this review (Page et al., 2021).

Figure I

PRISMA (Page et al., 2021) Flow Diagram



1.3.5 Quality assessment

Following retrieval of the final research papers, the research was critically appraised using the Critical Appraisal Skills Programme Qualitative Checklist (CASP, 2018, Appendix B). The CASP is a ten- question tool that is used to critically appraise different methodological aspects of a qualitative study (Long et al., 2020). The CASP tool was chosen as it is one of the most used tools for appraising the strengths and limitations across different types of qualitative research and was devised for use within health-related research (Long et al., 2020). Although the CASP tool does not have guidance around the response choices, it was decided as a research team that the option 'Can't tell' will be chosen when there is insufficient information reported in the research to make a judgement. As there is no established criteria for the scoring of the CASP checklist, criteria used in previous systematic reviews (e.g., Watson et al., 2021) was used to rate the quality of the studies; studies were categorised as low, medium, or high in quality if zero to four, five to seven, or eight to ten of the CASP questions were answered 'yes' respectively. It was decided to not include the final question of the CASP tool 'How valuable is the research?' as there are no response options to choose from and instead the question is thought to be more subjective in nature (Wallace-Watkin et al., 2022). It was decided as a research team, that research would not be excluded from the systematic review based on the quality check, as it has been suggested that through excluding lower quality studies from a qualitative synthesis, key findings may be lost (Long et al., 2020). Alternatively, it is recommended to include all studies, whilst ensuring the quality of the research is considered and moderated to consider the strengths and limitations of the research (Long et al., 2020). It has been acknowledged that the CASP qualitative checklist can be subjective in nature (Long et al., 2020), therefore, studies were assessed independently by the first researcher, and the research assistant also reviewed a random selection of half of the papers, to check inter-rater reliability.

1.3.6 Data extraction

Data was extracted from the eight final research papers to include the following information: author, year, country the study was conducted, qualitative data collection method, sample and recruitment method, data analysis method and key findings. Data extraction was completed by the first researcher only.

1.3.7 Data synthesis

Thematic synthesis was used within this systematic review, as it is one of the most developed qualitative synthesis approaches that allows the data from studies to be reviewed on a descriptive level, whilst also allowing for new insights and interpretations to be developed (Flemming & Noyes, 2021). It was also evident that the richness of the data collected across studies within this review varied. It was decided that thematic synthesis would be an appropriate method for this review, as it allows for the incorporation of both 'thin' and' thick' data (Flemming & Noyes, 2021).

The thematic synthesis approach developed by Thomas and Harden (2008) was followed, whereby, initially the data from the final studies were read multiple times to allow the researcher to become familiar with the findings. Following this the whole of the results and findings sections, relating to the qualitative data, was extracted from each of the included research papers within the software NVivo (QSR International Pty Ltd, 2020). Due to the fact a thematic synthesis was carried out, in instances where quantitative data had also been reported with the research papers' results and findings sections, this data was not extracted for analysis. Line-by-line coding was then performed across each of the studies' results and findings sections, where qualitative data was reported. Following this, codes were organised into descriptive themes. These stages were performed by the first researcher only, however, these descriptive themes were reviewed with the wider research team, from which analytical themes were then developed.

1.3.8 Researcher reflexivity

Thematic synthesis is an approach that can be used across a range of epistemologies (Cruzes & Dybå, 2011). For this review a critical realist stance was taken whereby it is assumed that the 'observable world' is to be understood through our own subjective understanding (Koopans & Schiller, 2022). Therefore, within regular supervision sessions it was important for the research team to reflect upon their similarities and differences to the participants within the research, to consider and address biases when analysing the data (Dodgson, 2019). Initially, all members of the research team had clinical experience in supporting young people diagnosed with autism and their families. Whilst this was beneficial as the researchers had prior understanding around the potential impacts the diagnosis of autism can have on the family, it was important to maintain awareness of how the researchers may bring their own assumptions from their own professional experience. The research team is primarily female who are not parents or grandparents. It was considered how this lack of personal experience in being a carer for a child may have influenced the way they perceived the caring experiences of grandparents. In contrast, one member of the research team is a male researcher who is a father. This difference in both the position of gender and the personal experience of being a carer potentially allowed for a useful, differing stance towards the interpretation of the data and development of themes. Considering the potential researcher biases when analysing the data, theme development was discussed across the whole research team.

1.4 Results

1.4.1 Study and participant characteristics

Eight papers were included in the final synthesis (Margetts et al., 2006, D'Astous et al., 2013, Hillman et al., 2017, Boyd & Goodwin, 2019, Hillman & Anderson, 2019, Prenderville & Kinsella, 2019, Lilakos, 2021 and Raheli & Abdalla, 2022); each paper was assigned a number for the purpose of this review. Table IV includes the details of each study extracted during the data extraction stage. The research papers were published between 2006-2022, and were conducted across several countries; Canada, England, Ireland, Israel and United States of America. Most of the studies used semi-structured interviews as the data collection method. However, Raheli & Abdula (2022) used a narrative interview, Hillman et al., (2017) and Hillman& Anderson (2019) used a survey.

The total number of participants was 2,057 (1,687 female/ 370 male). However, this number was skewed by the Hillman et al's research (2017), which had a much larger sample size due to their data collection being an online survey. Most of the studies recruited grandparents who were not primary caregivers, however Hillman & Anderson (2019) and Lilakos (2021) recruited grandparents who were custodial caregivers of their grandchildren. In terms of ethnicity, most studies used participants who were of White Caucasian ethnicity. Two studies (Margetts et al., 2006 and Raheli & Abdalla, 2022) do not refer to the ethnicity of the participants. Only Boyd & Goodwin (2019) and D'Astous et al., (2013) reported participants class (middle-class/middle to upper class), however Hillman et al., (2017) and Hillman & Anderson (2019) reported participants to be well-educated. For the majority of studies grandparent's grandchildren were only reported to have been diagnosed with autism, apart from in Prenderville and Kinsella's (2019) research where grandparents had grandchildren diagnosed with autism and an Intellectual Disability (ID). However, as the focus of the research was understanding the experiences associated with the autism diagnosis, this research was still included within this review.

1.4.2 Quality assessment

All eight research papers were critically appraised using the CASP tool (see Table V for CASP ratings) independently by the first researcher and the research assistant also reviewed half of the papers to check inter-rater reliability. The Kappa statistic (Cohen, 1960) was used in order to test the interrater reliability between the two raters. The Kappa statistic for these checks was 1.0, showing there was a perfect agreement (McHugh, 2012). It was identified that the majority of the research papers were of high quality (n= 5) (Margetts et al., 2006, Boyd & Goodwin 2019, Hillman & Anderson 2019, Prenderville & Kinsella, 2019, Lilakos 2021. The rest of the papers were rated as medium quality (n=3), due to the fact they appeared to lack detail around the relationship between the researcher and participants (D' Astous et al., 2013, Hillman et al., 2017, Raheli & Abdalla, 2022) and ethical issues (D'Astous et al., 2013, Hillman et al., 2017, Raheli & Abdalla, 2022).

Table IV

Studies Details from Data Extraction Stage

Study number	Author/Year /Country	Aim	Qualitative data collection method	Sample/Recruitment method	Data analysis method	Key findings
1	Margetts et al., 2006 UK	To understand the grandparent experience for children diagnosed with autism	Semi-structured interview which took place face to face	Sample: -Six grandparents (Five female/One male) of children with diagnosed with autism -Five grandparents had one autistic grandchild and one grandparent had two autistic grandchildren -Current age of grandparents not stated, but grandparents age when child was diagnosed ranged from 52- 74 years. Recruitment method: Purposive/	General Inductive method	Three main themes were identified: 1. The Parental Bond: Four subthemes: • Caring for the child • Adopting a favourite • Watching milestones • Re-enacting parenthood 2. Striving for answers: Three subthemes: • How do support without undermining? • Am I supposed to be the expert? • Who is to blame? 3. Keeping intact: Two subthemes: • Rediscovering the grandparent role

				convenience sampling technique		• Handing back responsibility
2	D'Astous et al., 2013 USA	Aimed to explore grandparent's interactions with their autistic grandchildren and their perceptions of the relationship.	Semi-structured interview either in person or over the telephone.	Sample: -14 grandparents (Eight female, Six male) of grandchildren diagnosed with autism. -Ages ranged from 56-81 years. -Primarily middle- and upper-class Caucasians. -Number of grandchildren ranged from two-eight (mean=five).	Framework analysis	Factors that influenced more engagement: • Positive communication • Appreciation • Inclusion • Good understanding of the disability Factors that influenced less engagement: • Poor communication • Intergenerational tension, including criticism • Feelings of exclusion • Lack of understanding of the disability
3	Hillman et al., 2017 USA	To understand the first-hand experience of (non-custodial) grandparents of autistic children, to understand both positive and	Survey using open-ended questions.	Sample: -1870 (1533 female/337 male) non-custodial grandparents of grandchildren diagnosed with autism.	Grounded theory	4 categories were identified with underlying themes: 1. Desire for connection • Physical affection • Value of verbal language • Inappropriate autism behaviour as barrier • Intrinsic bond

	negative aspects of grandparenting.	--56% were aged under 65 years old/44% were aged 65 or older. -86% had one grandchild diagnosed with autism, 14% had two or more grandchildren diagnosed with autism. -Well educated sample - 97% white, 2% black, 1% American Indian or native Alaskan -Age of grandchildren: Age 1-18 (98%), age 19+ (2%). Recruitment method: Recruited through research advert on newsletter and website.	2. Barriers to care • Family denial of diagnosis • Instrumental challenges • Poor systemic support 3. Celebration of progress • Recognising progress, no matter how small • Effort of both parents and grandchild • Achieving developmental milestones 4. Personal reactions • Worry for entire family • Despair • Juxtaposition of extreme highs and lows • Resilience

4	Boyd & Goodwin 2019 Canada	To gain an understanding of how a young family with a child with autism experiences dignity during family leisure in the community.	Semi-structured, conversational interviews and field notes conducted face-to-face.	Sample: -One family included one grandmother (age 56 years) of a child diagnosed with Autism (child aged six years) -Ethnicity: White -Class: Middle class Recruitment method: Family volunteered for the research, known to researcher.	Interpretative phenomenological analysis	Three themes were identified (only themes where it was clear that the grandmothers' first-hand narratives were relevant to theme have been included in this data extraction). 1. Living under a microscope 2. Screw your microscope, we're going anyway 3. Emerging stories of belonging
5	Hillman & Anderson 2019 USA	To examine the first-person perspective of custodial grandparents of autistic children, with the aim to develop recommendations of how to best support these grandparents.	Online survey	Sample: -117 custodial grandparents (108 female/nine male) of grandchildren diagnosed with autism. -Number of grandchildren diagnosed with autism: One= 91%, Two= 7%, Three=0.8%). -Age of grandparents: 44 and younger=3%,	Grounded theory	Four categories were identified with underlying themes: 1. Issues with adult children • Origins of custodial care • Legal issues • Conflict during visitation 2. Caregiver burden • Autism behaviour problems • Insufficient Autism services • Finances • 24/7 demands • Fear for the future

		45-54=33%, 65-74=15%, 75-84=0%, 85 and older=0.8). -Race: White=86%, Black or African American= 7%, American Indian or Native Alaskan= 3%, Asian=1%. -Well educated sample. Recruitment method: Recruited with assistance from the Grandparent Autism Network, Autism Speaks and the American Association of Retired Persons, as well as using the IAN community website and research e-newsletters.		3. Coping • Celebration of progress • Unconditional love • Faith/moral imperative • Focus on the positive 4. Wisdom • Personal growth • Connection with village • Insight for others

6	Prenderville & Kinsella 2019 Ireland	To explore the perspectives of both parents and grandparents, to understand the role of grandparents towards their autistic children.	Semi- structured interviews conducted face-to-face in the family's home/school settings.	Sample: -12 grandparents of autistic grandchildren (also diagnosed with Intellectual Disability (ID). -Seven female/Five male. -Age range: 50-84 years. -Caucasian, Irish -Grandchildren aged 5-18 years old. Recruitment method: Snowball sampling strategy, participants were recruited from primary schools that had satellite classes for children with autism and Intellectual Disabilities.	Thematic analysis	Three themes with underlying subthemes were identified (only themes/subthemes where it was clear that the grandparents' first-hand narratives were relevant to theme). 1. Family recalibrating • Limiting life • Impact on family 2. Strengthening the family system • The active role of grandparents 3. Current needs and future concerns • Needs of grandparents • Concerns for future

7	Lilakos 2021 USA	To examine the implications of grandparent caregivers raising autistic grandchildren.	Semi-structured interviews, field notes and focus groups	Sample: -Seven grandparent (Five females/Two males) custodial caregivers raising grandchildren diagnosed with autism. -Age of grandparents: 52-76 years (mean=69 years). -Ethnicity of grandparents: Six White American/One African American. Recruitment method: Purposeful snowball sampling. Research flyers were used to advertise the study in two private practice social work offices/private online social media group to	Thematic analysis	Themes were identified in terms of research questions: Research question one: What can be done to address the challenges experienced by grandparents raising autistic grandchildren? Themes identified: 1. Renewed purpose raising grandchildren with autism 2. Challenges with autism Research question two: What are the financial and other challenges of caregivers raising autistic grandchildren? Themes identified: 3. Sources of financial distress 4. Educational support Research question three: What issues of attachment need to be addressed with this population? Themes identified: 5. Love 6. Respite and resources

				which participants volunteered to take part		Research question four: What can clinicians and policymakers do to enhance support for these families? Themes identified: 7. Respite and resources
8	Raheli & Abdalla 2022 Israel	To explore the leisure experience of grandparents whilst spending time with autistic grandchildren and to understand how this contributes to grandparents' resilience.	Open narrative interview	Sample: -30 grandparents (20 female, 10 male) of grandchildren diagnosed with autism. Recruitment method: Recruited through Facebook social medica platform through a closed group intended solely for grandparents of children diagnosed with autism. Participants responded voluntarily.	Content analysis	Several themes were extracted from the interviews: 1. Crisis events: • Crisis when getting information about autism. • Inability to share information about the grandchild. • Crises while staying with the grandchild in public areas. 2. The feeling of frustration while staying with the grandchild. • Frustration resulting from expectations. • Frustration at the grandchild's lack of cooperation. • Frustration from society-related situations. • Anger at the system.

- Quality time that becomes a punishment.
- Acceptance of the grandchild despite the physical or mental difficulties involved in meeting.
- Empowerment.
- Another approach was also introduced.

3. Practical conduct following the situation.
    - The ability to mobilise intuition.
    - The ability to ask for help.

Table V

Critical Appraisal Skills Programme (CASP, 2018) Ratings

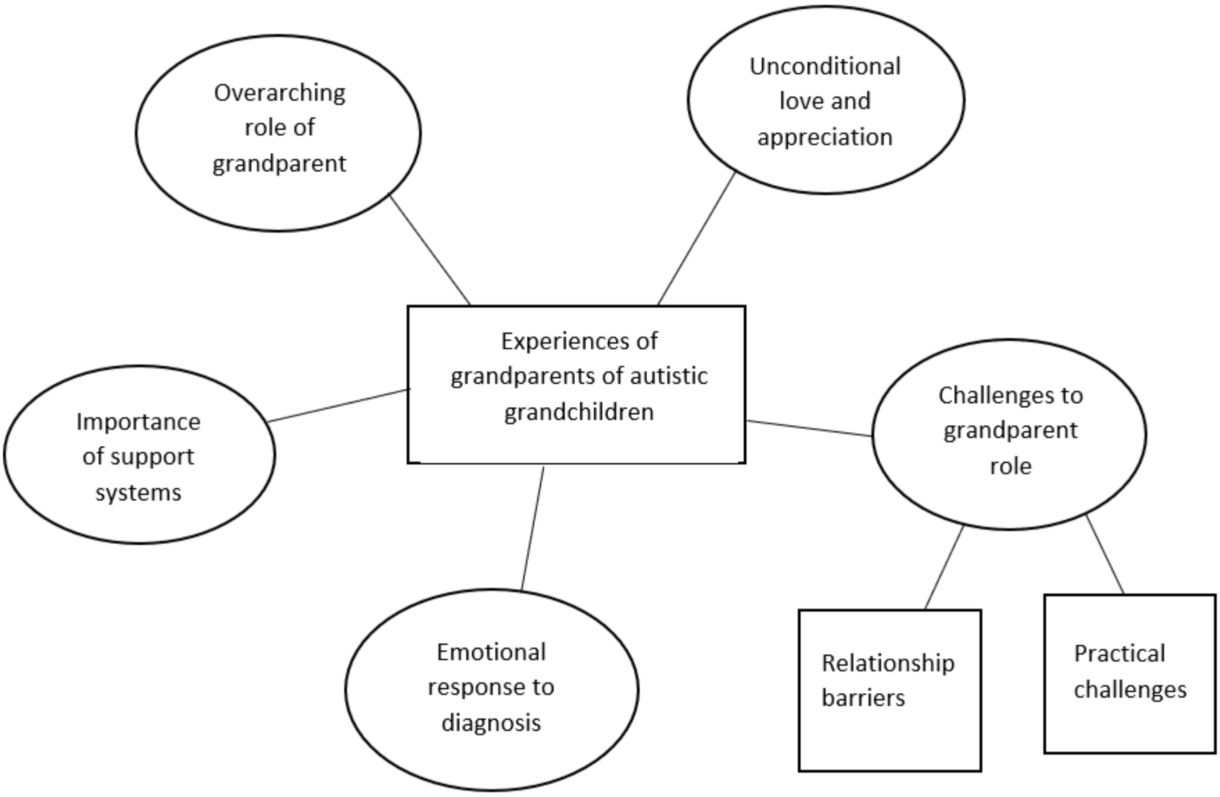
Study number	Author	Year	Q1. Aim	Q2. Methodology	Q3. Research design	Q4. Recruitment strategy	Q5. Data collection	Q6. Consideration of relationship between researcher and participants	Q7. Ethics	Q8. Data analysis	Q9. Findings
1	Margetts et al	2006	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2	D'Astous et al	2013	Yes	Yes	Yes	Yes	Yes	Can't tell	No	Yes	Yes
3	Hillman et al	2017	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Yes	Yes
4	Boyd & Goodwin	2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
5	Hillman & Anderson	2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
6	Prenderville & Kinsella	2019	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes
7 (GREY LIT)	Lilakos	2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
8	Raheli & Abdalla	2022	Yes	Yes	Yes	Yes	Yes	No	Can't tell	Yes	Yes

1.4.3 Thematic synthesis

From the thematic synthesis, five analytical themes were identified: ‘Overarching Role of Grandparent’, ‘Unconditional Love and Appreciation’, ‘Challenges to Grandparent Role’, ‘Emotional Response to Diagnosis’ and ‘Importance of Support Systems’ (Figure II).

