Exploring the parenting experiences of autistic fathers

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June, 2021

Research submitted in partial fulfilment of the requirements for the degree of Doctor in Clinical Psychology (DClinPsy), Royal Holloway, University of London.

Acknowledgements

I would first like to express my gratitude to my supervisor, Dr Kate Theodore. Your guidance and feedback over the past two years has been invaluable. Not only that, but your kind, supportive, and flexible approach is exactly what I needed to help me to stay grounded throughout this process. Thank you.

I would also like to thank my field supervisor, Dr Elizabeth Kock, for helping me to come up with the idea for the project and for sharing your knowledge and time so freely.

Andy, thank you for sharing your expertise with me and helping me make the adjustments needed to the study.

Thank you to my family and friends, who have encouraged me along the way. This includes my wonderful cohort who have been a source of knowledge, support, and (much needed) humour throughout the last three years.

A special thanks to my parents who I am sure did not anticipate me moving back home in the middle of a global pandemic while finishing my thesis. You made the whole process a lot easier for me. I will always be grateful for your ongoing support, love, and patience.

Finally, thank you to the fathers that took part in my study. I feel privileged to have heard your stories and have learned something from each of you. I hope that the findings do your experiences justice.

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Lay Summary

Parenthood and autism

Becoming a parent and raising children is an integral part of many people's lives. Yet despite autism being a lifelong condition that affects around 1 in 100 people, there is little information about the experience of autistic parents. This project set out to explore their experience of parenting, with a specific focus on the experiences of autistic fathers.

Autism is a spectrum condition, meaning it affects people to varying degrees. Difficulties in social communication mean that autistic people can find it harder to interpret verbal and non-verbal communication and understand other people's feelings or intentions. Autistic people also tend to prefer predictability and routine. They may experience sensory sensitivities, such as being over or under-sensitive to sensations such as light, touch, or smell.

As autism is lifelong, it is important to understand how it may affect roles that people take in adulthood. It is possible that some of the difficulties associated with autism could make aspects of parenthood more challenging for autistic parents. However there has been very little research to date on autistic parents. This project aimed to improve our understanding of their experiences of parenting. The project was split into two parts; 1) a review of the research that had already been done in the area and 2) an in-depth study of nine autistic fathers' experiences of parenting.

1) A review of the research on autistic parents

To find out more about the experiences of autistic parents, we first completed a review of the research that had already been done in the area. To do this, we conducted a systematic search of the research literature up until August 2020 to identify research that explored the experiences of autistic parents, or parents with a high number of autistic traits. Ten studies were identified in total, with a total number of 1,288 participants (1,063 mothers, 225 fathers). The studies were carried out with parents mostly from Western countries, including the US, UK, Netherlands, and Australia. The studies varied in how they approached the topic. Some of the studies compared different aspects of parenting between autistic parents and non-autistic parents, whereas others gathered in-depth information about autistic parents' experiences without a comparison group. Half of the studies included only autistic mothers in their sample, three of these focusing on their experiences of pregnancy and childbirth.

The ability to draw firm conclusions from the review was limited by the small number of studies identified and the differences in methods used. However, there were several key findings from the review, including the following:

- Research so far has shown that autistic parents experience parenthood as rewarding and are extremely dedicated to their children.
- However, autistic parents may experience more challenges than non-autistic parents in some areas of parenting. These challenges included: balancing their need for time alone with their children's need for interaction; increased difficulties with sensory sensitivities due to aspects of the parenting role; and difficulty coping with the multi-tasking elements of parenthood.
- The findings also highlighted the stigma and discrimination autistic mothers experienced when receiving support from services. They felt that others made

presumptions around their parenting ability, which reduced their desire to seek support around parenting.

- Possible gender differences were noted in two studies. Autistic fathers reported feeling less confident in their parenting abilities and reported higher levels of stress compared to autistic mothers and non-autistic parents.

2) Study of autistic fathers

The review clearly showed that autistic fathers are underrepresented in the research to date. The few studies that included fathers highlighted potential differences in the experiences of autistic mothers and fathers. We therefore felt it was important to find out more about fathers' experiences.

To do this, we recruited nine autistic fathers from NHS adult autism services and social groups run by the National Autistic Society (NAS). We interviewed these fathers individually over video call, which involved speaking in-depth about their experiences of parenting and their relationships with their children. Once we had interviewed all the fathers, we transcribed the recordings of the interviews and analysed the data using a qualitative methodology called Interpretative Phenomenological Analysis. This involved looking for connections and patterns across the fathers' accounts of parenting, as well as paying attention to individual experiences.

The main findings from the study included:

- The fathers highly valued their role as a parent. Most found parenthood to be a rewarding experience which gave them a sense of purpose.

- Autism appeared to make some aspects of parenting more challenging for the fathers due to clashes between their own sensory needs and their children's needs. This was particularly the case for fathers of younger children who experienced their children's liveliness and need for interaction overwhelming at times.
- Receiving a diagnosis of autism was helpful in enhancing understanding for the fathers, especially around some of the challenges they experienced when parenting. The diagnosis also helped their partners or co-parents to understand them better and could bring about positive changes in the family.
- The fathers' partners had a significant impact on their experience of parenting. This could impact how close fathers felt to their children.
- The fathers whose children also had autism felt that the shared diagnosis meant they could relate to and understand their children's behaviour.
- Peer support from other autistic parents was perceived as valuable. It helped fathers to feel less alone with their experiences and provided a platform for sharing coping strategies.

Conclusion

Overall, this project provides important insight into the experiences of autistic parents. Although the second part of the project was small-scale, it sheds light on the experiences of autistic fathers which had been notably absent in the research prior to the current study. The findings highlight challenges that autistic parents may face, such as balancing their own sensory needs with their children's needs, as well as the satisfaction and purpose they can get from parenthood.

The findings have implications for services and professionals working with autistic parents. These recommendations for services and professionals include:

- Earlier recognition of autism in parents; this is important as it may help to aid understanding across the family and improve their parenting experience.
- Services should provide opportunities for parents to have peer support.
- Services could improve the accessibility of their care for autistic parents and include fathers more in parenting interventions.
- Professionals should consider the impact of stigma on autistic parents and their desire to seek help for parenting.

The findings from this research will be shared with services who work with autistic parents. They will also be shared on several online platforms with the aim to reach autistic parents or autistic adults who are hoping to become parents.

Chapter 1 - Parenthood and autism: a mixed methods systematic review of the literature on the parenting experiences of autistic parents

Abstract

As awareness and understanding of Autistic Spectrum Disorder (ASD) has risen, more attention has been paid to how ASD can affect the varying roles that adults take. Yet there is little awareness of how autistic people experience parenthood. This paper describes a mixed methods systematic review which aimed to identify and synthesise studies exploring the experiences of autistic parents. A systematic search of the literature was performed up to August 2020 using PubMed, PsycINFO and Web of Science. Ten studies met inclusion criteria for the review, with a total of 1,288 participants across the studies (1,063 mothers, 225 fathers). Five of the studies used quantitative designs comparing different aspects of parenting between autistic parents and non-autistic parents. The other five studies used qualitative designs, with three of these studies focusing on the experiences of autistic mothers in the perinatal period. Most of the studies were deemed moderate quality and none of the studies were considered high quality. Thematic synthesis was used to synthesise the data from the qualitative studies, and the quantitative studies were synthesised narratively. The findings indicated that autistic parents may experience more challenges in parenting, such as managing their sensory needs while parenting and coping with multi-tasking elements of the parental role. Experience of stigma and discrimination was a common experience across the autistic mothers' accounts, including when accessing health and social care services. Potential gender differences between the experiences of autistic mothers and autistic fathers were noted in two of the studies. The conclusions that can be drawn from the review are limited due to the small number of studies identified and the heterogeneity between the methodologies employed in the studies. The practical implications of the findings are discussed, as well as considerations for future research.

Terminology

Throughout this paper ‘autistic’ will be used instead of ‘person with autism’. This is because autistic individuals have expressed a preference for identity-first language rather than person-first language (Bottema-Beutel, Kapp, Lester, Sasson, & Hand, 2020; Kenny et al., 2016).

Introduction

Autistic Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder characterised by difficulties with social communication and interaction, and restrictive and repetitive interests or patterns of behaviour (American Psychiatric Association, 2013, APA). ASD is diagnosed more often in men and the prevalence of autism is currently estimated at around 1% of the population (Brugha et al., 2011). Common features associated with autism include difficulties in interpreting verbal and non-verbal communication and recognising or understanding others' emotions and intentions. Autistic people often show a preference for predictability and routine and may have atypical sensory experiences (Vannucchi et al., 2014). While autistic individuals must share some characteristics to meet criteria for diagnosis, the degree of ASD traits and associated difficulties varies greatly between those on the autistic spectrum.