Figure II

Thematic Network Diagram (Attride-Stirling, 2001)



Note. Within this figure (rectangles represents research question, circles represent analytical themes and squares represent sub-themes).

Analytical themes were developed through grouping codes into descriptive themes. For example, codes ‘worry for adult child’ and ‘role of holding family together’ were categorised into the descriptive theme ‘Worry for Family’. This was then developed into the analytical theme ‘Overarching Role of Grandparent’.

1.4.3.1 Overarching Role of Grandparent

Across the studies a common theme that was reported was that the role of grandparents was extensive due to the fact they adopted a wide variety of roles and responsibilities, that not only involved caring for their autistic grandchildren, but also their wider family. Whilst it was noted across the studies that the grandparents’ role included providing emotional and functional support to their autistic grandchildren, it was noted across some of the studies (Margetts et al., 2006, Prenderville & Kinsella, 2019) that the level of grandparent’s involvement in their grandchild’s care varied depending on the current intensity and impact of their grandchildren’s behaviour. For example, grandparents reported that changes in grandparent roles were particularly important during times of stress for the family (Prenderville & Kinsella, 2019). It is important to note that whilst the majority of the studies included reports from non-custodial grandparents, two of the studies (Hillman & Anderson, 2019 and Lilakos, 2021) included grandparents who were custodial caregivers. Therefore, understandably these grandparents appeared to note an even more significant role in the care for their grandchildren, that led to grandparents’ experiencing caregiver burden (Hillman and Anderson, 2019 and Lilakos, 2021). For example, one grandparent reported experiencing *“struggles every day and just (being) tired all the time”* (Hillman & Anderson, 2019).

As well as providing care and support to their grandchild, a common narrative described by grandparents was that they embodied a wider protective role, whereby they felt worried about their adult child and felt they needed to provide them with support to manage the stress they experienced in their parenting role (Margetts et al., 2006, D’Astous et al., 2013, Hillman et al., 2017, Prenderville & Kinsella, 2019, Raheli & Abdalla, 2022); *"I worry about my daughter's stress in raising a child with Autism"* (Hillman et al., 2017). Consequently, grandparents reflected how they felt they had to increase the support they provided their child: *"I help my daughter as much as possible, supporting her financially, taking care of the girl's needs and helping find solutions to any problems that arise, but the hardest part for me is that she thinks the situation can improve and is unable to see the real situation"* (Raheli & Abdalla, 2022).

Grandparents also reflected how they were aware of the impact their grandchild's diagnosis had on the whole family and consequently their worry also extended to the wider family, with grandparents reflecting that they felt responsibility to hold a protective role and hold the whole family together (Margetts et al., 2006, Hillman et al., 2017). For example, one grandparent reported *"I am worrier. I feel I must look out for all the family"* (Margetts et al., 2006). For some grandparents this worry extended to worrying about their grandchild's future, with grandparents worrying about how their diagnosis may impact their later life (D'Astous et al., 2013, Hillman et al., 2017, Hillman & Anderson, 2019, Prenderville & Kinsella, 2019). For example, one grandparent stated *"(I have great) concern about how this dear child will be able to make his way in the world"* (Hillman et al. 2017). Some grandparents reflected how they were worried about how they will not be around to care and support for their grandchild *"The biggest worry that we have is we won't be there for him you know and how will she cope with (child's name) but it's the future that's the problem"* (Prenderville & Kinsella, 2019). It is important to note in one of the studies where grandparents were the primary caregivers, the worry around their grandchild's future was associated with concerns as to who would be their grandchild's primary caregiver, following their death; *"I worry about what will happen when I am gone…[My granddaughter]* *probably can never live on her own and [I have] concerns about [my grandson's] future… after we are in heaven"* (Hillman & Anderson, 2019).

1.4.3.2 Unconditional Love and Appreciation

A common theme that was expressed across studies were the positives participants felt about their role as a grandparent to their autistic grandchildren. Grandparents commonly described feeling unconditional love towards their grandchild (Margetts et al., 2006, D'Astous et al., 2013, Hillman et al., 2017, Hillman & Anderson, 2019, Lilakos, 2021, and Raheli & Abdalla, 2022). For example, one grandparent reported *"There was something about his eyes…He was special from the beginning. I love [other grandchild] but I love him best of all"* (Margetts et al., 2006). Some participants acknowledged that despite the difficulties they acknowledged in supporting their autistic grandchild, the love they had for them was strong: *"[My grandson with Autism] is my greatest joy and my greatest despair and I still hate autism, but love this [grand] child."* (Hillman et al., 2017).

Grandparents also commonly reported that an important positive to their role was being able to recognise and observe their grandchildren develop through their milestones (Margetts et al., 2006, Hillman et al., 2017, Hillman & Anderson, 2009). Seeing their grandchildren's achievements, no matter how small, was noted as an enjoyable part of grandparenting, that helped them cope with the challenges associated with their grandchild's diagnosis: *"(When my grandchild achieves something), those are the little moments that make the battle worth the fight"* (Hillman & Anderson, 2019).

As well as appreciating their grandchild's achievements, some grandparents reflected how they were grateful for the own personal growth they felt their role as a grandparent provided them (Hillman et al., 2017, Hillman & Anderson, 2019, Lilakos, 2021, Raheli & Abdalla, 2022). Grandparents reflected that their role allowed them to develop their own patience, strength, and unconditional love. For example, one grandparent stated, "*The greatest education I have ever received was from my grandchild; without him speaking a word he has taught me patience, advocacy, unconditional love (and) strength"* (Hillman et al., 2017).

1.4.3.3 Challenges to Grandparent Role

1.4.3.3.1 Relationship Barriers

Whilst grandparents reflected upon the positives of grandparenting an autistic child, a further common theme across the studies was the challenges of their role. Grandparents discussed how the difficulties in social interaction and communication their grandchild presented with impacted their own relationship with them (D'Astous et al., 2013, Hillman et al., 2017, Hillman & Anderson, 2019, Raheli & Abdalla. 2022). For example, one grandparent stated, *"When he is in a bad mood, he'll say, 'leave me alone, don't touch me.' I find that discouraging"* (D'Astous et al., 2013). A further grandparent acknowledged the greatest challenge was *"simply trying to connect with (my granddaughter)"* (Hillman et al., 2017).

Grandparents' narratives also reflected how their grandchild's challenging behaviours, such as physical behaviours, were emotionally difficult for them (D'Astous et al., 2013, Hillman et al., 2017, Hillman & Anderson., 2019); *"(My greatest challenge is) learning to deal with my grandson in situations like tantrums (and him) throwing stuff around the house"* (Hillman et al., 2017). In the two studies which recruited grandparents who were primary caregivers of their grandchildren (Hillman & Anderson, 2019, Lilakos. 2021) they discussed how these challenges were exacerbated by being a full-time carer. For example, one grandparent reported *"I can't take my eyes off (my 6-year-old grand-son) for a second and I* *have to stay by the phone all day because of the trouble at home and school"* (Hillman & Anderson, 2019).

1.4.3.3.2 Practical Challenges

Grandparents also reflected on the practical challenges they faced within their grandparent role. Many of the grandparents commented on the financial challenges associated with supporting their grandchild with the additional care and support they require (Hillman et al., 2017, Hillman & Anderson, 2019, Lilakos, 2021): *"The financial burden to the entire family has been tremendous"* (Hillman et all., 2017). These challenges were most commonly reported in the research including grandparents who were the primary caregivers (Hillman & Anderson, 2019 and Lilakos, 2021), as they reflected on how they were the ones responsible for covering these costs; *"It's so expensive to get the help (my grandchildren) need, the special foods, the extra activities that he needs to have, the list goes on and we have provided the therapies (our grandson) needed out of our own pockets"* (Hillman & Anderson, 2019).

Another practical barrier that grandparents, who were not primary caregivers of their grandchild reported, was the difficulties associated with not living near their grandchild (D'Astous et al., 2013, Hillman et al., 2017) and how this reduced the amount of time and interaction they had with their grandchild. Some grandparents also expressed how their increasing age affected their ability to be involved in their grandchild's care (D'Astous et al., 2013, Prenderville & Kinsella, 2019).

1.4.3.4 Emotional Response to Diagnosis

Across the studies, grandparents commonly described the emotional experiences they experienced when discovering their grandchild was diagnosed with autism. In many of the studies, grandparents described the difficulties associated with processing their grandchild's diagnosis (Margetts et al., 2006, D'Astous et al., 2013, Hillman et al., 2017, Raheli &

Abdalla, 2022). Grandparents expressed feeling shame, sadness, and denial around their grandchild's diagnosis: "*The discovery of my grandson's autism pretty much broke me. It took me very hard"* (Raheli & Abdalla, 2022). Grandparents appeared to cope with these difficulties by either attributing blame, for example, some grandparents discussed what they thought to be the 'cause' to their grandchild's diagnosis; *"I saw her the day after the MMR. I feel it was the cause. 99% of people seem to deny (it)*" (Margetts et al., 2006). Whilst others coped by denying the diagnosis altogether (D'Astous et al., 2013, Hillman et al., 2017); *"You know I don't like to ask, because I don't like to hear bad things"* (D'Astous et al., 2013). Some grandparents also reported a sense of shame towards their grandchild's diagnosis and kept this information private from society; "*I find it difficult to come out and say 'This is my grandchild'; that is my weakness, so I'm constantly covering it up."* (Raheli & Abdalla, 2022). Whilst other grandparents were aware of how they had to manage external opinions from others around their grandchild's diagnosis when in public settings (Boyd & Goodwin, 2019, Hillman et al., 2017); *"I have learned…how important it is to educate others about (autism). Even when we're at the park…and (our grandson) behaves a little differently, to be able to ask a child if they know what autism is and then give a brief explanation"* (Hillman et al., 2017).

For some grandparents, receiving their grandchild's diagnosis provided them with a sense of relief and helped them make sense of their grandchild's difficulties (D'Astous et al., 2013, Lilakos, 2021). For example, one grandparent stated: *"The autism diagnosis helped me to better understand what was going on with my grandchild"* (Lilakos. 2021). Some grandparents also reflected how accepting the diagnosis improved their level of coping (Margetts et al., 2006, D'Astous. 2013, Raheli & Abdalla, 2022): ***"****When we found out what was wrong with him, it made it so much easier"* (D'Astous et al., 2013). Grandparents who were more accepting of their grandchild’s diagnosis, also reported being more involved in their grandchild’s care (D’Astous et al., 2013, Prenderville & Kinsella, 2019).

1.4.3.5 Importance of Support Systems

A common theme that was discussed across grandparent’s narratives was their frustration towards the insufficient support available for their grandchild. In particular, grandparents expressed concerns towards the educational support their grandchild received and reported they felt support was not individualised to their grandchild’s needs (Hillman et al., 2017, Hillman & Anderson, 2019, Lilakos, 2021, Raheli & Abdalla, 2022): *“Attempting to make the education system understand the importance of educating the WHOLE child, and not just the part of them that masters academics, can be, and is much of the time, an unending fight”* (Hillman et al., 2017). Some grandparents also expressed distrust towards health professionals, reporting that they felt their grandchild’s care and support was inconsistent (Hillman et al., 2017, Raheli & Adballa, 2022). For example, one grandparent reported *“The health care system is the one to blame because the treatment is always delayed…. We feel that every passing day hurts our grandson”* (Raheli & Abdalla, 2022).

As well as the care their grandchild received, grandparent’s also expressed the need for others in their position to receive additional support around their care role, to help them become more informed with their grandchild’s diagnosis and how to support them (Hillman & Anderson,, 2019, Prenderville & Kinsella, 2019, Lilakos, 2021, Raheli & Abdalla, 2022); *“It doesn’t happen that it’s explained to grandparents… there needs to be more of the likes of you (the researcher) now doing this and going round meeting grandparents”* (Prenderville & Kinsella, 2019). Within the two studies’ whose participants were primary caregiver grandparents, the importance of social support was a key theme (Hillman & Anderson, 2019, Lilakos, 2021) suggesting the increased care demands saw grandparents requiring more support from their social systems; *"The family therapist told us about respite and a support group for grandparent caregivers. We started to attend the group, and it was the first time I felt like I was not alone"* (Lilakos, 2021). Some grandparents who were not primary caregivers also reflected how social support from others when caring for their grandchild was beneficial. For example, one grandparent commented how when supporting their grandchild in a leisure setting *"I guess people can make us feel welcome and included."* (Boyd & Goodwin, 2019).

1.5 Discussion

This systematic review synthesised the qualitative research exploring the experiences of grandparents of grandchildren diagnosed with autism. The synthesis process elicited five analytical themes: 'Overarching Role of Grandparents', 'Unconditional Love and Appreciation', 'Challenges to Grandparent Role', 'Emotional Response to Diagnosis' and 'Importance of Support Systems'.

The role of the grandparent in their autistic grandchild's life appeared to be extensive and complex and involved a wide variety of responsibilities. Grandparents played an important part in supporting not only the care of their grandchild, but also the wider family with the emotional challenges associated with parenting an autistic child. This appeared to be an additional challenge compared to parents of autistic children (Corcoran et al., 2015), whereby grandparents felt responsibility for caring for their family across generations. This demonstrates how the influence of stresses to the family life cycle can cause disruption (Newby, 1996) and consequently increased the responsibilities of grandparents in supporting their grandchildren. Whilst this review did not compare the experiences of grandparents of autistic grandchildren and non-autistic grandchildren, given that there is increased levels of stress associated with caring for an autistic child (Baker- Ericzén et al., 2005, Kissel &

Nelson, 2016), that can impact the whole family, it may be that the feeling of increased responsibility of caring for all generations may be unique to grandparents of children with additional needs. This is further evidenced by the fact a review exploring the experiences of grandparents of children with a range of developmental disabilities (e.g. ID, Down Syndrome, ASD), concluded similar findings that grandparents were highly involved in the care and support of their grandchildren and in the support of the wider family (Novak-Pavlic et al., 2022). This suggests the additional demands and stressors associated with caring for a child with developmental disabilities may influence the level of responsibility the grandparent has in their grandchild's care. However, considering the limited amount of research in this area, it is important further research explores this further.

Many grandparents reflected upon the personal challenges they felt in being able to connect with their grandchild and managing their behaviours. The practical challenges associated with their role were also discussed, with reference to the financial responsibility they felt in supporting with their grandchild's care. The emotional challenges reported by grandparents are similar to those reported in the research exploring parental experiences (Corcoran et al., 2015), emphasising the importance of considering the whole family system involved with the care and support of a child diagnosed with autism.