Considering ASD is a lifelong condition, it is important to consider how ASD may impact on the varying roles that adults take. The literature on the lives of autistic adults and their experiences of employment, relationships, and social settings is growing (Bury, Flower, Zulla, Nicholas, & Hedley, 2020; Dewinter, De Graaf, & Begeer, 2017; Strunz et al., 2017). However, the research is very limited regarding parental roles and there are no current estimates on the number of autistic adults who are parents (Pohl, Crockford, Blakemore, Allison, & Baron-Cohen, 2020). Despite a lack of information about their experiences of parenthood, the National Institute for Health and Care Excellence (NICE) guidelines highlight the importance of services providing accessible support for autistic adults who are parents (NICE, 2012).

People on the autistic spectrum struggle to identify and understand other people's mental states and emotions (Rajendran & Mitchell, 2007), which is understood in the ASD literature as a deficit or delay in theory of mind (Baron-Cohen, Leslie, & Frith, 1985). It is possible that difficulties with theory of mind could impact on a parent's ability to understand and respond to their child’s needs and communication. In addition, the impairments in executive functioning associated with ASD can make tasks involving organising, planning, and flexibility more difficult for autistic individuals (Hill, 2004; Wallace et al., 2016). Parenthood often involves competing demands, and it is possible that the multi-tasking elements and changing routines may pose additional challenges for autistic parents (Pohl et al. 2020).

Until recently, the literature has focused on the experiences and perspectives of parents who are raising autistic children as opposed to exploring the influence of parental ASD diagnosis. Given the heritable nature of autism, it is likely that some of these parents would meet criteria for ASD themselves or have a high number of autistic traits (Rubenstein & Chawla, 2018; Tick, Bolton, Happé, Rutter, & Rijsdijk, 2016). Research into parenting a child with autism has often focused on the difficulties that these parents experience, including increased parental stress (Hayes & Watson, 2013), lower confidence in their parenting abilities (Smart, 2017), and a greater number of depressive symptoms (Singer, 2006), compared to parents of neurotypical children. There is also evidence of alternative narratives around what it is like to be a parent of an autistic child, which include qualitative accounts of acceptance, fulfilment, and family connectedness (Bayat, 2007; Potter, 2016). For autistic parents, there may be advantages from having a shared diagnosis. Marriot (2018) proposes a ‘similarity-fit’ in which the autistic parent may relate to and have a better understanding of their child’s needs and behaviours associated with ASD.

With a lack of information regarding the experiences of autistic parents, research into parents with intellectual disabilities may provide a useful comparison. While it is estimated that more than half of individuals on the autistic spectrum do not meet criteria for an intellectual disability (Centers for Disease Control and Prevention, 2014), both conditions are developmental by nature and affect social communication and executive functioning. In addition, the stigma associated with these conditions may affect a person’s experience of parenthood. Studies exploring the lived experiences of parents with intellectual disabilities have provided insight into the challenges that these individuals face. Parents with intellectual disabilities have considerably less social support available to them (Llewellyn & McConnell, 2002), which has been linked to reduced confidence in their parenting abilities and poorer psychological wellbeing (Stenfert Kroese, Hussein, Clifford, & Ahmed, 2002). Other common themes identified in the literature include parents' perceptions of negative attitudes and discrimination from others, including presumptions of parenting incompetence from health and social care professionals (Symonds, Abbott, & Dugdale, 2021; Theodore et al., 2018). These concerns are rooted in reality; parents with intellectual disabilities are at a disproportionate risk of having their children removed from their care (Booth, Booth, & McConnell, 2005). Yet studies evaluating parenting interventions have demonstrated that parents with intellectual disabilities can develop skills and confidence in their parenting ability, when given appropriate support tailored to their needs (Coren, Ramsbotham, & Gschwandtner, 2018).

The negative impact of stigma on the experiences of parents with mental illness has also been documented, posing a barrier for parents when seeking informal and professional support around parenting (Dolman, Jones, & Howard, 2013; Oyserman, Mowbray, Meares, & Firminger, 2000). Individuals on the autistic spectrum experience significantly higher rates of mental health difficulties than the general population (Lai et al., 2019) and already face significant barriers to accessing healthcare services (Walsh, Lydon, O'Dowd, & O'Connor, 2020). While it is not known how comorbid mental health difficulties may impact on autistic parents' experience of parenthood, poorer psychological wellbeing has been linked to other adverse experiences for parents. These include higher levels of parenting stress, a reduced belief in one's ability to be a competent parent, and increased likelihood of finding parenthood an isolating experience (Oyserman et al., 2000). Despite these challenges, qualitative accounts from mothers with serious mental illness show how highly they value their role as a mother, which creates a sense of purpose and meaning in their lives (Diaz-Caneja & Johnson, 2004; Dolman et al., 2013).

While it is possible that autistic parents may share some of the experiences outlined above, there are also likely to be experiences that are more unique to autistic parents. For example, studies exploring the experiences of autistic mothers in the perinatal period have highlighted the impact of sensory differences on specific parenting activities, such as breastfeeding (Gardner, Suplee, Block, & Lecks, 2016; Pohl et al., 2020). For services and professionals to better understand how to tailor their support to parents on the autistic spectrum, there is a need to develop our understanding of their subjective experiences of parenthood. It is also important to consider parents' experiences as they are likely to have a direct impact on the behavioural and mental health outcomes of their children. It was therefore believed to be important to synthesise the literature to date that has explored the experiences and perspectives of autistic parents. As a novel area of research, it was understood that there were no published systematic reviews on this topic at the time of this review.

Aims of the review

The current review aimed to synthesise the literature on the self-reported experiences of autistic parents, including autistic mothers' perinatal experiences. The review also aimed to explore how experiences of parenting compared between parents with and without a diagnosis of ASD/with fewer and greater number of ASD traits. The findings from this review could have implications for services, providing information for health and social care professionals working with autistic parents.

Method

Search strategy

To identify relevant studies, a comprehensive search of the literature was undertaken to the end of August 2020 in the following electronic databases: PubMed, PsycINFO and Web of Science. No publication date restrictions were set and only studies in the English language were included. The search terms consisted of two main categories, one to describe parenting and the other to describe ASD. These categories were combined using the Boolean operator 'AND'. Search terms within the categories were combined with Boolean operator 'OR' (see Appendix A for specific search terms).

Due to the anticipated small number of studies available in the area, grey literature was also searched. This included searching EThOS for unpublished theses and the conference proceedings from the last five years from International Society for Autism Research (INSAR). To complete the search, the reference lists from any of the included articles were hand-searched to identify further relevant studies.

Inclusion and exclusion criteria

Studies were identified as being suitable for the review if they met the follow criteria:

- Studies using quantitative, qualitative, and mixed methods designs. Given the anticipated limited research in this area to date, the inclusion criteria for the study designs included in the review was kept as broad as possible to maximise data that could be included.
- Studies whose participants had a clinical or self-reported diagnosis of ASD or a high number of ASD traits measured on a validated ASD screening tool.

- Studies whose participants were parents or primary caregivers to children of any age, including pre-birth i.e. expectant parents.

The criteria for being excluded from the review included:

- Studies where the full text was not available in English.
- Studies whose participants also had intellectual disabilities.
- Studies only reporting the experiences of professionals, without reporting the experiences of the parents themselves.
- Studies which did not focus specifically on parenting experiences.
- Book chapters, book reviews, opinion pieces, conference presentations and abstracts which did not report an empirical research study.

Data management

Citations retrieved from searching the three databases were exported into Mendeley Reference Management Software. Any duplicates were removed at this stage. The main reviewer screened the title and abstract of each article to assess whether they met the inclusion criteria for the review. For those that initially appeared to meet the criteria, the full text articles were obtained and reviewed. When the reviewer was unsure whether the study met criteria after reading the full text, this was discussed with the internal supervisor until a decision was made as to whether the study should be included or not.

Data extraction

For quantitative studies, all data relevant to self-reported parenting experiences were extracted into a Microsoft Excel document. For qualitative studies, all relevant data from the results or findings section of the articles were transferred to NVivo qualitative data analysis software.

The following details were extracted from the articles and summarised in a table: authors, date of publication, location of study, nature of sample, study design, measurement of ASD, measurement of parenting experience, and any findings relevant to self-reported parenting experiences.

Assessment of methodological quality

The methodological quality of the quantitative studies was assessed using Joanna Brigg's Institute (JBI) Critical Appraisal Checklist for Analytic Cross-Sectional Studies (Appendix B). The quality of the qualitative studies was assessed using the Critical Appraisal Skills Programme checklist (Appendix C). Both checklists consist of several items which focus on different methodological aspects of a study. Reviewers rated each item as yes, no or can't tell/unclear, with regards to whether the study met criteria for the item. To help check credibility of the quality assessment, 50% of the studies were independently assessed by a second reviewer. Any disagreements were resolved in discussion. Overall scores for the quality of each study are not provided as neither the JBI checklist nor the CASP checklist recommend doing so. All studies were included in the synthesis regardless of the results of the quality assessments. However, the findings from the quality assessments are reported and were considered where any conclusions are drawn.