Whilst the challenges of their role were discussed, grandparents also reflected on the positives. Grandparents commonly referred to the unconditional love they had for their grandchild and how recognising their grandchild's developmental progress was an important, positive part to their role. Grandparents were also reflective around how being a grandparent to their autistic grandchild provided them with their own personal growth and development, allowing them to develop their own patience, strength, and unconditional love. This was also in line with the findings from a systematic review which explored the experiences of siblings of children diagnosed with autism, which also concluded that their role had a positive impact on their own personal attributes (Watson et al., 2021).

The stage of processing and understanding their grandchild's diagnosis was a common theme across the studies. Some grandparents reflected on how they struggled with processing the diagnosis and reported experiencing shame and denial. This is a similar finding to a systematic review exploring the experiences of parents following their child's diagnosis of autism, with parents reporting denial, grief, and disappointment (Corcoran et al., 2015), suggesting the emotional response to the diagnosis is felt within the extended family system too. Whilst some grandparents reflected on the difficulties in processing the diagnosis, others reflected how finding out about their grandchild's diagnosis was helpful in improving their understanding of their grandchild's difficulties.

While the majority of the studies included grandparents who were non-custodial grandparents, two studies included a sample of grandparents who were the primary custodial caregiver for their grandchildren (Hillman & Anderson, 2019, Lilakos. 2021). It is important to consider how these experiences compared, given the difference in their roles. For example, in custodial grandparents' narratives, the impact of caregiver burden and the consequent need for social support was a more prominent theme than in the studies exploring the experiences of non-custodial grandparents. This is line with the findings from previous research which has explored the experiences of parent caregivers of autistic children, where the emotional strain of being the primary caregiver for an autistic child is commonly described (Corcoran et al., 2015).

It is important to note that the research included with this review was published across a time period of 16 years. Across generations it is helpful to consider the influence of cultural norms and historical events (Laidlaw et al., 2003). Through considering the cohort experience of a generation, it can help to better understand an individual's attitudes or behaviours (Laidlaw et al., 2003). Research suggests cohorts born across different time periods can present with differing approaches to child-rearing (McGoldrick et al., 2011). Bearing this in mind, considering the earliest research paper in this review was published in 2006 and the latest was 2022, whilst it cannot be fully determined as to when the data was collected, it can be assumed that the population of grandparents within these research papers may have different cohort experiences that may influence their role as a grandparent. Further to this, the prevalence of autism has increased over the years which has consequently improved the awareness and understanding of the diagnosis (Golson et al., 2022), which may have also influenced the grandparents' experiences of supporting their autistic grandchild across different cohorts. Despite this, similar themes were extracted from the earliest paper and the latest paper, suggesting within this review, the difference in publication year did not appear to have a significant influence on the findings.

1.5.1 Strengths and limitations of the review

This review elicited eight studies, which in comparison to other thematic synthesis reviews exploring the experiences of autistic children's parents (Corcoran et al., 2015) and their siblings (Watson et al., 2021) is a relatively small number. However, given that a comprehensive search strategy was followed, eliciting studies from a range of sources; electronic databases, grey literature, and hand-searching, it can be suggested that all research relevant to the research question was gathered and synthesised within this review.

Whilst most of the studies included in this review are peer-reviewed published studies, it is important to consider the fact one study is grey literature (Lilakos, 2021). Whilst the inclusion of grey literature mitigates against publication bias (Hopewell et al., 2005), previous research has suggested that grey literature may be of poorer methodological quality than publishes studies (Hopewell et al., 2005). However, whilst this is the case, this quality of this study was assessed through the CASP tool and was rated as high quality. A strength of this review is also that the majority of the studies included were rated as high quality using the CASP (2018) tool. However, it is important to consider the fact three studies (D' Astous et al., 2013, Hillman et al., 2017, Raheli & Abdalla, 2022) were rated as medium quality due to the fact they were limited in the details they provided around the relationship between the researcher and participants, and details around ethical issues.

It is also important to note that whilst this review explored studies using qualitative design, it does not include the findings from quantitative studies, therefore, some research may be unaccounted for within this review. However, given the review question wanting to explore the lived experiences of grandparents of autistic children, it was felt most appropriate to include qualitative findings.

It is important to consider that most studies reported on grandparents of white ethnicity, from western countries. This review does not represent the experiences of grandparents of different ethnicities, or grandparents living within underdeveloped countries, where the care systems may be less established. Previous research exploring parental experiences of autistic children has found that their care experiences are influenced by cultural factors (Lai & Oei, 2014), Blanche et al., 2015, Gordiollo et al., 2020, Fisher et al., 2022). For example, research has considered how ways of coping with parenting an autistic child may differ across collectivistic and individualist cultures, with parents from collectivistic cultures using coping methods that rely on drawing support from their wider networks, whereas parents from individualistic cultures may instead use self-focused coping methods such as avoidance (Lai & Oei, 2014). Further to this, research has shown that the experiences of caregivers of colour reported that they faced significant barriers in accessing support for their autistic child, such as the societal cultural norms of whiteness preventing people of colour from representation in services (Fisher et al., 2022).

Similarly, the attitudes and behaviour of grandparents has been found to vary cross-culturally. For example, Strom & Strom, (2017) highlighted how Caucasian- American grandparents were reported to spend significantly less time with their grandchildren than African-American and Mexican-American grandparents Furthermore, grandparents in African-American families were also found to play a more significant role in enforcing discipline with their grandchildren. Bearing this in mind, it is important for future research to consider the experiences of grandparents of autistic children, cross-culturally. Grandparents included in the studies' samples were also predominately female. Previous research has suggested that there are differences in the way mothers and fathers experience parenting a child diagnosed with autism, yet fathers are commonly underrepresented in the research (Paynter et al., 2018). It is, therefore, important to consider how this gap in the experiences of males also appears to be evident in the grandparent generation and highlights the need for future research to explore grandfather's experiences grandparenting an autistic child.

Whilst the majority of studies reported the only diagnosis the grandparent's grandchildren had was autism, it is important to acknowledge that within Prenderville and Kinsella's (2019) research, the grandchildren were diagnosed with both autism and ID. Whilst the focus of the research was on the experiences associated with autism, it is important to consider the potential influences the ID diagnosis may have had on the grandparent's experiences of supporting their grandchild. Research has shown that children diagnosed with co-occurring autism and intellectual disabilities were at significantly increased risk of self-injurious behaviours, abnormal fear responses and eating problems (Kurzius-Spencer et al., 2018), as well as externalising behaviours such as aggression and temper tantrums (Estes et al., 2007), than those children who were just diagnosed with autism, suggesting there can be added complexities associated with the dual-diagnosis. However, whilst this is important to consider, the research did not appear to significantly differ to the other studies included within this review, and instead similar themes were extracted.

1.5.2 Implications and future research

To the researchers' knowledge this is the first systematic review to explore the experiences of grandparents of autistic grandchildren, and a relatively small number of studies was elicited, highlighting how research within this area is under-researched. Therefore, this review emphasises the need for future research to further explore the grandparental experience. Given this review included both grandparents who were custodial caregivers as well as those who were not, it would be helpful for future reviews to filter the experiences across the two populations, to explore the individual experiences across these roles. It suggests that there is a population of grandparents who are taking on the primary caregiver role for their autistic grandchildren, and therefore, this highlights the importance of exploring the potential challenges this population may face, and how they can be supported further within these roles. In particular, within this review this sub-population of grandparents expressed feeling under-supported by the system, and therefore this emphasises the need for services to improve the care-giving support provided to grandparents who take on the custodial role of their grandchildren. Furthermore, custodial grandparents also emphasised the importance of social support, which highlights how the use of peer support groups may be beneficial in providing grandparents with a space to feel supported by others who are in similar caring roles to themselves.

This review highlights the significant role grandparents play in the care and support of their autistic grandchildren. However, it has shown that whilst grandparents play an important role, the support available for them is often limited. With some grandparents having reflected that an improved understanding around the diagnosis saw their involvement and level of coping improve, services should consider including the wider family system within the diagnostic process. It is evident that National Institute of Health and Care Excellence (NICE, 2013) guidance for supporting autistic children reports all families and carers should be provided with advice, support and training. Therefore, consideration should be taken to include the wider family within this, whereby grandparents are also offered opportunities for learning, to expand their understanding around the diagnosis and to learn strategies in order to support their autistic grandchildren. This review also highlights the importance of services introducing family autism support groups that can be accessed by the wider family system, so that grandparents also have a space to reflect on their care-giving experiences and feel socially supported by others.

1.5.3 Conclusion

In conclusion, this review highlights the significant role grandparents can play in their autistic grandchildren's life. Grandparents reported both the positives and challenges to their role, which to some extent appeared to be in line with the experiences of parents and siblings of autistic children. This emphasises the importance of ensuring grandparents are included in the support provided to families of autistic children. Given the limited evidence base of research exploring grandparents' experiences, future research is needed to further explore this population to identify how best they can be supported.

Chapter 2 The parenting experiences of autistic fathers: An Interpretative Phenomenological Analysis

This paper has been written in the format required for the *Journal of Autism and Developmental Disorders,* see Appendix C for submission guidelines. Whilst these have been followed, tables and figures have been included in the text for the purpose of thesis submission. These will be changed when submitting to the journal.

2.1 Abstract

Research has begun to explore the parenting experiences of autistic parents, through which it has been identified that, whilst they report positives to their role, there are challenges they experience in managing the pressures and responsibility of being a parent. However, to date these explorations have been mainly focused on the experiences of autistic mothers. Using a qualitative, Interpretative Phenomenological Analysis (IPA) approach, this present study aimed to explore the lived parenting experiences of six autistic fathers. Semi-structured interviews were administered through which four Group Experiential Themes were identified; ‘The Meaning of Fatherhood’, ‘Impact of Autism on Parenting’, ‘Understanding of Diagnosis’ and ‘Importance of Coping Strategies and Support Systems’. The findings highlight how fathers saw their role as coming with varying responsibilities and expectations. Whilst fathers report various positives to their parenting role, they discussed how their sensory experiences, social interaction and communication difficulties and preference for routine and structure brought challenges, for which fathers had adopted their own coping strategies. Fathers also experienced a lack of support from service-providers and felt there was a lack of understanding and awareness around their diagnosis. This research emphasises the importance of a greater understanding from professionals around the experiences of autistic fathers during their role as a parent, and the need for wider support to be available for fathers to access.

2.1.1 Keywords

Autism Spectrum Conditions, Autism, Fathers, Parenting, Interpretative Phenomenological Analysis

2.2 Introduction

Parenthood is associated with extremes of emotions, from the joys and unconditional love, to the worries around the responsibility and pressure of being a parent (Williams Veazey, 2018). Considering the life course theory, it is suggested that throughout people's lives, people experience various transitions, such as the birth of their child, which can be significantly impactful on their life course (Hutchison, 2016). Research has shown that the experience of parenting is multi-faceted and can be influenced by various factors including; parental employment, family structure, and the child's social, cognitive and physical development (Deater-Deakard, 2008). Another factor that has been known to influence parenting experiences is parent's mental health (Deater-Dearkard, 2008, Sell et al., 2021). The lived experiences of parents diagnosed with mental health difficulties has highlighted that this population experiences challenges around stigma and inadequate support (Boursnell, 2007), as well as challenges with managing daily responsibilities (Bassett et al., 1999, Gladstone et al., 2011). Research has also explored the experiences of parents diagnosed with intellectual disabilities (ID) where a common challenge found was the difficulties in negative perceptions they received from others around their parenting capacity, as well as limited access to services and support (Theodore et al., 2018). However, it is of note that there has been a lack of research exploring the experiences of parents diagnosed with autism.

Autism (Autism Spectrum Disorder, ASD) is characterised by difficulties in social communication and interaction, as well as repetitive patterns of behaviour, interest or activities (American Psychological Association APA, 2013). Considering the autistic-preferred terminology, the terms autism and autistic will be used when referring to the condition within this research (Monk et al., 2022). Whilst there has been extensive research exploring the experiences of autistic children, there has been less focus on exploring the experiences of autistic adults (Finch et al., 2022). Within the research that has been published to date, it has been shown that autistic adults experience social difficulties, which has impacted their ability to navigate and understand social relationships (Finch et al., 2022). With this in mind, given that parenthood can be a significant life stage that adults experience, it emphasises the importance of exploring the experiences of autistic parents.

When considering attachment theory, it is known that a parent’s attachment style can influence their parenting (Jones et al., 2015). For example, Bowlby theorised that increased activation of parent’s attachment system may result in the reduced activation of their caregiving system, and therefore, affect the way they respond to their child’s needs (Jones et al., 2015). Research has found that avoidant attachment styles in adults has been associated with less sensitive and responsive parenting behaviours (Jones et al., 2015). Further to this avoidant and anxious attachment styles in parents were related to higher levels of parental stress (Jones et al., 2015). Research has suggested that the attachment styles in autistic adults may differ to non-autistic adults. For example, when comparing the romantic attachment styles of autistic and non-autistic married adults, autistic adults were significantly more likely to be an insecure avoidant attachment style (Lau & Peterson, 2011). Therefore, this suggests that there could be a difference in the way autistic adults experience parenting.

Whilst there has been limited exploration to date, recent research has begun to explore the experiences of autistic parents. Research exploring the experiences of autistic parents compared to that of neurotypical parents, found that whilst there was an overlap in the experiences of the two groups of parents, there were areas of differences between their experiences (Crane et al., 2021). In particular, having their own personal experience with the diagnosis has been outlined as a key benefit in being an autistic parent to autistic children, as it allows for a greater level of understanding towards their child's condition (Crane et al., 2021, Lilley et al., 2023).

Whilst positives to being an autistic parent have been identified, further research has highlighted challenges faced by autistic parents. Research has shown, autistic mothers reported feeling reluctant to disclose their diagnoses to professionals, due to their worries around how it would influence the professional's attitude towards them (Pohl et al., 2020). Autistic mothers also reported greater challenges with multi-tasking, organisation and domestic responsibilities within their role as a parent (Pohl et al., 2020).

Research has also explored the lived parenting experiences of autistic parents through the use of Interpretative Phenomenological Analysis (IPA). Within Winnard et al.'s (2022) exploration of autistic mothers' parenting experiences, mothers reported how they found the positives of their parent role to be sharing and receiving love, spending quality time with their children and the unique insight they had into their children's diagnosis of autism (Winnard et al., 2022). Mothers also described how they faced several challenges in managing the impact their diagnosis had on parenting, considering sensory experiences and their need for routine and structure. Mothers also experienced difficulties in accessing services for parenting and for their children (Winnard et al., 2022). A further IPA study explored autistic mothers' experiences, whereby similar themes were found (Dugdale et al., 2021). Mothers described the positives to motherhood, such as intense connection, enjoyment and rewards. However, they felt misunderstood in their experiences, which led to them receiving insufficient support for themselves and their children. Mothers also spoke of their shared diagnosis with their children and the difficulties they experienced in raising an autistic child, which at times led them to question their capability as a parent (Dugdale et al., 2021).

It is evident that whilst IPA has begun to be used to explore the experiences of autistic parents, this research has predominately been with mothers. Whilst Smit et al., (2023) used IPA to explore the experiences of autistic parents, the sample involved eight mothers and only one father. Despite this, similar findings were found to that of Winnard et al., (2022) and Dugdale et al., (2021), where parents spoke of similar positives to their role being the unconditional love and connection they had for their child. Parents also spoke of the own personal growth they experienced in their role which shifted their perceptions of themselves. As with previous IPA research, parents also reflected upon their frustration towards the lack of support and understanding from professionals (Smit et al., 2023).

Whilst research has explored the positives and challenges to the role of an autistic parent, it is clear that this research is predominately focused on the experiences of mothers, and there is an evident gap in the research exploring the experiences of autistic fathers. Parenting literature suggests that there are evident differences in the parenting styles between mothers and fathers (Starrells, 1994) and fathers experience their own unique parenting challenges (Paynter et al., 2018). Whilst this is the case, the experiences of fathers have been significantly underrepresented in parenting research (Paynter et al., 2018), highlighting the importance of research exploring and understanding the role of the fathers further. With this in mind, this research aims to explore the lived experiences of autistic fathers, in order to better understand the positives, challenges and support needs of this sub-population of parents. To the author’s knowledge this is the first study to solely explore the first-hand parenting experiences of autistic fathers.

2.3 Methods

A qualitative research design was used to explore the experiences of autistic fathers. IPA was chosen as the analysis method, as it allows for a comprehensive exploration of participants' experiences, as well as considering the contextual influences (MacLeod, 2019). It has been suggested that IPA is a useful qualitative method for use with autistic participants, as it illuminates the potential barriers of the 'double empathy problem' (Milton, 2012), which assumes that non-autistic individuals may have difficulty in understanding the lived experiences of autistic individuals (Howard et al., 2019). Therefore, the use of IPA allows for a greater, in-depth understanding of autistic individuals' experiences, by holding the assumption that participants are the experts of their own lived experiences (Howard et al., 2019). Ethical approval (ERGO: 72753) was granted for this research by the Ethics and Research Governance Committee at the University of Southampton (Appendix D).