Strategy for data synthesis

A convergent-segregated approach was used to synthesise the data. This is a methodological approach for mixed methods systematic reviews where the quantitative and qualitative data are synthesised independently and then integrated together in a narrative summary (Joanna Briggs Institute, 2020). The quantitative data was synthesised narratively due to the limited data available and the variety in measures used. When the data was continuous (e.g. scores on a questionnaire) the means and standard deviations were described, if available. For categorical data the percentages were reported. Where studies researched similar areas of parenting experience, the findings are reported together.

For qualitative studies, thematic synthesis was used. This is a three-step process used to synthesise qualitative data which is outlined by Thomas and Harden (2008). First the text from the result/findings section of each study were coded line-by-line, then descriptive themes were developed, followed by the generation of analytical themes (Thomas & Harden, 2008). Given the nature of the studies that were identified, the thematic synthesis was split into two sections: experiences of mothers with autism in the perinatal period, and the parenting experiences (post-birth) of mothers and fathers with autism.

Findings

Search results

The initial database search produced a total of 10,087 articles. These were exported into Mendeley and 4,549 duplicates were removed, taking the number of articles to be screened down to 5,538. An additional two articles were found when searching EThOS. The titles and abstracts of these articles were screened against the inclusion/exclusion criteria, which led to 5,527 of the articles being excluded at this stage. Most of the studies were excluded at this stage because their sample consisted of parents who had a child with ASD, rather than a diagnosis themselves. The remaining thirteen articles were then read in full, eight of which met the inclusion criteria. Information on why some articles were excluded when the full text was accessed is included in Figure 1. An additional two studies were identified from hand-searching the reference lists of the included studies. This meant that ten studies were included in the review in total.

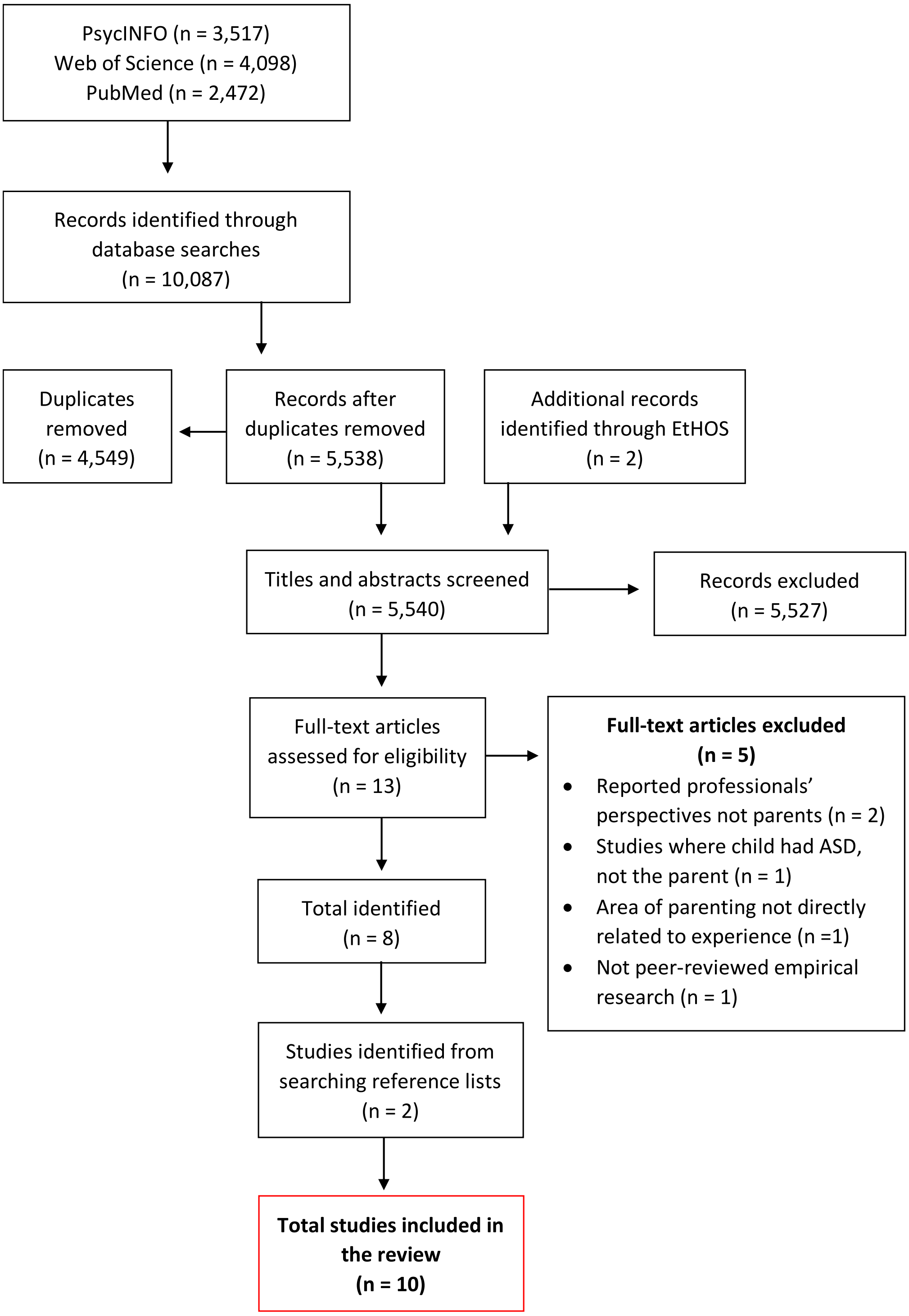

Figure 1: PRISMA flow diagram of the search process

Table 1: Quality assessment of quantitative studies using JBI Critical Appraisal Checklist for Analytic Cross-Sectional Studies

<u>Reference</u>	**1. Were the criteria for inclusion in the sample clearly defined?**	**2. Were the study subjects and the setting described in detail?**	**3. Was the exposure measured in a valid and reliable way?**	**4. Were objective, standard criteria used for measurement of the condition?**	**5. Were confounding factors identified?**	**6. Were strategies to deal with confounding factors stated?**	**7. Were the outcomes measured in a valid and reliable way?**	**8. Was appropriate statistical analysis used?**
Dissanayake, Richdale, Kolivas & Pamment (2020)	Yes	No	Yes	No	Yes	Yes	No	Yes
Pohl et al. (2020)	Yes	Yes	Yes	No	Yes	No	No	Yes
Lau, Peterson, Attwood, Garnett & Kelly (2016)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
Van Steijn et al. (2014)	Yes	Yes	Yes	No	No	No	Yes	Yes
Lau & Peterson (2011)	Yes	Yes	Yes	Yes	No	No	Yes	Yes

Table 2: Quality assessment of qualitative studies using CASP (2018) checklist

Reference	**1. Was there a clear statement of the aims of the research?**	**2. Is a qualitative methodology appropriate?**	**3. Was the research design appropriate to address the aims of the research?**	**4. Was the recruitment strategy appropriate to the aims of the research?**	**5. Was the data collected in a way that addressed the research issue?**	**6. Has the relationship between research and participants been adequately considered?**	**7. Have ethical issues been taken into consideration?**	**8. Was the data analysis sufficiently rigorous?**	**9. Is there a clear statement of findings?**
Burton (2016)	Yes	Yes	Yes	No	Yes	No	Yes	Can’t tell	Yes
Gardner, Suplee, Block & Lecks (2016)	Yes	Yes	Can’t tell	Can’t tell	Can’t tell	Can’t tell	Can’t tell	Yes	Yes
Rogers, Lepherd, Ganguly, Jacob-Rogers (2017)	Yes	Yes	Yes	No	Can’t tell	No	Can’t tell	No	Yes
Marriott (2018)	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes

Donovan (2020)	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes

Quality assessment

The quality assessment for each study is presented in Table 1 and 2.

The methodological quality of the studies varied. None of the included studies could be considered high quality. The most common issue in the quantitative studies included the measurement tools used; most of the studies used questionnaires or outcome measures that had not been validated in the autistic population. Additionally, confounding factors that could have impacted on parenting experience were rarely identified or controlled for. The most common issue regarding the quality of the qualitative studies was the recruitment strategies, which allowed for parents who self-reported as having ASD to take part which could have affected the validity of the findings. In addition, only one study adequately considered the relationship between the researcher and the participants. A strength of the qualitative studies was the way in which the findings were reported; four out of five of the studies presented the findings in a coherent way and included specific examples from the data to evidence their findings.

Characteristics of included studies

Methodology and design

Across the ten studies identified for the review, five used a qualitative design, four used a quantitative design and one was mixed methods. The mixed method study only reported the findings from the quantitative data. The reviewer contacted the authors of the paper to request the qualitative findings from the study, however received no response. The four quantitative studies and the mixed method study used a cross-sectional design comparing different aspects of parenthood between parents with a diagnosis of ASD/a high number of ASD traits to those without ASD/with a lower number of ASD traits. The qualitative studies focused solely on the experiences of autistic parents. Three of the qualitative studies used thematic analysis and the other two used interpretative phenomenological analysis (IPA, Smith, Flowers & Larkin, 2009). One of the qualitative studies was a case study.