2.3.1 Participants and recruitment

A poster was used to recruit participants through advertising on social media (Appendix E) and through autism charity organisations throughout the period of August 2022- February 2023. Considering the theoretical foundations of the IPA approach, a smaller number of participants were recruited, to ensure an in-depth analysis of the experiences of a particular sample were explored (Pietkiewicz & Smith, 2014). It has also been recommended by UK Doctoral Programmes in Clinical Psychology that six to eight participants is appropriate for an IPA study (Turpin et al., 1997).

The following inclusion criteria was used to recruit participants; aged at least 18 years old, that had a formal diagnosis on the autism spectrum and had at least one biological child aged at least four years old. It was decided to include fathers of children who are least four years old, as by this stage fathers would have experienced parenting a child throughout the entire early childhood period (Landry et al., 2003). It was also considered how at this age it is likely that the child may have begun attending pre-school/school and therefore this stage of parenting could be considered within the research. Fathers also had to be at least 18 years old when they became a father, in order to account for any possible influences that teenage parenting may have on their experiences, as research has suggested teenage parents may experience different stressors in parenting (Beers & Hollo, 2009). Fathers had to have had 'regular contact' with their child/children, which for the purpose of this research, was defined, as having a continued presence in the child's life and having contact with them on at least a monthly basis. This definition was decided upon through considering the research team's experience in working with young people and their families. If the participant's child was above the age of 18 years, there was no expectation the parent had to continue to have regular contact with their child/children, but regular contact must have been evident during the childhood years. Participants were excluded if they were unable to understand and speak fluently in the English language and if they were experiencing significant mental health illness, which was determined through the use the Clinical Outcomes in Routine Evaluation (CORE-10) measure (Barkham et al., 2013). The CORE-10 measure was administered with participants during the week leading up to their interview over the telephone. It was decided, to be eligible for the study, participants had to score below 15, as a score of 15 or above is indicative of moderate to severe psychological distress (Barkham et al., 2013). No participants showed signs of significant mental health illness, therefore were all recruited for the study. The telephone call with participants was also an opportunity for the researcher to collect demographic information and allow for an initial rapport to be developed prior to the interview.

Six participants, with a formal diagnosis of autism (or corresponding diagnosis), were recruited. To confirm each participant had a formal diagnosis, participants were asked to send a copy of their diagnostic report, which were reviewed by two members of the research team who are ‘Health and Care Professions Council’ (HCPC) registered Practitioner Psychologists with experience in assessing and diagnosing autism. Five participants had the diagnosis of ‘Autism Spectrum Disorder (ASD)’ and one participant had the diagnosis ‘Atypical Autism’. Following the release of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) in 2013, the diagnoses of autism and its related disorders were classified into a single category Autism Spectrum Disorders (Ohan et al., 2015). Therefore, for the purpose of the research it was decided that participants with the formal diagnosis of ASD or corresponding diagnoses (such as Autism, Aspergers) would be included to account for participants who may have been diagnosed prior to this change. At the time of the interview all participants were still in a relationship with the mother of their child/children, and all participant’s children resided full time with both their mother and father throughout their childhood years (0-18 years old). All participants received their autism diagnosis in their adult years. Four participants had children also diagnosed with Autism, one of whom had two children diagnosed. All participants were also in employment at the time of the interview. Participant demographic characteristics are included in Table 6.

Table VI

Participants Demographics

Age (years)	Ethnic origin	Age of diagnosis (years)	Number of children	Age of children (years)	Child Autism diagnosis	Age of child diagnosed with Autism
49	White British	46	2	17, 19	Y	17
49	White British	48	1	12	Y	12
35	White British	35	2	2, 7	N	/
52	White American	48	3	13, 15, 16	Y	13
59	White British	47	2	28, 31	N	/
54	White British	42	2	23, 25	Y	23, 25

2.3.2 Interview schedule development

A semi-structured interview schedule was developed by the researchers all of whom have professional experience with working with autistic individuals (Appendix F). The interview schedule was developed through examining the literature that had used IPA within autism research, in particular, those that explored the parenting experiences of autistic mothers (Winnard et al., 2022). Guidelines for conducting research with autistic participants emphasises the importance of involving ‘experts-by-experience’ within the research development (Gowen et al., 2019). With this in mind, the interview schedule was piloted with an autistic father, who met the inclusion/exclusion criteria, to ask for his views towards the interview questions and the interview process. Following this, as the interview question structure was not changed, this participant's interview was also included in the main data analysis. However, following the pilot interview it was recommended to add the interview questions to the chat box on the remote screen to help the participants recall the question, therefore, this adaptation was used in the remaining interviews.

2.3.3 Procedure

Following participants contacting the researcher and confirming they met eligibility, participants were sent the research participant information sheet (Appendix G), which provided full details as to the procedure. All participants were asked to sign and return a consent form (Appendix H). At this stage participants were then asked to send confirmation of their diagnosis, by sending their diagnostic report for reviewing. To ensure confidentiality was kept, the first researcher removed all identifiable information before they were provided to the rest of the research team. Following confirmation of diagnosis, an interview was scheduled with the participant. All participants were given the option to either have the interviews face-to-face or virtually, however all participants chose to have their interviews conducted virtually, due to reasons such as convenience and being able to be within their own environment. The last stage of eligibility screening was administered in the week running up to the interview, where the CORE-10 measure was administered with the participant over the telephone. As well as ensuring the participant did not have significant mental health difficulties, this telephone call was also used to gather demographic information (Appendix I). Autism research guidelines have emphasised the importance of considering the researcher-participant relationship to help build trust (Fletcher-Watson et al., 2019) therefore this telephone call prior to the interview also allowed an opportunity for the researcher to gain an initial rapport with the participant. This was also recommended by the 'expert-by-experience' in the piloting stage of the research. Guidelines have also emphasised the importance of preparing autistic participants prior to the research, by informing them explicitly what will be involved. Therefore, participants were sent the interview questions prior to the interview, to allow them to familiarise themselves with the content (Gowen et al., 2019).

Interviews took place virtually (Microsoft Teams) at a time convenient to the participant. To ensure a standardised approach was followed, all interviews were administered by the first researcher. Interviews were audio-recorded on a dictaphone and lasted between 42 to 77 minutes. Data collection took place over a seven-month period. Following the interview all participants were debriefed (Appendix J), offering them a chance to ask questions regarding the research. Participants were also provided with a £25 voucher to thank them for their contribution to the research. Research has emphasised the importance of tailoring the language used regarding their diagnosis to each individual's preference (Cascio et al., 2020). Therefore, at the start of the interview each participant was firstly asked how they would like to be addressed (e.g., autistic).

2.3.4 Analysis

The six stages of IPA were followed to analyse the qualitative data collected (Smith et al., 2022). Firstly, familiarisation of the data was conducted by the first researcher reading and re-reading the transcripts, as well as listening to the audio-recordings. Exploratory notes were recorded for each transcript, noting down descriptive and linguistic ideas in the left-hand margin (Appendix K). Experiential statements were then constructed in the right-hand margin through the summary and analysis of exploratory notes. Following this Personal Experiential Themes were developed for each participant (see Appendix L). This process was repeated for each participant's transcripts. After this was completed, Group Experiential Themes were developed through analysing the Personal Experiential Themes and looking for areas of commonality and divergence. Themes were discussed with the wider research team before finalising the final themes and sub-themes.

2.3.5 Researcher reflexivity

Within IPA research, the experiences of participants are understood and interpreted through the lens of the researcher (Smith et al., 2022). Therefore, it is important to consider the position of the researchers and how this may influence their interpretation of the data. Throughout the process reflexive notes and supervision was utilised for reflection (Appendix M). Given that the majority of the research team are female, who are not parents, it was important to consider how this may have influenced the way that the male participant's experiences were conceptualised. Whilst this may have been helpful, in allowing the researchers to keeping an unbiased stance that is free from their own experiences of being a parent, the researchers may have been influenced by their own assumptions as to what parenthood involves. On the other hand, one of the research team is a male who is a father, therefore, it is helpful to consider how his own personal experiences of fatherhood may have influenced the way he understood the participant's experiences. All members of the research team have clinical experience in working with autistic individuals and their families. Consequently, awareness was given, as to how this may have influenced the research team's interpretations of the participant's experiences. At the same time, all members of the research team are also not diagnosed with autism, and as research has suggested that there may be barriers in the way non-autistic individuals understand the experiences of autistic experiences (Howard et al., 2019), it is important to consider the influence of this on data interpretation.

2.4 Results

Four Group Experiential Themes and eleven subthemes emerged from the IPA analysis; (see Table VII). Each participant has been assigned a pseudonym to maximise confidentiality.

Table VII

Group Experiential Themes and Sub-Themes

Group Experiential Theme	Sub-theme	Ps
1. The Meaning of Fatherhood	Positives of fatherhood	Tony, Edward, Adam, Robert, Daniel, Kevin
	Managing responsibilities	Tony, Edward, Adam, Robert, Kevin
	Being a ‘good enough’ father	Tony, Edward, Adam, Robert, Daniel
2. Impact of Autism on Parenting	Sensory experiences	Tony, Edward, Adam, Robert, Daniel, Kevin
	Social interaction and communication	Tony, Edward, Adam, Robert, Daniel, Kevin
	Unpredictability and change	Tony, Adam, Robert, Daniel
3. Understanding of Diagnosis	Benefits of shared diagnosis	Tony, Edward, Robert, Kevin
	Frustration towards preconceptions and assumptions	Tony, Edward, Adam, Kevin
4. Importance of Coping Strategies and Support Systems	Importance of routine and structure	Tony, Adam, Robert, Daniel
	Self-soothing strategies	Tony, Edward, Adam, Robert, Daniel
	Access to support	Tony, Edward, Adam, Robert, Daniel, Kevin

2.4.1 Theme 1: The Meaning of Fatherhood

The first theme reflects participants accounts of what fatherhood meant to them. Participants reflected upon the positives of their role as a father and reported the challenges around managing varying responsibilities. Participants also reflected upon how at times they were self-critical towards their parenting ability, which was influenced by the comparisons they made towards them and others.

2.4.1.1 Positives of fatherhood

Participants spoke of the positives they experienced through their role as a father. Many spoke of how being a father was important to them and gave them *"purpose"* (Tony). Some participants reflected how they felt a societal expectation to become a father and consequently they felt a sense of achievement for stepping into this role:

> *"I think there's always that deep-down sort of sense, almost an evolutionary sense, of wanting to carry on your genes in a way and maybe that was in the back of my mind, autistic or not." (Edward)*

Within Edward's account there is a sense that he acknowledges this evolutionary drive to become a father is not distinct to being an autistic father, as he states *"autistic or not"*.

Participants also spoke of how they valued spending quality time with their children, and valued feeling love and connection towards them:

> *"I think my general memories are a lot of good times and just being together, doing stuff, going for walks, whatever it might be." (Daniel)*

For Robert, the experience of being a father was also positive in the sense that it provided him with his own personal growth:

> *"being able to engage with each of them on their level, that really is a very good thing not only for them but also it's a good thing as far as an exercise in kind of expanding the theory of mind issues that I'm sometimes challenged with." (Robert)*

For many observing their children develop and achieve developmental milestones was a highlight of parenting. Kevin, whose child was also diagnosed with autism, reflected how it was special to watch his child speak their first words:

> *"Did I hear that right? Did you say something?" "Look, there's a sheep." And we're like, "Wow!" You know, you know, sometimes they will get there and sometimes you may not go from A to C via B, you may have to via D, E, F, G but still get there." (Kevin)*

Kevin acknowledged how a child's developmental trajectory can vary, depending on their individual needs. For Kevin, he reflects how despite his child's difficulties, it was very much still a momentous occasion for him, when his child met their developmental milestones.

2.4.1.2 Managing responsibilities

Participants spoke of what expectations and responsibilities they felt they had as a father. Participants reflected how they felt their role involved keeping their children safe and nurturing and modelling to them through their own life experiences. Participants reflected how the role of a father can feel all-encompassing at times and they acknowledged the high level of responsibility they felt. Kevin's account evokes a sense of frustration as to how at times the responsibility he had felt unachievable:

> *"if something went wrong and you're Dad, your job is to fix things as a father, getting late. Like turn the sun off. Oh yeah, I can do that." (Kevin)*

Some participants acknowledged that felt they had to tolerate the difficulties they experienced associated with their diagnosis, in order to meet the expectations and responsibilities they felt they had as a father. For example, Adam spoke about how *"it's just a question of grinning and bearing it"*. Participants also reflected how they felt they held many different roles and at times this was hard to manage. In Robert's account he describes this through the following image:

> *"like a juggler who is juggling balls in the air, trying to keep them all in the air and juggling, juggling. So my work, you know, that's a ball, you know, my life as a husband, that's another one, my life as a parent…And then, you know, whatever other kinds of obligations that I have, like being a son to my ageing father, you know, just all those things, so those are all balls up in the air. And so it's difficult for me to, you know, feel like I can just…that I need to, and you know, it's kind of something that mentally, you know, can be draining at times, and so the parenting part of it is definitely… Those are pretty large balls that I'm juggling" (Robert)*

Robert's use of imagery emphasises the challenges he acknowledged in keeping hold of all the different roles and responsibilities he held, whilst emphasising the significance that his parenting role had.

2.4.1.3 Being a 'good enough' father

Many participants spoke about how at times they felt they were not living up to the expectations they had for themselves as a father and reflected how they strived to be 'good enough'. Participants reflected how they could be self-critical towards their own parenting ability and felt guilty if they felt their partner did more than them in terms of parenting:

> *"often all the heavy lifting is done by, by my wife and there's a sense of massive guilt in me as well because I don't feel like I'm doing enough" (Edward)*

Whilst some participants compared themselves to their partners, Robert questioned whether his parenting abilities differed to that of other fathers. His use of the word *"fear"* suggests being able to connect with his children was a significant worry of his:

> *"I would say another challenge is also having a fear of not connecting with my kids, you know, or wondering about, you know, do other dads connect the same way or more" (Robert)*

For some there appeared to be a conflict between the values they wanted to follow as a father and the barriers their autistic experiences gave them. Participants reflected how at times they felt they could not be the way they wanted to be as a father, due to the difficulties they experienced associated with their diagnosis. Adam spoke of how he would take his children to birthday parties, despite the anxiety he felt around this associated with his sensory experiences, due to the fact he felt it was important in his role as a father:

> *"I suppose sometimes those values are in conflict with my experience" (Adam)*

2.4.2 Theme 2: Impact of Autism on Parenting

All participants reflected on how they felt their diagnosis impacted their role as a father. Whilst most participants acknowledged the challenges they faced because of their autistic experiences, some reflected on how they also provided positives to their parenting role.

2.4.2.1 Sensory experiences

Participants commonly described their parenting role to be influenced, both positively and negatively by their sensory experiences. A common sensory experience that was described was their heightened sensitivities to noise, and how this was particularly difficult to manage during their child's infant years, when there was more of a tendency for their children cry.

> *"There were times when they were younger, you know babies, you know from when they were born probably for the first 18 months where the crying particularly, I found staggeringly difficult. You know, unbelievably difficult." (Tony)*

Tony's use of repetition, emphasising the word *"difficult"* and use of the word *"staggeringly*" emphasises how intolerable Tony feels this sensory experience to be.

Sensory experiences around touch were also commonly discussed by participants as impacting their role as a father. Some participants described how they were hyper-sensitive to touch, and therefore, at times struggled with the aspects of fatherhood that involved physical connection.

> *"Something that is very much about being a father is that I hate… No, I don't hate, 'hate's the wrong word, I really dislike being touched" (Edward)*

Whilst Edward acknowledges the challenges he faces around this, he reflects how he felt it was important for him to *"tolerate"* physical affection from his child, due to the strong love he had for them:

> *"I, I, I tolerate it for her because I, I love her so much." (Edward)*

Whilst this was the case for most participants, this was juxtaposed by two participants who instead discussed a difference in sensory experience, whereby they were very tactile and physical affection was important to them. Whilst Daniel saw this as a positive to his role of parenting, Kevin felt there were challenges to this, particularly when his children were less tactile:

> *"So, as you can imagine, if you're a tactile person and your child's the opposite, that can be quite difficult and you think well sometimes you just need a hug." (Kevin)*

Tony also reflected how he felt his tendency to be kinaesthetic positively influenced his interaction with his children in their younger years, given the perceived similarities in sensory experience:

> *"I am quite kinaesthetic, I do like to touch things…I do wonder whether when they were younger that would have helped, because children are very kinaesthetic". (Tony)*

2.4.2.2 Social interaction and communication

Participants described the challenges they experienced with social interaction and communication within their role as a father and how they felt their diagnosis impacted this. A common narrative described by participants was the difficulties in interacting with their children during their infant years due to the difference in cognitive abilities between themselves and their child:

> *"when they're sort of on the cusp of being verbal that's the part I've just found… I've found it so hard, to be honest, so hard. "(Adam)*

Adam's use of repetition emphasises how *"hard"* he finds the challenges he faced with interacting with his children when they within the non-verbal stage of development. Adam added that once his child was aged above four years old, he found interacting with them significantly easier, due to the fact he found it easier to connect with his child when he was able to have a logical conversation with them.

Many participants also spoke about how they were aware of their tendency to be very literal and often adopted a 'black and white' thinking style which led to several challenges within their parenting role. In particular, participants spoke of how this impacted the way they viewed and understood their children's behaviours. Robert reflected how his tendency to be very literal in his understanding meant at times he could be catastrophic in his thinking around his children's behaviour, if they were to be even slightly disruptive:

> *"In my mind, it's, like, kind of the black and white thinking, it's, like, everything's okay,…or it's not okay and it's a crisis, you know. So that was a very challenging thing as far as not realising that, "Hey, this is a kind of thing again, it's normal, it's not World War III, the house isn't going to fall down, you know, this is going to work itself out." (Robert)*

Robert also associated this to his difficulties with theory of mind, reflecting how he found it challenging to understand why his children may not understand instructions in the way he does. Robert's use of repetition within his account evokes a sense of frustration around the repetitive nature of parenting:

> *"why would you need to explain that to somebody over and over and over again, you just wouldn't think that you would, but you know, again, those are kids, and so that's really hard for me to wrap my head around, you know, just kind of that training and parenting and repetition, repetition, repetition" (Robert)*

A few participants also discussed how this impacted how they internalised their children's behaviours, and at times they noticed their tendency to take their children's behaviour personally and would feel rejected or dismissed if their child were to be behaving in a way that appeared avoidant:

> *"It can feel very personal and I know it's not and, and thinking… You know, just remembering the kids are going through their own stuff" (Adam)*

Tony also reflected how due his literal thinking style he struggled with lying and had observed how following children's make belief traditions (e.g., Father Christmas) was really difficult for him:

> *"You know, I almost cannot lie. It is almost an impossibility. I found it difficult, I really found it difficult saying to the kids there was such a thing as Father Christmas, because … I mean, honestly it was one of those kind of, "I am still lying to them. I am still lying to them about something which is really important". (Tony)*

Tony's use of the word "impossibility" emphasises the sheer difficulty he experienced in being able to engage with make belief traditions.

Whilst the majority of participants spoke about how their social difficulties impacted their relationship with their children, Adam spoke about how these difficulties extended to his interaction with other parents. Adam reflected how he found play-dates difficult and coped with this by either avoiding these interactions, or masking his difficulties:

> *"I do try and avoid most of that where, where I can. If I can't I will obviously do it but, umm, it's, it is just so aversive and I find it so hard to, I suppose, mask what's going on for me and still be there for my kids and to talk to other parents and things like that." (Adam)*

2.4.2.3 Unpredictability and change

Many participants discussed how they struggled with managing unexpected change and unpredictability. Participants reflected how their role as a father saw them often exposed to unpredictable situations, as for example Robert explained *"Kid's aren't always predictable".* Consequently, participants reflected how this brought challenges to their role as a father:

> *"So I might have plans of something we're gonna do as a family or myself or something like that and, kids being kids, they can do their thing, umm, and I guess when the plans change I find that quite difficult". (Adam)*

Participants reflected how their preference for familiarity saw them struggle with spontaneity, with a few participants discussing about how they felt this limited the opportunities and experiences their children received.

> *"I think I've probably been quite narrow in probably kind of the opportunities that we gave them in a way" (Daniel)*

2.4.3 Theme 3: Understanding of Diagnosis

The third theme relates to participants experiences of receiving an autism diagnosis in the context of parenthood. Participants discussed the benefits of having a shared diagnosis with their children and expressed their frustrations towards others' misconceptions towards autism.

2.4.3.1 Shared diagnosis

Four participants had a child/children diagnosed with autism. These participants discussed how the shared diagnosis brought benefits not just to themselves, but also to their children. Many participants spoke about how the trigger for their own diagnostic assessment was following their children being diagnosed with autism, and them observing similar experiences in themselves. Kevin reflected how despite the challenges he had experienced in supporting his autistic children and getting them appropriate support, these experiences had led him to accessing his own assessment and diagnosis.

> *"So, well, the main positive part of it was if it wasn't for all the rubbish that we had 16 years ago, I wouldn't have been diagnosed probably." (Kevin)*

Many participants spoke about how it allowed for a greater connection with their autistic child due to the shared understanding and insight into their difficulties.

> *"I've often said to her, you know, "You and I are the same, we go through this together," (Edward)*

Edward’s use of the phrase “*we go through this together”* evokes the sense of connection he felt with his child through the experiences they encounter associated with their diagnoses.

The shared diagnosis also allowed many participants to have a greater understanding into their autistic child’s behaviours. Some participants shared how they felt this insight exceeded that of their non-autistic partner, due to experiencing similar difficulties to their children.

> *“she asked him to put away the clean dishes from the dishwasher, and in her mind, that also meant, “Once you put away those, take the dirty dishes and put the dirty dishes in that empty dishwasher,” and he only put away the clean dishes because that’s what she had asked him to… And you know, I told her, I said, “You have to tell him every step, you can’t…otherwise he’s going to be very literal and assuming you just mean that first part,” (Daniel)*

2.4.3.2 Frustrations towards preconceptions and assumptions

A common narrative described by participants was that they felt misunderstood as an autistic individual and acknowledged that there was limited understanding from others around their diagnosis and experiences. Most participants spoke about how they felt this was societal wide:

> *“So this is the battle we have as autistic people, that the majority of the population really do not understand it at all.” (Edward)*

Some participants reflected how they consequently worried about how others viewed them, considering their diagnosis, and as a result a few participants felt reluctant to inform professionals involved in their children’s care, of their diagnosis:

> “I’m not gonna tell because I feel like in the wrong hands with people that don’t understand autism in depth it could be used against me in a way that I’m not quite happy with.” (Adam)

Adam’s account highlighted how he felt concerned as to how others having limited understanding around the diagnosis could result in them behaving differently towards him. Some participants also reflected how they were worried as to how professionals would view their children, considering their own diagnosis.

> *“I feel like if they were to know stuff like that their only practical… or one of their practical applications of that knowledge might be “Ooh, I wonder if their kids have got autism” and then look out for those traits as opposed to look out for other things. “(Adam)*

Similarly, Kevin reflected how he felt his diagnosis might be used as a *“weapon”* against him by professionals, whereby he felt they may attribute the difficulties his children experienced as them *“copying dad”.* The use of the word *“weapon”* emphasises the extent to which Kevin feels threatened by professionals due to his diagnosis.

Tony added a differing view, whereby he felt more personally misunderstood by his wider family system, and consequently he felt frustrated by the limited understanding that his wider family system had towards his diagnosis and the assumptions they would make around his behaviour:

> *“they make assumptions that just aren’t true, “Oh, Tony is autistic. He doesn’t like socialising. We won’t bother visiting anymore,” which isn’t necessarily true. So, there is those sort of slightly weird family and friend dynamics where they think they understand, but they don’t, but they don’t want to ask any more questions to understand more” (Tony)*

2.4.4 Theme 4: Importance of Coping Strategies and Support Systems

Within the final theme, participants reflected on whilst they experienced challenges within their role as an autistic father, they had learnt and developed many helpful coping strategies.

2.4.4.1 Importance of routine and structure

Participants spoke of the importance of family life to be highly structured and how disruptions to routine were challenging. Routine was an important part of all aspects of the participant's life's and therefore, it was important to them that family life was also well structured:

> *"Our family life is very, very structured, very structured. You know, my life is very structured in how I work and everything that I do, so our family, you know we have always had a set routine where you know we know what we do, bedtime routines, television routines, eating routines." (Tony).*

Some participants spoke about how this was helped by the fact their partners and children often liked structure and routine too, which meant it was easier to implement this into family life:

> *"I guess my wife's a little bit similar and I think our children are also, to an extent. Neither of them are hugely adventurous."* (Daniel)

Given these difficulties, for some, it was helpful to have plans in place to cope if there were to be an expected change. Further to this, Adam reflected how he also found it helpful to have prepared lists of activities he could use with his children, due to his difficulties with being spontaneous:

> *"So one of the things I have is this big old list of things I can dip into and think, "Oh we can do this today or we can do that or we can go here and we can go to that,"*

> *umm, 'cos otherwise the thought of just being at home with both of them with no plan is a little bit like, "Agh!" (Adam)*

2.4.4.2 Self-soothing strategies

Participants reflected on how they used self-soothing strategies in order to cope with difficulties they experienced associated with their diagnosis. Some participants spoke about the importance of using ear defenders in order to cope with the sensory difficulties they experienced when their children would scream or cry:

> *"out of desperation, I would take, like, paper napkins, pieces of paper napkins and kind of wad them up and stick them in my ears as makeshift earplugs. And that was really the only way that I could get through that kind of thing." (Robert)*

Robert's use of the word "desperation" emphasises the importance of this coping mechanism in managing the sensitivities to noise he experienced.

Participants also spoke of how in order to cope with the difficulties they experienced in managing long periods of social interaction with their children, they used home as a safe place to unwind and unmask:

> *"it can get to a point where it's just like I need time to switch off." (Daniel)*

Kevin reflected how home was his "sanctuary", "place to recharge "and a "place to make sense". In particular Kevin noted that having a place in his house for his own where he could be away from social interaction and fully unwind, was important to him.

2.4.4.3 Access to support

Participants spoke of the support they received from others within their role as a father. Many participants reflected how their partner and children were very supportive towards them and this was important in helping them to cope with any difficulties they experienced. In particular, they spoke of how they valued the support of their partners and saw themselves as a *"team"* (Edward), who try and *"try and tag team"* (Adam) when parenting.

Participants spoke of how it was helpful and supportive when their children were accepting of their diagnosis and differences. For example, Robert described how his children were accepting of his differences. In his account Robert reflects how his children were accepting of the fact Robert wore ear defenders to manage his noise sensitivities:

> *"I think the good thing is since kids are so adaptable, you know, the idea of me having to wear things like that, you know, when things are loud, it doesn't faze them at all, you know, it's just that's how things are, you know, and so I think that's been kind of a relief" (Robert)*

Whilst participants acknowledged the positive support they received from their families; some participants spoke about how they felt the external support services available to fathers were insufficient:

> *"But it's tough, it really is, that I think being a father is… I think with most books written about autism, and I know this as well from university because I'm doing a course as well, is the parents' books are nearly always written by women, because they seem to the main carers" (Kevin)*

Kevin's account evoked a sense of disappointment when reflecting how he felt support and resources for Autism were often tailored to mothers.

2.5 Discussion

Using IPA, four Group Experiential Themes were elicited, through which autistic fathers described the positives and challenges in their role as a father. Throughout the discussion each theme will be discussed and interpreted further.

Participants described parenthood to involve managing a range of responsibilities and roles that at times felt demanding and all-encompassing. There was a sense of self-criticism from participants whereby they felt they were not living up to the expectations they had for themselves. Participants also reflected how they often compared their parenting to that of their partners and other fathers. Given that self-critical rumination has been found to lead to increased levels of parenting stress (Moreira & Canavarro, 2018), it may be that this further exacerbated the challenges they faced in parenting. However, participants also described experiencing many positives in their role as a father. Fathers valued the sense of connection and love they had with their children, a similar finding to previous research exploring the experiences of autistic parents (Dugdale et al., 2021, Winnard et al., 2022, Smit et al., 2023). Participants also reflected on the sense of purpose and achievement fatherhood provided them.

The second theme within this study described how participants felt their autism diagnosis impacted their role as a father, both positively and negatively. This is in line with previous research exploring the experiences of autistic mothers, who also describe the positives and challenges to their diagnosis on motherhood (Dugdale et al., 2021, Winnard et al., 2022). A common experience of participants was how their sensory experiences influenced their parent role. With research finding that 96% of autistic individuals experience sensory processing difficulties (Talcer et al., 2021), and given the high sensory demands associated with parenting a child, autistic fathers described how their sensory sensitivities had a significant influence on their role as a parent. In particular fathers reflected how their sensory sensitivities to noise and reactivity to touch were most impactful. This is in line with previous research exploring the sensory experiences of autistic mothers that found auditory and tactile-over reactivity were most frequently described as impacting their parent role (Tacler et al., 2021). Autistic parents are experiencing sensory differences that have been highlighted to cause increased levels of stress and anxiety (Tacler et al., 2021). Consequently, autistic parents may require coping strategies, such as the use of ear defenders or time to unwind away from situations that are high in sensory overload, in order to cope with these challenges.

Difficulties with social interaction and communication were also commonly described as affecting participants role as a father. Theory of Mind, being the ability to impute mental states to the self and others, has been shown to be impaired in autistic individuals (Hughes & Leekham, 2004). Participants described how their difficulties with adopting Theory of Mind, and their tendency to think literally, saw them experiencing challenges in understanding their children's behaviour. It is evident that fathers predominately discussed how their social interaction and communication difficulties impacted the connections with their children. In comparison, previous research exploring autistic mother's experiences, discussed how their social difficulties were impactful on their interactions with their children's teachers and peer groups (Winnard et al., 2022). This could be explained by the fact research suggests mothers tend to be more involved in the organisation of social events with other children and parents, due to the pre-existing social contacts established in maternity leave, or the tendency for parent group meet ups to feel tailored towards mothers (Hodkinson & Brooks, 2020). Therefore, fathers in this study may have had less exposure to social interaction across their children's wider network.

Managing unexpected change and uncertainty was a predominant challenge experienced by most fathers in this study. It is commonly known that at times parenting can be unpredictable and keeping to a strict routine can be difficult (Winnard et al., 2022). For many autistic individuals, uncertainty and change can lead to distress and anxiety (Jenkinson et al., 2020). Consequently, fathers spoke of how it was important for them to keep to a routine and structure to cope. Research exploring the experiences of autistic mothers, also found routine and structure to be significantly beneficial for the mothers in order to cope with the inevitable changes that come with parenthood (Winnard et al., 2022, Dugdale et al., 2021).

Four participants had children that were also diagnosed with autism. These participants commonly reflected how this shared diagnosis allowed for a mutual understanding across their autistic experiences, which consequently led to a greater connection between them. It has been previously found that autistic parents felt their own experience of the diagnosis is beneficial in allowing for an increased understanding and empathy towards their autistic children (Crane et al., 2021). Consequently, it is suggested that being autistic themselves is advantageous when parenting an autistic child, compared to neuro-typical parents who rely on self-education in order to better understand their children's experiences (Woodgate & Secco, 2008). It also important to consider how some of the participants' reflected how their own child's diagnosis was often a trigger for them to access their own assessment. Therefore, for these participants it could be that the improved awareness around the diagnosis, prior to their own, may have influenced their own understanding and acceptance of their diagnosis.

Participants also expressed their frustrations around the limited understanding from others around their diagnosis, which saw some participants worried how professionals may view them and their children. This supports the 'double-empathy problem' theory, which refers to the difficulties in understanding across autistic and non-autistic individuals (Milton, 2012). It is theorised that whilst autistic people may have needed to develop their insight into the experiences of non-autistic people in order to live within a non-autistic culture, unless they are related to an autistic individual, non-autistic people may see no pressing need to better understand the minds of autistic people (Milton, 2012). This supports the idea that fathers who had children diagnosed with autism felt they better understood their children's experiences, due to their own personal experiences of the diagnosis. Previous research also found that autistic mothers were more likely to feel misunderstood by professionals involved in their child's care, than non-autistic mothers (Pohl et al., 2020). This emphasises the importance of greater understanding from the system around autistic individuals, to improve their sense of belonging and security, particularly to those professionals involved in their children's care.

The final theme elicited from this study, saw fathers emphasising the importance of coping strategies in order to manage their difficulties. Fathers had learnt to adopt helpful ways of coping to manage which were crucial in keeping to their responsibilities as a father. As well as this, receiving support from others was seen as an important part of parenting. Fathers commonly reflected how the support they received from their partners and their children was helpful in managing their difficulties. This is line with previous research exploring autistic mother's experiences, who also emphasised how the support they received from their neurotypical partners was helpful in managing aspects of parenting they found challenging (Dugdale et al., 2021). Some fathers in this study reflected how they felt there was insufficient support available for autistic fathers. Similarly, previous literature has shown autistic mothers also emphasised the challenges they faced in accessing specialist support for parenting (Winnard et al., 2022), suggesting this is a common barrier faced by both autistic mothers and fathers. It is important that services improve the accessibility of parenting support for autistic parents to ensure they feel supported in their role.