Location and sample

Five studies were conducted in Australia (Dissanayake, Richdale, Kolivas, & Pamment, 2020; Donovan, 2020; Lau & Peterson, 2011; Lau, Peterson, Attwood, Garnett, & Kelly, 2016; Rogers, Lepherd, Ganguly, & Jacob-Rogers, 2017), two studies were unpublished theses completed as part of a Clinical Psychology Doctorate in the UK (Burton, 2016; Marriott, 2018), one study was conducted in the Netherlands (van Steijn, Oerlemans, van Aken, Buitelaar, & Rommelse, 2014), and one study in the US (Gardner et al., 2016). The remaining study was UK based but collected data worldwide from participants from mostly Western countries (Pohl et al., 2020). Sample size ranged from 58 to 487 in the quantitative/mixed method studies, with a total of 1,240 participants (1,016 mothers, 224 fathers). Sample size ranged from 1 to 24 in the qualitative studies, with a total of 48 participants (47 mothers, 1 father). There were differences in the inclusion criteria regarding gender across the studies. The four quantitative studies included both mothers and fathers in their sample whereas the mixed method study only surveyed mothers' experiences. Four out of the five qualitative studies only included mothers in their research. The remaining study included one father out of a total of eight participants (Marriott, 2018).

ASD inclusion criteria

The studies also differed in whether they required participants to have a clinically confirmed diagnosis of ASD. Six studies included parents with self-report or clinically confirmed ASD diagnoses, whereas four studies specified that participants had to have a clinical diagnosis of ASD i.e. had been assessed and diagnosed with ASD by a qualified professional. Seven studies used a version of the Autism Quotient (AQ), a self-report questionnaire, to measure the degree of ASD traits in participants (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001). Two studies explored the association between the degree of ASD traits and scores on the parenting questionnaires, and therefore did not require participants to have a diagnosis of ASD. However, both these studies specified that participants had to have a child with an ASD diagnosis, which meant the samples included a significant number of participants who scored above clinical threshold in the number of ASD traits on the screening tool.

Measurement of parenting experiences

The four quantitative studies used existing standardised questionnaires to measure different areas of parenting, such as self-reported parenting competency, stress, and satisfaction. These questionnaires consisted of a range of items in which participants rated their agreement with each item on a Likert scale. The mixed method study used a survey comprising of a range of questions about the experience of motherhood. The quantitative data was gathered from forced-choice items which required a binary agree/disagree or yes/no answer (Pohl et al., 2020).

The qualitative studies all used semi-structured interviews as their main method of data collection. These included open-ended questions asking participants about their experience of parenthood. Three out of the five qualitative studies focused primarily on the experiences of women in the perinatal period (Donovan, 2020; Gardner et al., 2016; Rogers et al., 2017).

Table 3: Summary of quantitative studies

Author, year, location	**Sample**	**Design & Analysis**	**Measures**	**Main Findings**
Dissanayake, Richdale, Kolivas & Pamment (2020), Australia	58 parents with a diagnosis of ASD or blood relative with clinical diagnosis of ASD (9 fathers, 49 mothers)	Cross-sectional design. Used regression analyses to explore association between degree of autism traits and scores on questionnaires measuring different domains of parenting.	The Autism Spectrum Quotient (AQ-50), Parenting Sense of Competence Scale (PSOC), Parenting Needs Questionnaire (PNQ).	• Degree of autism traits in parents was not found to significantly correlate with scores of parenting self-esteem. • Hierarchal regression showed that the degree of autism traits did not make a unique contribution to parenting satisfaction, after controlling for psychological wellbeing. • Regression analyses indicated that higher autism traits were associated with greater parenting difficulties (r= .48, p=0.001). Hierarchal regression showed that ASD traits explained a further 10% of the variance in the overall parenting difficulties, after psychological wellbeing.

				- To examine the association between parenting difficulties and autism traits further, two subgroups were created: the High AQ group and the Low AQ group. Parents in the HAQ group reported more parenting difficulties across the subscales, with MANOVA showing a significant multivariate group effect, F (9,43) = 2.69, p > .02, n2 =0.39. The univariate analyses showed that only two of the subscales did not have a significant difference, with similar ratings found on the Affection and Danger Awareness subscales.
Pohl, Crockford, Blakemore, Allison & Baron-Cohen	355 mothers with self-reported ASD and 132 mothers without ASD	Mixed methods survey – qualitative data not included in analysis. Chi-square used to compare answers	The Autism Spectrum Quotient, brief version (AQ-10). Parenting	- Autistic mothers were more likely to have experienced pre-natal (autistic mothers: 40%, control: 25%) and post-natal depression (autistic mothers: 60%, control: 45%). - Autistic mothers reported greater difficulties in areas such as multi-tasking (autistic mothers: 51%, control: 94%),

(2020), Global survey		between autistic mothers and non-autistic mothers.	experiences were measured using a survey comprising of forced-choice questions requiring an agree/disagree or yes/no answer.	coping with domestic responsibilities (autistic mothers: 47%, control: 85%) and creating social opportunities for their child (autistic mothers: 71%, control: 92%). • Autistic mothers were less likely to report that they communicate well with professionals about their child (autistic mothers: 70%, control: 95%) and reported greater anxiety when interacting with professionals (autistic mothers: 60%, control: 25%). • Autistic mothers were less likely to report feeling able to ask for support when they needed it (autistic mothers: 41%, control: 68%).
Lau, Peterson, Attwood, Garnett &	346 parents (82 fathers, 264	Cross-sectional design. Compared scores from the three groups on a	The Autism Spectrum Quotient (AQ-50), Parenting	• Initial analyses suggested that ASD diagnosis in the child contributed to lower scores of parenting efficacy, however parental ASD diagnosis did not.

Kelly (2016), Australia	mothers) split into three groups: 1) Parents and child with ASD clinically diagnosed (n=109) 2) ASD in the child only (n=128) 3) No ASD evident in parent or child (n=109)	measure of parenting efficacy using ANOVA.	Sense of Efficacy (PSOE) subscale from Parenting Sense of Competency (PSOC) questionnaire	• Further analyses by gender showed that males in Group 1 (M = 24.45) had significantly lower scores on the parenting efficacy subscale than males in Group 2 (M = 31.40) and Group 3 (M = 33.25). • There were no differences across the three groups for female parents.
Van Steijn et al. (2014), Netherlands	96 pairs of parents (96 mothers, 96 fathers) with a	Cross-sectional design. Used structural equation modelling to	The Autism Spectrum Quotient (AQ-50), Parental	• Higher scores on the AQ were associated with parenting stress in fathers (r= .23), indicating that the greater degree of ASD traits, the higher the levels of stress experienced.

	child with clinically diagnosed ASD and a sibling with no ASD evident	estimate the best fitting model linking parental ASD symptoms and depressive symptoms, with self-reported parenting stress	Stress Index (PSI), The General Health Questionnaire (GHQ-28)	This finding did not appear to be mediated by depressive symptoms. • No relationship was found between maternal ASD symptoms and parenting stress.
Lau & Peterson (2011), Australia	157 parents (37 fathers, 120 mothers) split into four groups: 1) Parents and child with ASD	Cross-sectional design. Compared scores from the four groups on measure of parenting satisfaction using ANOVA	The Autism Spectrum Quotient (AQ-50), Subscale of Parenting Sense of Competency (PSOC)	• Scores of parenting satisfaction were higher in Group 4 (M= 40.87), compared to Group 1 (M= 34.29), Group 2 (M= 38.90), and Group 3 (M= 35.59). • No significant differences were found in parenting satisfaction between groups 1, 2 & 3.

	clinically diagnosed (n=22) 2) Parents whose spouse and child clinically diagnosed (n=11) 3) Parents whose child had ASD (n=49) 4) Parents with no ASD in family (n=75)			• These findings suggest that having a child with ASD reduced parenting satisfaction, whereas ASD diagnosis in the parent or spouse did not affect parenting satisfaction.