When considering the findings, it is important to consider how the life course theory (Hutchison, 2014) may influence participant's individual's experiences. The life course theory considers how factors such as age, relationships, life transitions, social change and human agency influence a person's life (Hutchison, 2014). For this research, it is evident the range of ages across participants varied, with a difference of 24 years between the youngest and oldest participant. Therefore, these participants were born into a different cohort, who would have experienced different societal factors e.g., opportunities for education and employment (Hutchison, 2014). These participants would have also transitioned into fatherhood across different decades. With this in mind, it has also been discussed how the generation in which an individual is born and raised in, can influence their approach to child-rearing (McGoldrick et al., 2011). Therefore, given that the youngest and oldest participants were born across different time periods, it is important to consider how this may have been a further factor in influencing the way they experience parenting.

2.5.1 Strengths and limitations

To the author's knowledge, this study is the first to solely explore the lived experiences of autistic fathers. The use of IPA allows for an in-depth understanding of their experiences, taking the stance that autistic participants are the experts of their own experiences (Howard et al., 2019). A further strength of this research is that the interview schedule was piloted by an 'expert-by-experience' in order to determine the suitability of the process for autistic individuals. Whilst the interview schedule was piloted with an 'expert-by- experience', autism research guidelines have recommended that input from an expert by experience should be implemented at all stages of the research (Gowen et al., 2019). Therefore, future research should endeavour to ensure an 'expert by experience' is also used at all stages of the research process. For example, within this research is may have been helpful to use an 'expert-by-experience' when determining the inclusion/exclusion criteria for recruitment, such as determining how to operationalise 'regular contact' or with deciding what requirements there should be around the age of the father's children, to help gather an in-depth understanding of their parenting experiences. A further strength of this research is adaptations to the interview process were used, such as sending the interview questions beforehand and considering the choice of language used, to ensure the research was tailored to the population of participants (Gowen et al., 2019).

Whilst a smaller sample size was used, it has been argued that within IPA analysis this allows for a deeper exploration of the data collected (Reid et al., 2005). Within IPA research it is recommended to recruit a sample that has similar characteristics to each other, (Pietkiewicz & Smith, 2014). A strength of the sample recruited was whilst the participant's differed on characteristics such as the length of time it had been since diagnosis, the participants had several similarities to one another, for example, all participants were diagnosed with autism as an adult and were all in long-term relationships with the mother of their children.

Whilst similarities across the sample is beneficial, and generalisability is not aimed for in IPA research (Reid et al., 2005), these similarities limit the generalisability of the findings across the wider autistic father population. Given that parenting experiences (Lansford, 2022) and the experiences of autistic individuals (Matson et al., 2011, Norbury & Sparks, 2013) have been shown to differ cross-culturally, it would be helpful for future investigations to explore the experiences of autistic fathers from different cultures, given that the participants in this research were all white, Caucasian ethnicity. Furthermore, whilst all participants were in long-term relationships with the mother of their children, research has shown that parents who are in coresidential relationships with the biological partner of their children, reported lower levels of parenting stress than those who were no longer in a relationship with the biological partner of their children (Cooper et al., 2009). Therefore, it is important to understand participants in this study's experiences in the context of their relationship, and how their experiences may have differed if there were disruptions to their family system. All participants were also diagnosed as an adult, and therefore, this may have influenced their understanding of their diagnosis, given that research suggests self-acceptance is facilitated through diagnosis (Lewis, 2016).

One participant had a co-occurring diagnosis of Attention Deficit Hyperactivity Disorder (ADHD). Research shows the rates of co-occurrence between Autism and ADHD diagnoses range between 14-78% (Panagiotidi et al., 2019), suggesting participants diagnosed with ADHD make up a large proportion of autistic individuals. Whilst the participant was informed that the focus of the interview was to discuss autism, it is evitable that his experiences are also understood in the context of his ADHD diagnosis. With the diagnosis of ADHD characterised by difficulties in attention, hyperactivity and impulsivity, research has suggested that parents diagnosed with ADHD can experience differences in parenting to adults without ADHD (Johnston et al., 2012). For example, difficulties with inattention may be associated with reduced parenting monitoring of the child's activities (Johnston et al., 2012). Furthermore, individuals with ADHD tend to benefit from high-intensity reinforcement and they can struggle with situations where the reinforcement is delayed. Therefore, parents with ADHD may experience difficulties in the aspects of parenting that involve patience and perseverance in teaching young children new skills (Johnston et al., 2012). Given the difficulties associated with ADHD and parenting, it is important to consider how these may have influenced the participant's experiences of parenting in this research.

Whilst all participants were diagnosed with autism in their adult years, it is important to consider how the length of time in which they had been aware of their diagnosis may influence their experiences. Research has shown that following acceptance of the diagnosis, autistic adults describe a period of learning to accept themselves (Lewis, 2016). Given that one participant's diagnosis was very recent, it would be helpful to consider how this may have influenced how he understood and conceptualised his experiences. Research exploring the experiences of adults post-diagnosis has shown that autistic adults can go through a period of reflection time following diagnosis where they describe experiencing a range of emotions such as denial and relief, and they describe self-acceptance towards their diagnosis as an 'ongoing journey' (Lewis, 2016). Therefore, it would be helpful to consider how the participants' very recent diagnosis may have meant he had less time than other participants to make sense of his diagnosis and the association with parenting. On the other hand, it has been argued that some autistic individuals know they are autistic long before their diagnosis (Lewis, 2016), therefore, whilst his diagnosis was recent, his awareness and understanding of his experiences may have been developed long before his diagnosis.

In terms of the procedure, it is important to consider that, as requested by participants, all the interviews were conducted remotely and not face-to-face. It has been suggested that conducting interviews remotely facilitates a comfortable environment for participants, that can help participants to feel more at ease when discussing topics that may be sensitive to them (Alase, 2017). Within this research participants also emphasised how the online format was their preference due to the fact they could be at home, in a place they were familiar with. However, it is important to consider the possible limitations the online format may have had to the IPA interview process. On occasion, within the interviews, distractions arose (e.g. drop out of participant's internet connection), which disrupted the flow of interaction. Research suggests that online qualitative interviews may be limited by the fact online interaction is not easily restarted once distractions occur (Kendall, 2014). This may have led to points being potentially missed from the conversation. Furthermore, within IPA it is important to record non-verbal observations that add more complexity to the understanding around participant's experiences

(Smith & Fieldsend, 2021). The online format of interviews may have caused a barrier in terms of the interviewer picking up non-verbal cues that may have been more noticeable if the interview were to be conducted face-to-face. Whilst this is the case, autistic individuals can have difficulty in integrating non-verbal communication with their verbal communication (American Psychological Association APA, 2013). It was noticed in the interviews that non-verbal communication was limited by all participants and consequently this was not discussed within the analysis.

2.5.2 Future research directions

It is evident that the research exploring autistic fathers is limited, therefore further research is needed to gain further knowledge and awareness of their needs and challenges. Given that all the fathers in this study were diagnosed as an adult, it may be helpful for future research to explore the experiences of fathers who were diagnosed with autism as a child, to determine whether a longer adjustment period following diagnosis, influences their experiences.

Four of the six participants had children who were also diagnosed with autism, given the additional challenges noted in parenting an autistic child, and the shared connection autistic fathers spoke of having with their autistic child, it would be helpful for future research to separately explore the experiences of fathers of children with and without autism.

As previously stated, further exploration of autistic fathers cross-culturally would also be insightful into understanding the wider experiences of this population further. The importance of improving the support available to autistic fathers was identified within this study, therefore, it would be helpful for future research to explore this further to determine what areas of support would be beneficial and how this can be implemented across services.

2.5.3 Clinical implications

It is evident that there is limited research exploring the experiences of autistic parents, in particular the experiences of autistic fathers. This research highlights the importance of raising awareness amongst professionals, in how this sub-population of fathers may experience parenting. Through raising awareness of the needs of autistic fathers, this research aims to help improve accessibility of services for autistic parents, as it highlights the importance of adapting parenting support to meet the father's individual needs. This will help to allow autistic fathers to receive more personalised support.

Whilst there is an extensive pool of support and parenting programs available (e.g., 'The Incredible Years, Webster-Stratton, 2015), these are typically written for general parenting experiences and therefore do not consider the specialist support or guidance autistic parents may require. Parenting programs help to improve parent's knowledge around parenting practices and skills, as well as helping to reduce parental stress (Barlow & Coren, 2018). Whilst the research shows these to be effective in improving parenting outcomes, it has been highlighted how further research is needed to explore the effectiveness of these programs for parents with additional needs (Barlow & Coren, 2018). From this, services can aim to provide more specialist support and guidance for autistic parents, considering the challenges they reported in this study (sensory experiences, social communication and interaction difficulties, difficulties with uncertainty and change). For example, fathers in this research discussed how their sensory sensitivities were impacted by the demands of parenting. Therefore, it would be helpful for services to offer autistic parents a sensory assessment, so they can explore their sensory needs and be provided with recommendations as to how to manage these.

The use of parent support groups for autistic parents may also be useful in allowing parents to reflect on their experiences and challenges with other autistic parents. Research has suggested that parent peer groups for parents of autistic children can provide a helpful space for parents to gather knowledge, understanding and acceptance from others, as well as an improved sense of belonging (Banach et al., 2010). Therefore, it should be considered how given that the fathers in this research also reflected on the importance of understanding and acceptance from others, the use of autistic parent peer groups may be a useful strategy in supporting this sub-population of parents.

Given that a few participants in this research stated they were reluctant to inform professionals about their diagnosis associated with worries around stigma, it is important to consider how this may be a potential barrier in fathers' accessing this support. Therefore, considerations should be made to consider how this population of autistic fathers could still access support. For example, the use of online, anonymous peer support groups may be a useful in improving the accessibility of support, even in cases where the individual is reluctant to disclose their identity.

2.5.4 Conclusion

In conclusion, this research explores the parenting experiences of autistic fathers, an area that, to date, and to the author's knowledge, has not been researched. The findings highlighted that fathers experience both positives and challenges in their role as a parent diagnosed with Autism. From this research, the importance of improving awareness around this sub-population is emphasised, as well as the need for services to improve their accessibility, providing parenting specialist support to autistic parents.

Appendix A Submission guidelines 'Review of Autism and Developmental Disorders'

Instructions for Authors

Editorial procedure

Double-blind peer review

The Journal uses a double-blind review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to RJAD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

- A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information.
- The blinded manuscript containing no author information (no name, no affiliation, and so forth).
- The Author Note

Types of papers

• **Review Articles:** The preferred article length is 20-23 manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.

Review your manuscript for these elements

Order of manuscript pages

- Title Page with all Author Contact Information & Abstract with keywords and the corresponding author e-mail information.
- Blinded Manuscript without contact information and blinded Abstract, and References
- Appendix
- Figure Caption Sheet
- Figures
- Tables
- Author Note

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

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Authors wishing to include figures, tables, or text passages that have already been published elsewhere are required to obtain permission from the copyright owner(s) for both the print and online format and to include evidence that such permission has been granted when submitting their papers. Any material received without such evidence will be assumed to originate from the authors.

Online Submission

Please follow the hyperlink “Submit manuscript” and upload all of your manuscript files following the instructions given on the screen.

Source Files

Please ensure you provide all relevant editable source files at every submission and revision. Failing to submit a complete set of editable source files will result in your article not being considered for review. For your manuscript text please always submit in common word processing formats such as .docx or LaTeX.

Title Page

The title page should include:

- The name(s) of the author(s)
- A concise and informative title
- The affiliation(s) and address(es) of the author(s)
- The e-mail address of the corresponding author

Abstract

Please provide an abstract of 120 words or less. The abstract should not contain any undefined abbreviations or unspecified references.

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Text

Text Formatting

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.

- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data).

Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgements

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

Body

- The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain: Introduction (The introduction has no label.) Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.) Results (Center the heading.) Discussion (Center the heading.)
- Headings Please use no more than three levels of displayed headings. Level 1: Centered Level 2: Centered Italicized Level 3: Flush left, Italicized
- Footnotes Center the label “Footnotes” at the top of a separate page. Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables. Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols. Always use footnotes instead of endnotes. Type all content footnotes and copyright permission footnotes together, and numbered consecutively in the order they appear in the article. Indent the first line of each footnote 5-7 spaces. The number of the

footnote should correspond to the number in the text. Superscript Arabic numerals are used to indicate the text material being footnoted.

- Author Note The first paragraph contains a separate phrase for each author's name and the affiliations of the authors at the time of the study (include region and country).The second paragraph identifies any changes in the author affiliation subsequent to the time of the study and includes region and country (wording: "authors name is now at affiliation".) The third paragraph is Acknowledgments. It identifies grants or other financial support and the source, if appropriate. It is also the place to acknowledge colleagues who assisted in the study and to mention any special circumstances such as the presentation of a version of the paper at a meeting, or its preparation from a doctoral dissertation, or the fact that it is based on an earlier study. The fourth paragraph states, "Correspondence concerning this article should be addressed to…" and includes the full address, telephone number and email address of the corresponding author.

Terminology

- Please always use internationally accepted signs and symbols for units (SI units).

Citation

Cite references in the text by name and year in parentheses. Some examples:

- Negotiation research spans many disciplines (Thompson 1990).
- This result was later contradicted by Becker and Seligman (1996).
- This effect has been widely studied (Abbott 1991; Barakat et al. 1995; Kelso and Smith 1998; Medvec et al. 1999).

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text. Do not use footnotes or endnotes as a substitute for a reference list.

Reference list entries should be alphabetized by the last names of the first author of each work.

- Journal article
  Harris, M., Karper, E., Stacks, G., Hoffman, D., DeNiro, R., Cruz, P., et al. (2001). Writing labs and the Hollywood connection. Journal of Film Writing, 44(3), 213-245
- Article by DOI
  Slifka, M. K., & Whitton, J. L. (2000) Clinical implications of dysregulated cytokine production. Journal of Molecular Medicine, doi:10.1007/s001090000086
- Book
  Calfee, R. C., & Valencia, R. R. (1991). APA guide to preparing manuscripts for journal publication. Washington, DC: American Psychological Association.
- Book chapter

O’Neil, J. M., & Egan, J. (1992). Men’s and women’s gender role journeys: Metaphor for healing, transition, and transformation. In B. R. Wainrib (Ed.), Gender issues across the life cycle (pp. 107–123). New York: Springer.

- Online document
  Abou-Allaban, Y., Dell, M. L., Greenberg, W., Lomax, J., Peteet, J., Torres, M., & Cowell, V. (2006). Religious/spiritual commitments and psychiatric practice. Resource document. American Psychiatric Association. http://www.psych.org/edu/other_res/lib_archives/archives/200604.pdf. Accessed 25 June 2007.

Journal names and book titles should be italicized.

Tables

- All tables are to be numbered using Arabic numerals.
- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within the text immediately after the phrase in which it is first mentioned. Copyright permission footnotes for tables are typed as a table note.

Appendix B CASP Qualitative Checklist (CASP, 2018)

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes, Can’t Tell, No

2. Is a qualitative methodology appropriate?

Yes, Can’t Tell No,

3. Was the research design appropriate to address the aims of the research?

Yes, Can’t Tell, No

4. Was the recruitment strategy appropriate to the aims of the research? Yes, Can’t Tell, No

5. Was the data collected in a way that addressed the research issue?

Yes, Can’t Tell, No

6. Has the relationship between researcher and participants been adequately considered?

Yes, Can’t Tell, No

Section B: What are the results?

7. Have ethical issues been taken into consideration? Yes, Can’t Tell

8. Was the data analysis sufficiently rigorous? Yes, Can’t Tell, No

9. Is there a clear statement of findings? Yes, Can’t Tell, No

Section C: Will the results help locally?

10. How valuable is the research?

Appendix C Submission guidelines for 'Autism and Developmental Disorders' Journal

Editorial procedure

Double-Anonymous Peer Review

MANUSCRIPT FORMAT

All JADD manuscripts should be submitted to Editorial Manager in 12-point Times New Roman with standard 1-inch borders around the margins. Please disregard the suggestion of 10-point font in the Text section below.

APA Style

APA Publication Manual standards must be followed.

As of January 20, 2011, the Journal has moved to a double-anonymous review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to JADD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

- A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information.
- The anonymized manuscripts containing no author information (no name, no affiliation, and so forth).

Types of papers

Articles, Commentaries Brief Reports, Letters to the Editor

*JADD is no longer accepting manuscripts with only one participant or group studies without an appropriate comparison group.