Table 4: Summary of qualitative studies

Author, year, location	**Sample**	**Design & Analysis**	**Main Findings**
Burton (2016), UK	7 mothers with a diagnosis of ASD	Interpretative phenomenological analysis (IPA) used to analyse semi-structured interviews exploring the mothers' experiences of pregnancy, birth, and parenting.	Four main themes identified: 1) We are different, 2) Negotiating difference, 3) The role of the mother-child relationship and 4) Navigating the parenting journey. The findings highlighted the connection the mothers experienced with their children, as well as the difficulties of coping with their own sensory processing needs within the parenting context.
Gardner, Suplee, Block & Lecks (2016), US	8 mothers, 6 with a formal diagnosis of Asperger's syndrome and 2 self-diagnosed	Thematic analysis used to analyse responses to questionnaire exploring experiences during	Four major themes emerged: 1) Processing sensations, 2) Needing to have control, 3) Walking in the dark, and 4) Motherhood on my own terms. The findings highlighted how pregnancy, childbirth and early parenting interacted with the mothers' sensory needs. They also showed how professionals' communication and interaction with the

		pregnancy, birth, and early motherhood.	mothers impacted on their experience, both positively and negatively.
Rogers, Lepherd, Ganguly, Jacob-Rogers (2017), Australia	1 mother with a diagnosis of Asperger's Syndrome	Case study design. Thematic analysis used to analyse semi-structured interview and email correspondence exploring issues during pregnancy, birth, and early motherhood.	Three main themes identified: 1) Communication and service difficulties, 2) Sensory stress, and 3) Parenting challenges. The findings highlighted how pregnancy and childbirth interacted with the mother's sensory needs, as well as the negative impact of others' perceptions on her experience of early motherhood.
Marriot (2018), UK	8 parents (1 father, 7 mothers) with an ASD diagnosis or a high number of ASD traits measured on the Autism Quotient (AQ). The	IPA used to analyse semi-structured interviews which explored experiences of family life, parenting their child with ASD, and support they had received.	Four main themes identified: 1) Parent-child relationship, 2) Positive and negative personal impact of being a parent, 3) Finding their home both accepting and challenging place to live and 4) Experiences of professional services and lack of support. The findings showed how the parents' own ASD traits could be a strength and a difficulty when parenting their child with ASD. They

	parents all had a child with a diagnosis of ASD.		also highlighted a lack of support experienced by parents and the impact of judgements from others outside the family.
Donovan (2020), US, UK & Australia	24 mothers with self-reported diagnosis of ASD.	Interpretive descriptive design. Semi-structured interviews exploring experiences of pregnancy and childbirth, with specific focus on experiences in hospital setting.	Three main themes identified: 1) Having difficulty communicating, 2) Feeling stressed in an uncertain environment, and 3) Being an autistic mother. The findings highlighted the challenges the mothers experienced in conveying their needs to healthcare professionals and the miscommunication that could occur during their pregnancy/childbirth. This could lead to feelings of anxiety and compounded attempts to communicate further.

Findings from quantitative studies

Experience of parenting in the perinatal period

Only one of the quantitative studies specifically explored the experiences of parenting during the perinatal period (Pohl et al., 2020). They found that, compared to the mothers without ASD, a significantly higher proportion of the autistic mothers reported experiencing prenatal depression (autistic mothers: 40%, control: 25%) and postnatal depression (autistic mothers: 60%, control: 45%). The survey also found that autistic mothers were significantly less likely to report that the process of birth had been adequately explained to them, in comparison to the mothers without ASD (autistic mothers: 62%, control: 79%).

Parenting difficulties

Two of the studies explored parenting difficulties (Dissanayake et al., 2020; Pohl et al., 2020), using different methods of measuring difficulties. The study by Dissanayake et al. (2020) developed a questionnaire specifically for the study; the Parenting Needs Questionnaire (PNQ). The PNQ consisted of 44 items depicting parenting behaviour/parent-child interactions in which participants rated how difficult they found each item on a four-point Likert scale. These items grouped into nine subscales including: Modelling/teaching, Understanding needs, Affection, Emotion control, Attention/connection, Spontaneity, Danger awareness, Sensory issues, and Communication.

Dissanayake et al. (2020) found that higher autism traits, measured on the Autism Quotient (AQ), significantly correlated with a greater number of parenting difficulties reported on the PNQ (r = .48, p =.001). This association was still significant after controlling for psychological wellbeing, suggesting that parents with a greater number of ASD traits experienced more difficulties in parenting independently of their psychological wellbeing. To explore this further they split the sample into two groups; one group of parents with low ASD traits and the other group with high ASD traits. They found that the parents with a high number of ASD traits reported significantly more difficulties in seven out of the nine subscales on the PNQ. There were no significant differences found on the danger awareness and affection subscales between the two groups of parents.

Pohl et al.'s (2020) survey asked participants whether they agreed or disagreed with statements regarding their ability in specific areas related to parenting. They found that autistic mothers were less likely to report that they could cope with the multi-tasking aspect of parenting (autistic mothers: 51%, control: 94%) and with the domestic responsibilities (autistic mothers: 47%, control: 85%). The findings also suggested that autistic mothers were less likely to put effort into creating social opportunities for their child (autistic mothers: 71%, control: 92%). However, the survey found no difference in mothers' self-reported ability to prioritise their child's needs above their own (autistic mothers: 96%, control: 97%) or look for opportunities to boost their child's self-confidence (autistic mothers: 95%, control: 98%).

Parenting efficacy

Three studies explored parenting efficacy in autistic parents, which can be defined as the belief that one can successfully perform the role of a parent (Lau et al., 2016). Pohl et al. (2020) found that autistic mothers were more likely to report feeling that they were not coping in being a mother (autistic mothers: 68%, control: 46%). The other two studies used a subscale of the Parent Sense of Competence (PSOC) scale to measure efficacy (Johnston & Mash, 1989). The subscale measuring efficacy consists of eight items which participants answer on a six-point Likert Scale ranging from strongly agree to strongly disagree.

Dissanayake et al. (2020) found no significant correlation between the degree of parental ASD traits measured on the AQ and scores on the parenting efficacy subscale (r=.28, p<.06). The other study by Lau et al. (2016) compared scores of parenting efficacy between three groups. Group 1 consisted of parents who had their own ASD diagnosis and a child with ASD (n=109), Group 2 consisted of parents who had a child with ASD (n=128), and Group 3 acted as a control group where no one in the family had an ASD diagnosis (n=109). No significant differences were found in scores of parenting efficacy between Group 1 (M = 29. 31, SD = 9.57) and Group 2 (M = 31.62, SD = 7.30), although a significant difference was found between Group 1 and Group 3 (M = 33.14, SD = 5.96). These findings suggest that it was the diagnosis in the child that contributed to lower scores of parenting efficacy, as opposed to the parents' ASD diagnosis. However, when Lau et al. (2016) completed further analyses to explore gender differences between the groups, they found that males in Group 1 (M = 24.45, SD = 9.01) had significantly lower scores on the parenting efficacy subscale than males in Group 2 (M = 31.40, SD = 8.49) and Group 3 (M = 33.25, SD = 3.28). This suggests that autism diagnosis in fathers contributed to a lower sense of efficacy. There were no differences across the three groups for female parents. Analysis by gender in Dissanayake's (2020) study was not possible due to the small number of fathers who took part in the study.

Parenting stress

One study explored the relationship between the degree of parental ASD symptoms, measured on the AQ, and parenting stress (van Steijn et al., 2014). Parenting stress was measured using the short version of the Parenting Stress Index (PSI-SF), which is a 25-item standardised questionnaire where participants respond to each item on a six-point Likert scale. Van Steijn et al. (2014) found that higher scores on the AQ was associated with parenting stress in fathers, indicating that the greater degree of ASD traits, the higher the levels of stress experienced (r = .23). The relationship between parenting stress and paternal ASD symptoms was found when fathers were reporting on their experience of parenting their child with ASD and the sibling without ASD. This finding was not mediated by depressive symptoms. No relationship was found between maternal ASD symptoms and parenting stress.

Parenting satisfaction

Three of the studies explored satisfaction with parenting. The survey by Pohl et al. (2020) found that the autistic mothers were significantly less likely to report motherhood being a rewarding experience, compared to mothers without ASD (autistic mothers: 86%, control: 94%). The other two studies measured satisfaction using the satisfaction subscale of the Parent Sense of Competence (PSOC) scale (Johnston& Mash, 1989). The subscale measuring satisfaction consists of nine items which participants answer on a six-point Likert Scale ranging from strongly agree to strongly disagree. The study by Lau and Peterson (2011) found no difference in scores of parenting satisfaction between autistic parents (M = 34.29) and parents without a diagnosis (M= 35.59). Both groups of parents had at least one child with ASD. In contrast, the study by Dissanayake et al. (2019) found that parental ASD traits negatively correlated with parenting satisfaction (r = -.37, p<0.01). However, once the researchers controlled for psychological wellbeing, they found that parental ASD traits were not independently associated with parenting satisfaction. This suggests that poorer psychological wellbeing in the parents with higher number of ASD traits accounted for the lower scores in parenting satisfaction, as opposed to the degree of ASD traits.

Support with parenting

Pohl et al.'s (2020) survey explored differences in support that autistic mothers received and how helpful they experienced this support compared to mothers without autism. Most of the autistic mothers in the survey (61%) felt they did need extra support with parenting because of their ASD. However, compared to the mothers without ASD they were less likely to report feeling able to ask for support when they needed it (autistic mothers: 41%, control: 68%). When they did receive support from services, autistic mothers were less likely to report that they communicate well with professionals about their child (autistic mothers: 70%, control: 95%) and were more likely to feel so anxious during interactions with professionals that they cannot think clearly (autistic mothers: 60%, control: 25%). Autistic mothers were also significantly more likely to report having felt that professionals involved in their child's care did not believe them (autistic mothers: 54%, control: 31%).

Findings from thematic synthesis

Four out of the five qualitative studies explored experiences of autistic mothers during the perinatal period. The synthesis of the findings from these studies led to the development of three themes and nine subthemes. The synthesis of the data on the experiences of parenting post-birth resulted in an additional three themes and seven subthemes (Table 5). Only one father's voice is heard within this synthesis.

Table 5: Themes and subthemes developed from thematic synthesis

Experiences during perinatal period		
Theme	**Subthemes**	**No. of papers contributing**
1) Interaction between ASD and perinatal experiences	• Altered sensory experiences • Interaction between pain, labour, and communication • The challenge of the medical environment	4 3 4
2) Powerful systems	• Feeling powerless • Lack of understanding around ASD • Challenging the system	4 4 3
3) Factors improving maternity care	• Information and preparation • Choice and permission • Accommodating sensory needs	4 3 3
Parenting experiences post-birth		
4) The parent-child relationship	• Understanding and prioritising child's needs • A different type of relationship • Sense of meaning and purpose	4 3 3
5) Influence of others	• Assumptions around parenting ability • Support from others	4 4
6) Interaction between ASD and parenting	• Diagnosis providing a framework for understanding • Benefits and challenges	3 4

Experiences during the perinatal period

Theme 1: Interaction between perinatal experiences and ASD

Mothers across the four studies commented on how pregnancy, labour, and being in the medical environment, interacted with the sensory processing and communication difficulties associated with ASD.

Subtheme 1: Altered sensory experiences

Many of the mothers experienced changes in their sensory processing during pregnancy, with the majority reporting an increased sensitivity to certain sounds, noises, touch, and/or bright lights.

> "They found odors that were not natural or fresh to be offensive. One woman commented that she *"could smell people's body odors"* and *"did not like to get in their cars or have them hug or kiss me".* Odors, such as neighbour cooking chicken, seemed magnified to some participants." (Gardner et al., 2016, p.32)

These sensory experiences could lead to significant discomfort and distress, especially when coupled with additional sensory input from other people or their environment.

> "As well as the hallucinations, Melanie, who had some strong sensory experiences normally during her life, found that they were exacerbated by the pregnancy. *"Sometimes I worried that I was going mad. Logically, I would tell myself that this is just like the Asperger's probably and it's just gone bananas, but I would still be anxious about it. And, the thing is, I seemed to able to cope with it, until people started to touch me, and seemed to be just the extra-sensory input that seemed to trip another level of stress."* (Rogers et al., 2016, p.93)

Despite the difficulties associated with their sensory experiences, parents were able to overcome these when they felt it would benefit their child. For example, mothers were determined to breastfeed even when it was associated with significant discomfort.

> “Despite their reported sensory modulation challenges, almost all these women breastfed their infants, and some for extensive periods of time; one pumped breastmilk because her infant had been in the NICU. The feeding choice was related to knowledge of benefits of breastfeeding for the baby. One remarked that, *“After all the reading I had done, I strongly wanted to breastfeed.”* Another woman stated, *“I did not enjoy breastfeeding, but I did it. Everything is thought through with me. Nothing comes easily.”* (Gardner et al., 2016, p.34)

Subtheme 2: Interaction between pain, labour, and communication

While it is not unique to autistic mothers to experience challenges communicating during labour, the findings from these studies suggest that this was compounded by existing communication difficulties. The pain and physical discomfort of labour severely impacted on some of the women’s ability to express themselves and comprehend information given to them.

> “Some found that the stress and pain of labor rendered them at times incapable of adequately communicating with the nurses. To cope with the pain of labor, these participants needed to “shut down” at various times throughout labor and could not talk.” (Donovan, 2020, p.169)

The women also reported finding it difficult to communicate the severity of pain they were in, resulting in healthcare staff underestimating their level of pain and discomfort.

> "Being misinterpreted often occurred when participants were asked about their pain. Many reported that their facial expressions or tone of voice did not always correlate with how they were feeling and they felt uncomfortable showing emotion." (Donovan, 2020, p.170)

Subtheme 3: The challenge of the medical environment

In general, the mothers in the studies found the hospital environment unaccommodating to their sensory and communication needs and trips to the hospital often exacerbated difficulties.

> "Penny found the hospital experiences difficult due to her sensory needs: "*just having a stranger putting their hands on you erm or standing too close to you or really brightly lit rooms or you know people rushing in and out and you don't know what's happening it's it really is erm it's not a nice experience at all*."(Burton 2016, p.58)

The lighting used in hospitals was a source of discomfort, with many of the mothers reporting that it induced unpleasant physical sensations such as dizziness and headaches.

> "Several women commented on discomfort associated with fluorescent lighting. One stated it made her feel dizzy and disoriented, another stated they could "*hear them*" (the lights)." (Gardner et al., 2016, p.32)

In addition, medical procedures involving physical touch were found to be particularly challenging for some women.

> "Women described negative experiences associated with prenatal checkups. Several commented that they disliked sensations on their bellies, including touch by others

> and the sensation of the gel used during fetal heart checks." (Gardner et al., 2016, p.32)

> "*I found that I coped with the sensations about the birthing quite well but I didn't cope with people touching with me in any way, shape or form. I found it really difficult when the midwives did an examination of the cervix to see how dilated I was. I couldn't stop screaming and just about jumped off the bed*." (Rogers et al., 2016, p.93)

Theme 2: Powerful systems

A theme that was present across all four studies was the power that services, medical and social care professionals held, in contrast to the mothers who often felt powerless throughout their pregnancy and early parenting journey.

Subtheme 1: Feeling powerless

Many of the mothers described feeling like they had no choice or control while they were in hospital or going for medical check-ups.

> "All the women experienced being treated as a medical object rather than a human individual within the hospital system. This led to professionals assuming that it was ok to touch or examine the mothers without asking or explaining why." (Burton, 2016, p.66)

Others felt that when they tried to speak-up they were dismissed and not listened to, placing them further into a powerless position.

> "At times, some felt their concerns were disregarded. For Helen, struggles with finding the right words often resulted in her being "dismissed"; consequently, she was reluctant to talk out of fear that her statements were not accurate. Helen explained, *"You get dismissed a lot, so you just tend to start keeping things to yourself 'cause, you know, it must be wrong."* (Donovan, 2020, p.169)

In a couple of instances, the mothers had their children removed from their care without fully understanding why this had happened.

> "Anne unexpectedly had her parental rights removed when expecting to take her baby home and due to her trust that the system knew best did not question this, "*I thought they were the people who knew best and they were putting Chloe's best interests at heart and things like that but as time came on I thought well I've done nothing wrong you've got no evidence so why take her?"* (Burton, 2016, p.59)

Subtheme 2: Lack of understanding around ASD

Many of the mothers in the studies reported that professionals they encountered around their pregnancy and birth, were not understanding or did not seem to care about their needs relating to ASD.

> "*The medical profession doesn't seem to understand or care about how pregnancy and Asperger's syndrome interact. I just feel there is not enough support services for people like me and I'm not sure where to go.*" (Rogers et al., 2016, p.92)

Some women reported that their behaviour and communication associated with ASD was misinterpreted by healthcare staff, often with detrimental effects.

> "However, nurses unfamiliar with stimming could misinterpret this behaviour. To cope with the stress and pain of labour, Donna began to visually stim by following

> the patterns on the window blinds with her eyes and physically stim by flapping and rocking. She believed the nurse witnessing the stimming behaviors interpreted them as “mental instability” and reported this behavior to the health care provider. After birth, a social worker visited Donna, which upset her, and she worried that her newborn would be taken away from her.” (Donovan, 2020, p.170)

This lack of awareness was not confined to individual interactions with professionals but across the system more widely. Hospitals did not appear to accommodate for the communication difficulties associated with ASD, and policies were prioritised above the needs of the individual.

> “Hospital policies were prioritised over individual needs, leaving some mothers feeling isolated and neglected: *“they sent Belinda (Polly’s partner) home so I was completely on my own and I hated it I didn’t want her to leave but because they said she’s got to go home she couldn’t stay (Polly).”* (Burton, 2016, p.66)

Subtheme 3: Challenging the system

Despite the position of powerlessness that the women were in, there were numerous examples across the studies where they fought back against the system. At times this was an attempt to cope with the lack of control they were experiencing, and at other times it was fighting for what they believed to be best for their child.

> “However, Mary and Melissa managed the lack of control and lack of explanation by resisting the interventions from staff. For Mary this meant crossing her legs during labour in protest as a result of the staff trying to give her pethidine when she did not want it, which delayed the birth process. Melissa refused to stay in the hospital

> overnight for a diabetes check because the staff had not let her know in advance” (Burton 2016, p.67)
>
> *“If I try to explain that it makes him sick they fob off the reflux, excessive vomiting, choking, distress and unsettled behaviour as normal new-born behaviour. They gave me a call to reschedule an appointment but I haven't answered. Not sure what I'll do with that lot.”* (Rogers et al., 2016, p.92)

Theme 4: Factors improving maternity care

The studies also highlighted factors that helped to improve the mothers’ experiences during and after their pregnancy. This included what professionals did that helped at the time, as well as what the women felt could have been done to improve their care.