- The preferred article length is 20-23 double-spaced manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 double-spaced pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.
- Special Issue Article: The Guest Editor may dictate the article length; maximum pages allowed will be based on the issue's page allotment.
- A Brief Report: A Brief Report: About 8 double-spaced pages with shorter references and fewer tables/figures. Must meet the demands of scientific rigor required of a JADD article but can be preliminary findings.
- A Letter to the Editor/Commentary is 6 or less double spaced pages with shorter references, tables and figures.
  Style sheet for Letter to the Editor:

- A title page with the running head, manuscript title, and complete author information including corresponding author e-mail information

- The anonymized manuscripts containing no author information (no name, no affiliation, and so forth):-
  - 6 or less double spaced pages with shorter references, tables and figures
  - Line 1: “Letter to the Editor”
  - Line 6: Text begins; references and tables, figure caption sheet, and figures may follow (page break between each and see format rules)

Review your manuscript for these elements

1. Order of manuscript pages

Title Page with all Author Contact Information & Abstract with keywords and the corresponding author e-mail information.

Anonymized Abstract, manuscripts and References without contact information

Appendix

Figure Caption Sheet

Figures

Tables

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

Permissions

Authors wishing to include figures, tables, or text passages that have already been published elsewhere are required to obtain permission from the copyright owner(s) for both the print and online format and to include evidence that such permission has been granted when submitting their papers. Any material received without such evidence will be assumed to originate from the authors.

Online Submission

Please follow the hyperlink “Submit manuscript” and upload all of your manuscript files following the instructions given on the screen.

Source Files

Please ensure you provide all relevant editable source files at every submission and revision. Failing to submit a complete set of editable source files will result in your article not being considered for review. For your manuscript text please always submit in common word processing formats such as .docx or LaTeX.

Suggestions for Inclusive Language in JADD Submissions

JADD Inclusive Language Guide (Download pdf, 134 kB)

Title Page

Please make sure your title page contains the following information.

Title

The title should be concise and informative.

Author information

- The name(s) of the author(s)
- The affiliation(s) of the author(s), i.e. institution, (department), city, (state), country
- A clear indication and an active e-mail address of the corresponding author
- If available, the 16-digit ORCID of the author(s)

If address information is provided with the affiliation(s) it will also be published.

For authors that are (temporarily) unaffiliated we will only capture their city and country of residence, not their e-mail address unless specifically requested.

Large Language Models (LLMs), such as ChatGPT, do not currently satisfy our authorship criteria. Notably an attribution of authorship carries with it accountability for the work, which cannot be effectively applied to LLMs. Use of an LLM should be properly documented in the Methods section (and if a Methods section is not available, in a suitable alternative part) of the manuscript.

Abstract

Please provide a structured abstract of 150 to 250 words which should be divided into the following sections:

- Purpose (stating the main purposes and research question)
- Methods
- Results
- Conclusion

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Statements and Declarations

The following statements should be included under the heading "Statements and Declarations" for inclusion in the published paper. Please note that submissions that do not include relevant declarations will be returned as incomplete.

- **Competing Interests:** Authors are required to disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication. Please refer to “Competing Interests and Funding” below for more information on how to complete this section.

Please see the relevant sections in the submission guidelines for further information as well as various examples of wording. Please revise/customize the sample statements according to your own needs.

Text

Text Formatting

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data).

Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgements

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

Body

- The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:
- Introduction (The introduction has no label.)
- Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.)
- Results (Center the heading.)
- Discussion (Center the heading.)

Headings

Please use no more than three levels of displayed headings.

Level 1: Centered

Level 2: Centered Italicized

Level 3: Flush left, Italicized

Footnotes

Center the label “Footnotes” at the top of a separate page. Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes. Type all content footnotes and copyright permission footnotes together, double-spaced, and numbered consecutively in the order they appear in the article. Indent the first line of each footnote 5-7 spaces. The number of the footnote should correspond to the number in the text. Superscript Arabic numerals are used to indicate the text material being footnoted.

Terminology

- Please always use internationally accepted signs and symbols for units (SI units).

Scientific style

- Generic names of drugs and pesticides are preferred; if trade names are used, the generic name should be given at first mention.
- Please use the standard mathematical notation for formulae, symbols etc.: Italic for single letters that denote mathematical constants, variables, and unknown quantities Roman/upright for numerals, operators, and punctuation, and commonly defined functions or abbreviations, e.g., cos, det, e or exp, lim, log, max, min, sin, tan, d (for derivative) Bold for vectors, tensors, and matrices.

References

Citation

Cite references in the text by name and year in parentheses. Some examples:

- Negotiation research spans many disciplines (Thompson, 1990).
- This result was later contradicted by Becker and Seligman (1996).
- This effect has been widely studied (Abbott, 1991; Barakat et al., 1995; Kelso & Smith, 1998; Medvec et al., 1999).

Authors are encouraged to follow official APA version 7 guidelines on the number of authors included in reference list entries (i.e., include all authors up to 20; for larger groups, give the first 19 names followed by an ellipsis and the final author’s name). However, if authors shorten the author group by using et al., this will be retained.

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text.

Reference list entries should be alphabetized by the last names of the first author of each work.

Journal names and book titles should be *italicized*.

If available, please always include DOIs as full DOI links in your reference list (e.g., “https://doi.org/abc”).

- Journal article Grady, J. S., Her, M., Moreno, G., Perez, C., & Yelinek, J. (2019). Emotions in storybooks: A comparison of storybooks that represent ethnic and racial groups in the United States. *Psychology of Popular Media Culture, 8*(3), 207–217. https://doi.org/10.1037/ppm0000185
- Article by DOI Hong, I., Knox, S., Pryor, L., Mroz, T. M., Graham, J., Shields, M. F., & Reistetter, T. A. (2020). Is referral to home health rehabilitation following inpatient rehabilitation facility associated with 90-day hospital readmission for adult patients with stroke? *American Journal of Physical Medicine & Rehabilitation*. Advance online publication. https://doi.org/10.1097/PHM.0000000000001435
- Book Sapolsky, R. M. (2017). *Behave: The biology of humans at our best and worst*. Penguin Books.
- Book chapter Dillard, J. P. (2020). Currents in the study of persuasion. In M. B. Oliver, A. A. Raney, & J. Bryant (Eds.), *Media effects: Advances in theory and research* (4th ed., pp. 115–129). Routledge.
- Online document Fagan, J. (2019, March 25). *Nursing clinical brain*. OER Commons. Retrieved January 7, 2020, from https://www.oercommons.org/authoring/53029-nursing-clinical-brain/view

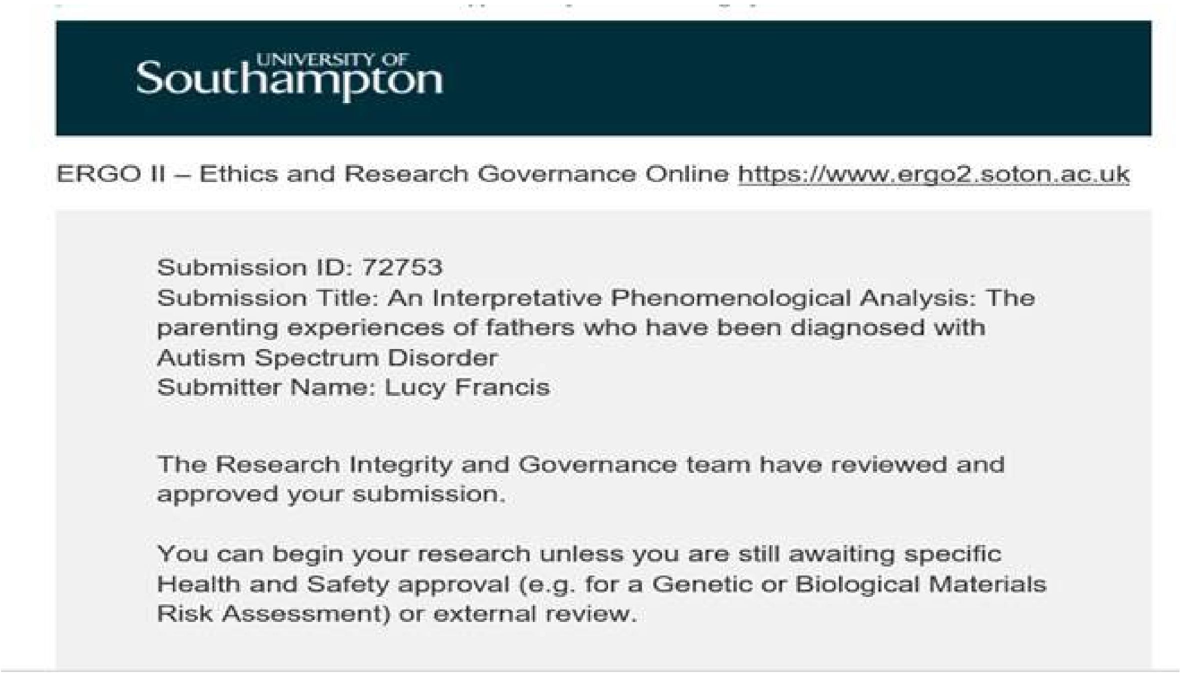
Tables

- All tables are to be numbered using Arabic numerals.
- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within the text immediately after the phrase in which it is first mentioned.

Copyright permission footnotes for tables are typed as a table note.

Appendix D Ethical Approval



ERGO II – Ethics and Research Governance Online https://www.ergo2.soton.ac.uk

Submission ID: 72753
Submission Title: An Interpretative Phenomenological Analysis: The parenting experiences of fathers who have been diagnosed with Autism Spectrum Disorder
Submitter Name: Lucy Francis

The Research Integrity and Governance team have reviewed and approved your submission.

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment) or external review.

Appendix E Recruitment Poster

UNIVERSITY OF Southampton

Ergo number: 72753

The parenting experiences of fathers who have been diagnosed with Autism Spectrum Disorder

We are looking to recruit participants for our research!

The aim of the research is to explore the **parenting experiences of fathers**, who have been **diagnosed with Autism Spectrum Disorder.**

This research will help to further our understanding around the parenting experiences of fathers, diagnosed with ASD, which can help to inform the development of additional provision and support strategies.

What does the research involve?

-You will be asked to take part in an interview for around **one hour** and will take place either **face-to-face** (in a place convenient to you) or **remotely.**

-Following the interview, you will be provided with a **£25 Amazon voucher** to reimburse you for your time.

If you meet the essential criteria and you are interested in taking part in our research, please contact, Lucy Francis, Trainee Clinical Psychologist, via email at L.francis@soton.ac.uk

We would be really grateful for your time-thank you!

Can I take part?

To take part in this research **you need to meet the following essential criteria:**

-Have a **formal clinical diagnosis of Autism Spectrum Disorder** (This may include a diagnosis of Autism, Aspergers syndrome). This would need to be shown through providing a copy of your diagnostic report.

-**Became a father** when you were aged at least **18 years old.**

-**Not diagnosed** with a **learning disability.**

-Able to **understand and speak fluently in the English language**.

-Have **at least one biological child aged at least 4 years old**, to which you have **'regular contact'** with (to have a continued presence in your child's life and having contact with them on at least a monthly basis). If your child is above the age of 18, you do not still need to have regular contact, however you need to have had regular contact during their childhood (until they were 18 years old).

-**No current significant mental health illness**. This will be assessed by using a short questionnaire at some point during the seven days before your interview.

Appendix F Interview Schedule

The parenting experiences of autistic fathers: An Interpretative Phenomenological Analysis

The interview will be structured as follows:

Good morning/afternoon. Thank you for agreeing to talk to me. I am interested in talking to participants, diagnosed with Autism, to explore your experiences of being a father.

I am hoping we can chat for around an hour. If you want to stop at any time, because you want to finish or if you need a break, then just tell me and we can do that.

Firstly, how would you like to be addressed as a person diagnosed with Autism (e.g., autistic, person with autism…)?

Subject focus	**Core Question**	**Prompts**
(orienting/setting the context)	Describe your experience of being a father..	-What are the best things about being a father? -What the difficult/not so good things about being a parent? -As an (autistic person/person diagnosed with autism- use phrase participant would prefer) do you have difficulty with sensory experiences, and how does this affect your role as a parent?
Effect of autism diagnostic label	Do you think having autism impacts or changes the way you parent?	No- Why is this the case? (encourage further explanation)

		Yes- Why is this the case? In what ways does autism impact or change the way you parent?
Reflection and learning	What have you learnt worked well/not so well in your role as a father diagnosed with autism?	-If there was an instruction manual for being a father, diagnosed with autism, what would it include? -If you were to do parenting all again, what would you do differently?
Close	Do you have anything else you would like to tell me?	
Mood repair	Have you got any plans for the rest of the day?	

Appendix G Participant Information Sheet

Study Title: The parenting experiences of autistic fathers: An Interpretative Phenomenological Analysis

Researcher: Lucy Francis, Dr Melanie Hodgkinson, Dr Matt Symes

ERGO number: 72753

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others, but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

There has been previous research exploring the parenting experiences of mothers who have been diagnosed with autism. There is a gap in the research for exploring fathers who have been diagnosed with autism on their parenting experiences, and therefore this research aims to explore father's experiences. Exploration of this area will be helpful in identifying areas that may be challenging to fathers to inform whether additional provision and support strategies would be beneficial.

I am currently a Trainee Clinical Psychologist studying on the Clinical Psychology Doctorate and this is my thesis research that goes towards my academic qualification.

Why have I been asked to participate?

You have been asked to participate as you are a father who has been diagnosed with Autism.

What will happen to me if I take part?

If you would like to take part the researcher will ask you to sign a consent form. This will be sent to you via email. Following this you will be asked to provide your autism diagnostic report as evidence of diagnosis, either by email or sending a copy via tracked post. If you sent your report via post the charges of this will be covered for you. If you cannot provide diagnostic proof that meets the criteria of the research, then you will not be eligible to take part in the research. Once your autism diagnostic report has been reviewed by a researcher in the team, (a registered psychologist) and they confirm this is valid proof for our research, you will be contacted by the researcher to arrange a time, date and location for the interview that is convenient for you. Once a time, date and location has been arranged, you will be sent confirmation of your appointment via email confirming your interview. During the week before the interview, you will be contacted via telephone to complete a brief mental health questionnaire to check whether you are not currently presenting with any significant mental health difficulties. If you were to show significant mental health difficulties, then the interview would no longer go ahead, and you will be signposted to the appropriate services. If your questionnaire shows you are not currently presenting with significant mental health difficulties, the interview will either be held remotely on Microsoft Teams, or at a community site or the University of Southampton. If the interview is face-to-face, you will be reimbursed for the cost of your travel.

The interview will take about an hour, and you will be asked some questions about your experience of being a father diagnosed with autism. You will also be asked some demographic information for the purpose of the research, to help provide further context to your role as a parent. This will be collected at the start of your interview and will include the following; your age, your ethnic origin, how old you were when you were diagnosed with autism, how many children you have, the age of your child/children, whether your child/children has the diagnosis of autism, whether you are in a relationship with the mother of your children, and your current contact arrangements with your child/children, whether you are in employment.

The interview will be recorded on a Dictaphone, or on Microsoft Teams (if remote) so that we can have a record of what was said, which we can then use to analyse the findings of the research. Following the interview, you will be provided with a debriefing statement sheet, within which you will be provided with further information about the research.

Are there any benefits in my taking part?

By taking part in this research, you will be helping us to understand the parenting experiences of fathers who have been diagnosed with autism. This will help us to have a greater understanding of the potential challenges fathers may face in their parent role which can aid professional understanding and inform the development of additional provision and support strategies.

You will be provided with a £25 Amazon voucher to thank you for your participation, as it is greatly appreciated.

Are there any risks involved?

Due to the nature of the research, it is not anticipated that you will be at risk of any physical or psychological harm. However, it is possible that discussing your parenting experiences alongside your diagnosis of autism may raise something that is upsetting for you. If this were to happen, the interviewer is a trainee clinical psychologist, and they will work with you in the interview to determine what you require in the moment or following the interview. For example, this may be having a break from the interview, termination of the interview or providing signposting information for local support services that can support you.

What data will be collected?

For the purposes of the research, we will collect your contact details; being your name, email address, address, and telephone number. These will only be used so that we can contact you for your interview and so that we can send you the documents required. Demographic information will also be collected including; your age, how old you were when you were diagnosed with autism, how many children you have, the age of your child/children, whether your child/children have the diagnosis of autism, whether you are relationship with the mother of your children, your current contact arrangements with your child/children, whether you are currently in employment and your ethnic origin.

Your autism diagnostic report will also be gathered, purely for the purpose of checking you meet eligibility criteria for the research. This report will be handled and stored safely to ensure confidentiality is always kept. If the report is sent to us via email, this will be stored on a password protected file on a password protected file, following which the email from yourself will be deleted. Following the review of this document, the copy will be deleted from our files. If you would prefer to send your report via post, we will reimburse you for the costs of sending this to us, at the University of Southampton, via tracked post. This will be stored safely, within a locked office, within a locked cabinet. This will be returned to you/destroyed following this review. Within both methods, the lead researcher will omit your name from the reports, before the secondary researchers (a registered psychologist) review this document, to ensure this information is kept confidential.