Subtheme 1: Information and preparation

The women in the studies shared that it was important for information to be explained clearly to them, using non-jargon language and in smaller chunks.

> “Many participants shared that they needed information explained several times and preferred it in smaller pieces. In addition, open-ended questions could be challenging for some to answer, and they felt that they could have answered questions had they been rephrased.” (Donovan, 2020, p.170)

They also needed time to process information and found it helpful when professionals gave them time to respond before going ahead with a procedure.

> “Some needed more time to process questions or statements from the nurse before they could respond.” (Donovan, 2020, p.170)

Subtheme 2: Choice and permission

Unsurprisingly, given their experiences of not having much control throughout their pregnancies, the women valued professionals giving them choices and asking for permission before going ahead with a procedure or task.

> *"I wasn't comfortable with the first lactation consultant. She was sitting too close to me on a couch and made me nervous. Second lactation consultant—I was sitting in a chair; she asked me to demo first what we were doing. Then she asked permission to help, helped from in front of me rather than sitting on my side. This worked better for me."* (Gardner et al., 2016, p.34)
>
> *"One of them, the midwife who delivered Jamie was great. She seemed to respect my wishes and didn't force pain relief on me. She also told me exactly what she was doing and why she was doing it. She didn't just touch me without telling me that she was going to do that, which probably stopped me from freaking out about it."* (Rogers et al., 2016, p. 92)

Subtheme 3: Accommodating sensory needs

Reducing discomfort from additional sensory input was important to many of the women. Some shared their own methods of coping with their sensory needs when faced with the hospital environment.

> "One suggested wearing sunglasses; another suggested dimming the lights." (Gardner et al., p.32)

Professionals could also help accommodate mothers' sensory needs. One woman explained how she appreciated the midwife explaining in detail how different aspects of the birthing process might feel in the body.

> *“She also explained how certain things would feel like. She told me, for example, that the placenta leaving my body would feel like “a heavy feeling in your vagina.” She didn’t have to do that and I am glad that she did because it made my life easier.”* (Rogers et al., 2016, p.92)

Parenting experiences post-birth

Theme 1: The parent-child relationship

Parents across the studies discussed their relationships with their children and how central their children were to their lives.

Subtheme 1: Understanding and prioritising child’s needs

Parents described how they understood and responded to their children’s needs. For some being in tune with their children appeared to come naturally, yet for others it was a process of learning how their child communicated and what they needed over time.

> “All participants described a level of knowledge of their child and their child’s needs, which was often described as a natural “instinct” (Tanya, 166) or “intune-ness” (Sarah, 123), suggesting a sense of effortlessness.” (Marriott, 2018, p.82)

While most parents will report that they prioritise their children’s needs above their own, the findings suggest that autistic parents may experience this to a greater degree due to conflicts with their needs around ASD. Several parents commented how parenthood had meant they had to face situations they would usually try to avoid, such as social situations which required significant interaction with others.

> “Previously the mothers may have avoided situations where these challenges arose in order to cope but when they have children they are less able to do this. For example, having to attend mother baby groups or meetings.” (Burton, 2016, p.63)

Understandably prioritising their child’s needs was reported as difficult at times and could impact on the parents’ own wellbeing.

> *“It’s really difficult. Because as the parent, you have to put their needs first…And both of them in their own ways are pushing me. She’s such a crier and that really…I find that really difficult to process. And then if Edward’s shouting and all I’m really trying to do is…kind of calm myself…There’s sort of 3 people who really want their needs met. And they want me to solve it. And they look to you, and actually all you want to do is sit in the corner going “No! [laughs] I can’t. I can’t do it!”* (Marriott, 2018, p.88).

Subtheme 2: A different type of relationship

Across the studies, parents highlighted how their relationship with their children was different to any they had experienced before. Parents commented on the unique bond they shared with their children and how this relationship was one of the most consistent in their lives.

> “The kind of love they felt for their children was different to other relationships they had and it was also the most stable relationship for some: *“I know that she’s never going to go sort of thing I’m always her mum and she’s always my daughter (Wendy).”* (Burton, 2016, p.64)

Parents spoke about how their quirks related to autism were accepted by their children. This acceptance created a sense of belonging, which was described as a contrast to experiences outside the family environment.

> *"It's a very accepting family and there are some really interesting people within it…with some…[smiles] interesting ways of being. [Pause] And I think it's the acceptance because within these 4 walls we are just who we are. Flaws and all. And…I think it's about being appreciated for who you are as a person."* (Marriott, 2018, p.93)

Subtheme 3: A sense of meaning and purpose

Parents in the studies described how parenthood had positively impacted them. It was clear for most parents that their children played a central role in their lives, creating meaning and purpose.

> "Four of the mothers spoke about how their child gave their life purpose and kept them functioning: *"so I've always focused around her so when she's not in the house I tend to fall apart a bit she doesn't but I do (Anne)."* (Burton, 2016, p.64)

Parents also commented on how parenting had led to development and personal growth.

> "Some described becoming a parent was a process of development such as being "*more laissez-faire with thing*s" (Hilary, 204), learning "*patience*" (Neil, 85) and becoming "*a more tolerant and accepting person*" (Tanya, 569). Sarah described having to learn to *"chit chat"* (Sarah, 324) which suggests informal social interactions were not a natural concept to her." (Marriot, 2018, p.89)

Theme 2: Influence of others

Parents across the studies discussed the influence of others, including assumptions made about their parenting abilities and support they received around their parenting.

Subtheme 1: Assumptions around parenting ability

A significant number of the parents in the studies reported that others made assumptions around their parenting ability, mostly presumptions of incompetence. This was often attributed to their ASD diagnosis and meant they felt they had to prove their ability to professionals.

> *"I've noticed that the more I strongly asserted my decisions on how to raise my own child, the more they put my behaviour down to some dysfunctional behaviour due to Asperger's Syndrome. In other words, they were questioning my function as an effective parent."* (Rogers et al., 2016, p.93)

Several parents commented that they felt they could not ask for help in fear that they would be judged negatively. Some mothers were concerned that their parental rights may be taken away from them.

> "Prejudice also appeared to lead to a different threshold for demonstrating parenting. The mothers had to demonstrate that they needed no help at all or their parental capacity would be questioned; if they needed help then this questioned their parental capacity." (Burton, 2016, p.59)

Concerns about judgement from others were often linked with their child's behaviours, which could be especially challenging for those with children with ASD.

> “Participants also spoke of concerns about societal judgment of their child’s challenging behaviours. Kate described: “*all the parents are looking at you like ‘Oh my God, she’s like…Year 1 and she’s doing that!’*” (Marriott, 2018, p.92)

For some parents, they internalised the stigma and started questioning their ability as a parent. This was particularly true for mothers who were also experiencing comorbid mental health difficulties.

> “Four women in this study shared beliefs about themselves that can be seen as a result of internalising these messages. They questioned their competency and even their right to be a parent. *“I just thought how could you be a mother when you’ve got issues (Wendy).”* (Burton, 2016, p.60)

Subtheme 2: Support from others

Parents discussed the formal and informal support they received from others around their parenting, and how useful they perceived this support to be. Parents whose child also had ASD were likely to be in contact with children’s social care and/or mental health services. They commented on the tendency for services to offer support only when their child’s behaviour was particularly difficult to manage or the family were at crisis point.

> “Parents often described their child being rejected from mental health, educational and social services due to their criteria being too high. For example, parents described services instructing them to *“come to us when it’s serious” (Kate, 274),* with a sense that services were invalidating their distress.” (Marriott, 2018, p.94)

On the whole, parents were more likely to perceive support from family members and partners as helpful compared to the support they received from services.

> "Most of this type of help came from their own mothers. On this topic, one participant said, *"Having my mother there. I knew to pick up the phone and call my mother. I would get out the books, I would read. Nothing would work. And my mother would say, "Now you know those books are second to human nature .. . and this is what you need to do" and she'd walk me through it*." (Gardner et al., p.33)

Other parents reported feeling very isolated and finding it difficult to ask for help from others, despite feeling that they would benefit from support. For some parents, this difficulty was not knowing how to communicate what they needed, yet for others it was fear of being viewed as incompetent.

> "Another women noted, "*We may not ask for help. Just because we don't, don't assume that all is well*" (Gardner et al., 2016, p.34)

Theme 3: Interaction between ASD and parenthood

Across the studies, parents commented on how they perceived ASD to interact with their experience of parenting.

Subtheme 1: Diagnosis providing a framework for understanding

Parents highlighted how receiving a diagnosis of autism helped them to understand themselves better and their responses to situations they found themselves when in the family environment.

> "Neil's self-realisation appeared to be a temporal process and enabled him to better manage his difficulties and the impact these had on his family, as he later described: *"One of the reasons I wanted to get the ASD diagnosis, is because you can have a lot*

> *of temper or a response to things that is disproportionate to the activity, which of course is distressing to everyone else […] So you have to work on…work on that."* (Marriott, 2018, p.90).