A transcript of what you said during your interview will also be collected. The only identifiable document will be your consent form where you will be asked to sign. All this data listed above will be stored electronically in a password protected file on a password protected laptop, and a password protected university one drive account, that only the research team will have access to.

Will my participation be confidential?

Your participation and the information we collect about you during the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

To ensure your confidentiality, all information; your interview audio recording, demographic information and interview transcript, will be identified by an identification number only. All documents will be stored in an electronic file on a password protected laptop that only the research team will have access to. Following transcription of the interview (which will be around 2 weeks after your interview) the audio recordings of the interviews will be destroyed.

The audio recordings will be transcribed using a professional transcription service, ‘PageSix’. The PageSix transcription service has a team of transcribers who have all signed confidentiality agreements, and the audio recordings are 256- bit encrypted during transfer through the online system and the researcher’s account will be securely password protected. Audio recordings will be uploaded onto this system confidentially, by only being identified by a participant number. Once transcribed the audio recordings will be deleted from the account.

All information said within the interview will remain confidential and only members of the project team and responsible members of the University of Southampton will have access to this data. However, if at any point during the interview you were to disclose any information that implies yourself or others may be at risk of harm this will need to be forwarded to the appropriate professionals. If this arises during an interview, we will talk to you about how and why this information may need to shared with a third party.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part. The consent form will be emailed to you prior to your interview appointment.

What happens if I change my mind?

You have the right to change your mind and withdraw at any time up until after the interviews have been transcribed (which will be around 2 weeks after your interview) without giving a reason and without your participant rights being affected. If you choose to withdraw up until this point all your data will be destroyed. After this point, we will keep the anonymous information about you we have already obtained for the purposes of achieving the objectives of the research only.

You also have the right to skip questions during the interview or stop the interview if you change your mind during the interview itself. If you choose to do this all your data will be destroyed.

If you would like to withdraw you should contact the researcher, Lucy Francis (l.francis@soton.ac.uk).

What will happen to the results of the research?

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent.

The results of this research will be written up as a report that goes towards my academic qualification. The thesis will also be submitted for publication to a research journal. If you would like a copy of the research you can request this from the researcher.

Your personal details will remain strictly confidential. Findings made available in any reports or publications will not include information that can directly identify you without your specific consent.

Where can I get more information?

If you would like further information about this project you can contact Lucy Francis (l.francis@soton.ac.uk), Dr Melanie Hodgkinson (m.j.hodgkinson@soton.ac.uk) or Dr Matt Symes (Matt.Symes@southernhealth.nhs.uk).

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you.

Thank the individual for taking the time to read the information sheet and considering taking part in the research.

Appendix H **Consent form**

CONSENT FORM

Study title: The parenting experiences of autistic fathers: An Interpretative Phenomenological Analysis

Researcher name: Lucy Francis

ERGO number: 72753

Participant Identification Number (if applicable*):*

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (July 2022/ v.4) and have had the opportunity to ask questions about the research.	
I agree to take part in this research study and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and I may withdraw during the interview and up until the point in which the interviews have been transcribed (which will be around two weeks after my interview), for any reason without my participation rights being affected.	
I understand that I may be quoted directly in reports but that I will not be directly identified (e.g., that my name will not be used).	
I understand that taking part in the research study involves audio recording which will be transcribed and then deleted for the purposes set out in the participation information sheet.	
I understand that personal information collected about me or my family such as my name or where I live will not be shared beyond the study team.	

I agree to my Autism diagnosis report being reviewed by a Clinical Psychologist to ensure I meet eligibility criteria for the research. I understand if I cannot provide diagnostic proof that meets the criteria of the research then I will not be eligible to take part in the research.	
I agree to completing a short mental health questionnaire at some point during the seven days before the interview to check whether I am not currently presenting with any significant mental health difficulties. I understand that if I were to show significant mental health difficulties, then the interview would no longer go ahead, and I will be given information about appropriate support services.	

Name of participant (print name)……………………………………………………..

Signature of participant………………………………………………………………

Date……………………………………………………………………………………..

Name of researcher (print name)……………………………………………………

Signature of researcher ………………………………………………………………

Date…………………………………………………………………………………….

Appendix I Demographic information form

Demographic information

This information will be collected from the participant at the start of the interview, in the form of a conversation.

1. What is your age?

2. What is your ethnic origin?

3. How old were you when you were diagnosed with Autism?

4. How many children do you have?

5. What is the age of your child/children?

6. Are your child/children diagnosed with Autism?

7. Are you in a relationship with the mother of your children?

8. If you are not living with your child permanently, what is your current contact arrangements?

9. Are you currently in employment?

Appendix J **Debriefing form**

UNIVERSITY OF Southampton

The parenting experiences of autistic fathers: An Interpretative Phenomenological Analysis

Debriefing Statement (Version no 1, May 2022)

ERGO ID: 72753

The aim of this research was to explore the parenting experiences of fathers who have been diagnosed with Autism. Your data will help our understanding of how fathers diagnosed with Autism experience the highs and challenges of parenting, to identify whether additional provision and support strategies would be beneficial.

Once again, the results of this study will not include your name or any other identifying characteristics. The research did not use deception.

It is possible that discussing your parenting experiences alongside your diagnosis of Autism may have raised something that is upsetting for you. If this were the case, the researcher will have worked with you in the interview to determine what you require in the moment. If further support is required following the interview, I would like to signpost you to the following services that can offer further support:

- **Samaritans-** You can contact the Samaritans 24/7, 365 days a year via calling 116 123
(Calls are free)
- **SHOUT-** By texting the word 'SHOUT' to 85258 you will start a conversation with a trained Shout Volunteer, who will text you back and forth, sharing only what you feel comfortable with.
- **National Autistic Society-** Website http://www.autism.org.uk, offering help and support through advice and guidance, signposting and an online community.

You may have a copy of this summary if you wish. You can also request a summary of the findings once the report is completed if you would like.

If you have any further questions please contact me, Lucy Francis at l.francis@soton.ac.uk, Dr Melanie Hodgkinson at m.j.hodgkinson@soton.ac.uk or Dr Matt Symes at matt.symes@southernhealth.nhs.uk.

Thank you for your participation in this research.

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the University of Southampton Head of Research Integrity and Governance (023 8059 5058, rgoinfo@soton.ac.uk).

Appendix K Excerpt of IPA analysis

PROMPT: Difficult things about being a parent?	**Interviewer:** Oh, that's interesting. Yeah, that's a nice way of looking at it, definitely. And I guess, that was my next question actually, what is then maybe more difficult? So, the not so good things about being a parent that you have found?	
	Participant: Umm, it's difficult really. I mean, I think just generally … as in not autistic related, just overall?	
	Interviewer: Umm, I guess for you and your experience, what is the difficult things about being a parent? So, that could be related to autism, or it could just be a general role of being a parent.	
Acknowledgement that participant wouldn't use word 'difficult' Constant responsibility- pressure for father? Father's role to keep children safe/nurture children/provide advice. Important to not shape children into himself- sense of promoting them to follow their own interests. Sensory difficulties related to Autism diagnosis. Difficulty of noise sensitivities- sound of babies crying. 'Staggeringly difficult'- emphasises the severity of the impact this difficulty this had on him. Importance of having structured family routine. Structure been in place since children were very young. Repetition of 'very', emphasising the significance.	**Participant:** I mean again, I wouldn't necessarily say it was difficult per se. I mean, I would just, again if I was having a discussion with somebody who is a more recent parent, I suppose again this maybe a way of looking at it, in terms of, difficult isn't necessarily the right word, but just realising, being aware, being conscious of it is a 24/7 thing kind of forever and ever. You know, again it is not back to those phases and so on, so you know always, within reason always being there, always being there to offer advice, look after them. You know, your job if you like is to keep them safe and nurture them, give them opportunities. But don't encourage them into things they don't necessarily …, don't make them mini versions of you, I suppose. There are very specific things I think which I now look back on now understanding my autism and my sensitisations, that I know I found very difficult, like sound particularly. So, there were times when they were younger, you know babies, you know from when they were born probably for the first 18 months where the crying particularly I found staggeringly difficult. You know, unbelievably difficult. And I know you are meant to because that is the whole point of a baby crying, is to you know get attention and then to do what you need to do, but you know because of my own autistic traits there are certain things I find very challenging. So sound when they were younger was absolutely one of them. Then I suppose the other thing is, it is a weird one because obviously I am who I am if you like. Our family life is very, very structured, very structured. You know, my life is very structured in how I work and everything that I do, so our family, you know we have always had a set routine where you know we know what we do, bedtime routines, television routines, eating routines. There is variability within that, but there's things that we have done with the kids when they were one, two, three years old where we	Father's responsibility to keep children safe and nurture them. Importance of promoting individuality in children. Difficulty of noise sensitivities in child's early years. Helpfulness of having a structured family routine.

Family considered father’s needs and kept to structured routine. Children like the structure and routine. ‘Probably because of me’- sense of ownership in terms of family adaptation. Difficulty when routine is disrupted. Family have adapted to let father know if changes to routine. Helpful that son is diagnosed with Autism too- improved understanding of his own diagnosis/his son’s. Importance of supportive family unit.	would have family television from 6:00pm until 6:30pm for instance. It might have been Teletubbies back in the day or whatever. We still do that now, even though now it is Game of Thrones, you know or whatever is coming out. And it has shifted to a bit later and so on, but we still have that kind of family stuff. So we are, probably because of me, but I think it works and I think children actually quite like structure and routine. So, to some extent I am very, very structured, so therefore what I find challenging is if there are things that disrupt that structure. That can make it more challenging for me. But the reality is that my kids are older, we have all evolved together, as in we all know that, so you know if things are going to change they, and my wife is the same, they will give me the heads up. You know, they will make sure that, “Oh, just to let you know we are not doing this tomorrow night. We are going to do this instead”. You know, so you know perspective or otherwise, just from a general long-term partnership with my wife and ultimately with my kids being 17 and 19, there is the evolution of it. You know, you all get used to each other’s quirks and differences, whether that is autism or otherwise I suppose, and then you know we support each other in that respect. It probably also helps that my son being diagnosed when he was 11, the preceding two years to his diagnosis were very challenging, and yet now we kind of know, we now realise that some of the challenges I may have had with him and vice versa probably was because of our autism, and was causing that kind of challenge which we now look back on and go, “Oh yeah (laughing), it makes so much more sense”. So, I am rambling a bit now, so I am prone to ramble, so please bring me back on track (laughing).	Difficulty of unexpected disruption to routine. Importance of immediate family support and cohesion. Diagnosis allows for greater understanding around own difficulties. Child being diagnosed with Autism allows for greater understanding towards own Autism diagnosis.
	Interviewer: No, it’s really interesting, and also some of the stuff you said links into the further questions, so it is really interesting.	
	Participant: Okay, yeah it would make sense, yeah.	
PROMPT: How has parenting difficulties developed across the different ages of childhood?	**Interviewer:** I guess one thing I was just thinking from what you said, you said obviously it evolves over time, so I am wondering has parenting been different levels of difficult at different ages, do you think? Has there been a particular age you found more difficult?	
Hardest difficulty was the sensory experiences around sound.	**Participant:** Yeah, I mean I think no doubt about it the hardest time from a sensory perspective particularly sound, so for me my heightened awareness is sound by a million miles, and then smell to some extent. I mean, I am quite tactile as well, but sound for me is a real big problem umm in terms of, you know in terms of things that can cause me real problems. So yeah, sound when	

Smell sensory difficulties to 'some extent'. Sound sensory difficulties were hardest when children were in younger years. 'Breaking point'- emphasises the severity of impact. Sense that ps has used coping strategies to manage difficulties. 'Emergency earplugs'- emphasises sense of impact the difficulties had. Adult-like communication to children Absence of child-like talk when communicating with children in younger years. Sense that ps used a similar approach to parenting communication across different development stages? Transactional communication with children in younger years. 'More transactional than maybe a typical parent'- sense that the ps acknowledges difference associated with diagnosis. 'People may have looked at me'- sense of feeling potentially judged for difference?	they were younger, absolutely, and almost to the breaking point. Now I would put strategies in place, even then before I knew I was autistic, like putting earplugs in. You know, simple stuff but it was like, "My God, what a difference that makes". So, there were coping mechanisms for me to some extent once I realised how difficult I found it when they were crying. Even if it was in the car, I would have you know literally my emergency earplugs if I am driving the car, "Right, let's put those in. Ah, that's better, right I can now deal with it," sort of thing. So, you find sort of coping strategies really. And I suppose the other thing for me, which people may find, not unusual I suppose, I don't treat babies or children like children. I don't treat them like adults either, but even with younger children, I still talk to them quite normally, quite adult-like. Like, I won't use big language if you like, and words that they are clearly not going to be able to understand. But I have never spoken to my kids or to babies like babies. I mean when they are babies, they are like you know, that sort of stuff, do you know what I mean? But as soon as they are you know probably three upwards, I just never did that. So, again that made it easier in terms of transition, so people may have just thought, people may have looked at me and just thought I treat my kids like they were too grown up, even though that isn't the case. We let them grow up naturally and normally if you like, in terms of what they did in activities and so on, but the way that I would communicate with them would have seemed quite transactional possibly, you know for others. It was quite frequent, I would have lots of conversations about lots of different things, but yeah probably people might see it as more transactional than maybe a typical parent, possibly.	Earplugs were essential in managing noise sensitivities. Absence of infant-like communication, instead used transactional communication with children in their early years.

Appendix L Example of Personal Experiential Theme (PET) table

Theme	Sub-theme	Experiential statements
Coping strategies		1. Helpful to adapt children’s social events to cope with own difficulties 2. Importance of having activity lists to cope with difficulties in creativity 3. Avoidance of children’s social events to cope 4. Routine and planning essential in parenting 5. Important to have structure and routine 6. Importance of continuing to have time to engage in interests 7. Helpful to have structure and routine when organising activities for children 8. Helpful to have supportive wife in managing difficulties 9. Supportive collaboration between self and partner in parenting 10. Importance of having time to unwind following social situations
Impact of Autism diagnosis on parenting	**The influence of social difficulties**	1. Difficulties in understanding children’s social interaction 2. Difficulty with engaging with children in infant years as relationship feels less reciprocal 3. Tendency to take children’s behaviours to heart 4. Social difficulties impact ability to interact with other parents 5. Found parenting most difficult in child’s infant years due to difficulties in reasoning with them 6. Difficult to interact with child in non-verbal stage 7. Managing unpredictability is difficult 8. Difficulty managing situations where child is unsettled 9. Difficulties with spontaneous plans
	Sensory sensitivities	1. Sensory difficulties impact ability to interact with others at children’s social events 2. Sensory sensitivities make children’s social events difficult 3. Difficulties tolerating screaming noises in child’s younger years due to noise sensitivities 4. Sensitivities to light can be debilitating in public places 5. Managing unpredictability of parenting is difficult
Affect of diagnostic label	Managing external assumptions	1. No value in telling professionals involved in child’s care about diagnosis 2. Other’s views towards diagnosis would change their assumptions towards him

		3. Worry around other’s opinion towards autism diagnosis 4. Lack of understanding from others around diagnosis 5. Negative consequences for children in telling others about his own diagnosis
	Validation of difficulties	1. Diagnosis was helpful in validating and understanding difficulties 2. Important to have understanding around difficulties associated with diagnosis 3. Diagnosis has significant impact on parenting
Values as a father		1. Role as a father changes as child develops 2. Important to provide children with fun experiences 3. Role of the father to be supportive to children 4. Tolerating difficulties due to expected role as a father 5. Coping strategies for autism difficulties are not in line with the way he wants to parent 6. Difficult to know if he is a ‘good enough’ dad 7. Conflict between values as a father and what he can do given difficulties associated with autism 8. Highlight of fatherhood is seeing children happy 9. Positives of seeing children develop through milestones 10. Helpful to share interests with child

Appendix M Reflexive Log Entry

Date: 12th December 2022

Following completing another research interview today I have been reflecting upon the process so far. In particular, I felt grateful that I have been able to listen to autistic father's experiences, given that they have reported feeling unsupported and unheard by services. I noticed this evoked a sense of frustration in myself, whilst at the same time, I felt pleased I had chosen to research this area to help increase awareness around the needs of autistic fathers.

As I near the end of my data collection process I also found myself reflecting on the process of interviewing. I have found it a really enjoyable method of data collection, as I have enjoyed the flexibility that a semi-structured interview schedule allows. I felt this enabled me to really explore each participants' own individual experiences. Prior to the interview process I had made the assumption that my lack of personal experience in parenting may have hindered how I approached the interview process, given that I may not have as much awareness to the typical challenges non-autistic parents may face. However, I have noticed that whilst this could be the case, it allows me to approach the interviews from an unbiased perspective and consequently I have felt I have really allowed participants to hold the 'expert' role when describing their experiences.

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