A significant proportion of parents in the studies were diagnosed with ASD after their children were diagnosed, or around the same time. This was usually due to increased awareness of ASD and identifying with traits they saw in their child. Some parents who had been diagnosed later in life reported feelings of disappointment and loss, from having missed the opportunity to understand themselves better in the context of ASD.

> "Polly thought that her experiences of depression during her last pregnancy and difficulties bonding with her baby were in part due to not having the diagnosis and this understanding of herself." (Burton, 2016, p.61)

For those with children who also had a diagnosis of ASD, their shared diagnosis meant they were able to relate to their children and understand their behaviour on a personal level.

> *"So, from my own experience of having been a child, and thought that way, and I'm looking at Charlie thinking the same way too. That kind of enabled me to connect a little bit because I kind of understood, firstly not to touch his stuff, but also to ask the sorts of questions. Because I knew what was going on in his head. A little bit about how he was dealing with all these patterns and stuff."* (Marriott, 2018, p.85).

Subtheme 2: Benefits and challenges

Parents reflected on what they experienced as some of the advantages and challenges of being an autistic parent. Some discussed how core features of ASD, such as difficulties with emotion recognition and executive functioning, impacted on some areas of parenting.

> “This concern was also reflected in Sarah’s account: *“…sometimes I have to sort of step back and think, am I missing the fluffy stuff?”* (204). She seemed to reproach herself for neglecting her children’s needs while at the same time her contemptuous use of the word “*fluffy*” seemed to excuse herself from this.” (Marriott, 2018, p.87)

> “Lucy and Melissa also found that their executive dysfunction difficulties made it hard to co-ordinate managing the house and looking after children.” (Burton, 2016, p.58)

Parents also recognised strengths that came from their diagnosis. The rigidity in their routines was perceived as an advantage to parenting at times.

> “The majority of the mothers also felt that their routines and black and white thinking provided good consistency for their children.” (Burton, 2016, p.60)

There were also numerous accounts from parents that challenged the dominant narrative around ASD and a lack of empathy. It appeared that the uniqueness of the parent-child bond enhanced parents’ ability to be emotionally in-tune with their child, even when they struggled with this in other areas in their lives.

> “This contrasts with the narrative about individuals with ASD lacking empathy due to difficulties with theory of mind which was highlighted by Lucy: *“I think there’s certain elements of empathy that can be affected but I think actually a lot of us are very very empathetic and in tune with our children.”* (Burton, 2016, p.60)

Discussion

This systematic review provides some insight into the experiences of autistic parents, which appears to be a largely neglected area in the research literature. Despite the wide search strategy, only ten studies were identified that explored the parenting experiences of autistic parents. While the limited number of studies makes it difficult to draw definite conclusions, the findings highlight some of the positive experiences of parenthood and challenges that autistic parents face, which may provide useful information for services and professionals working with autistic parents.

The quantitative and qualitative syntheses suggest that autistic parents may experience more difficulties in certain areas of parenting compared to parents without autism. There is evidence that some of these difficulties could be related to features of ASD, for example coping with sensory stimuli around their child (Dissanayake et al., 2020), creating opportunities for their child to socialise (Pohl et al., 2020), and finding it harder to manage the competing demands that accompany the parenting role (Pohl et al., 2020; Burton et al., 2016). However, there appears to be some inconsistency in the findings across the studies. For example, Pohl et al.'s (2020) survey found that autistic mothers were significantly more likely to report feeling they are not coping in their role as a mother, whereas other studies found that autistic mothers did not report lower confidence in their parenting abilities than mothers without ASD (Lau et al., 2016; Dissanayake et al., 2020). One explanation for discrepancies could be the way in which constructs are measured across the studies. The survey questions were co-produced with mothers with autism (Pohl et al., 2020), whereas the other studies used standardised questionnaires to measure self-efficacy, which had not been validated in the autistic population. There were also other factors which may have affected parenting experience between the autistic mothers and the non-autistic sample in Pohl's (2020) survey. The autistic mothers reported significantly higher rates of comorbid mental health difficulties than the non-autistic mothers, and poorer mental health has been linked to lower parenting self-esteem (Kohlhoff & Barnett, 2013; Oyserman et al., 2000).

Interestingly, gender differences in parenting experience were noted in two studies, suggesting that autistic fathers may feel less confident in their parenting abilities and experience more stress compared to autistic mothers and parents without ASD (Lau et al., 2016; van Steijn et al., 2014). These findings should be interpreted with caution as potential confounding factors were not identified or controlled for in the studies. The findings are also somewhat contradictory to findings from other studies that have explored gender differences in parents of autistic children, which have indicated increased levels of parenting stress in mothers (Hayes & Watson, 2013). However, it highlights the importance of considering the impact of gender on parenting experience for autistic parents. Even with a shift away from traditional gender roles being viewed as the norm within family units, fathers often take on different responsibilities and approaches to mothers in relation to parenting (Schoppe-Sullivan & Fagan, 2020). Van Steijn et al. (2014) hypothesise that the increased stress observed in autistic fathers may be related to the observation that men engage more in recreational activities with their children. This often requires significant spontaneous interaction which can be difficult for autistic people. Lau et al. (2016) wonder whether the lower scores in parental efficacy reported in fathers could be related to an observation reported in family literature, which has shown that men are more likely to avoid and have difficulty managing conflict in the family (Kelly & Fincham, 1999). They hypothesise that parent-child conflict may be more challenging for autistic fathers due to their difficulties with social communication, as well as the impact of their child's behaviour if they also have a diagnosis of ASD.

The findings from this review sheds light on some of the challenges that autistic mothers face during the early stages of their parenting journey. While some of the experiences that the women report are unlikely to be unique to autistic mothers, it seems that the interaction between ASD, pregnancy, and the medical setting further increase the likelihood of having particularly negative or distressing experiences. The findings also highlight the discrimination that autistic mothers may face when accessing services for maternity care. An overarching theme across the studies was a lack of understanding around ASD which affected the care the mothers received. Consistently, the findings from the larger scale survey also showed that autistic mothers were significantly more likely to feel that the process of birth had not been adequately explained to them and to report difficulties interacting with professionals (Pohl et al. 2020). These findings reflect a broader issue around accessibility of services, and findings from recent systematic reviews have highlighted similar barriers that autistic individuals face when accessing healthcare services (Adams & Young, 2020; Mason et al., 2019).

This review shows how stigma and discrimination affects autistic parents throughout parenthood. The parents in the qualitative studies shared concerns about being judged negatively by others and felt they had to prove their parenting ability above and beyond parents who do not have ASD. These findings are comparable to those in the literature regarding parents from other marginalised groups, including those with intellectual disabilities and serious mental illness (Dolman et al., 2013; Theodore et al., 2018). While it is possible that some of the core features of ASD may make some aspects of parenting more challenging, any difficulties experienced by autistic parents will be impacted and influenced by systemic factors. This includes health, social care and educational systems which are set up to favour neurotypical individuals (Walsh et al., 2020), and societal assumptions held around what constitutes a 'competent' parent. As discussed in Pohl et al.'s (2020) paper this could create a cycle in which parents do not ask for help due to fear of being judged negatively, therefore becoming more isolated and feeling less able to cope with parenthood.

The findings from this review also provide some indication of how mental health may interact with parenting experience for autistic parents. Individuals with ASD are more likely to experience mental health difficulties throughout their lives than the general population (Lai et al., 2019). This was reflected in the studies in this review; Pohl et al. (2020) found that autistic mothers reported higher rates of pre and postnatal depression, and most of the mothers in Burton's (2016) study reported comorbid mental health conditions. Qualitative accounts from mothers with additional mental health needs alongside ASD suggest they experience more stigma and negative attitudes from others regarding their parenting, and may internalise these messages (Burton, 2016). Lau and Peterson (2011) found that poorer psychological wellbeing accounted for lower parental satisfaction observed in those with a higher number of ASD traits. Given that reduced satisfaction is associated with more difficulties in parent-child interactions (Lerner & Galambos, 1985), these findings highlight the importance of providing adequate support to autistic parents around their own mental health.

Despite the systemic challenges that autistic parents face, the findings from this review also highlight the value and enjoyment they can get from parenthood. The quantitative studies indicate that most autistic parents find parenting a rewarding and satisfying experience, and the qualitative studies emphasise the meaning and purpose that children bring to their lives. Marriott (2018) and Burton (2016) highlight the connection that the parents describe with their children and how this may contrast with other relationships in their lives. For people on the autistic spectrum, building and sustaining longstanding relationships can be difficult for various reasons. A significant challenge includes having to actively monitor for cues from others and feeling the need to mask or camouflage autistic traits during social interactions (Hull et al., 2017). This is reported as exhausting and understandably reduces the desire to engage in opportunities to form relationships (Hull et al., 2017). Perhaps the relationship the parents experience with their children is different because the parents do not feel the need to alter who they are, or how they present, when spending time with their children. Additionally, it should be noted that there was little evidence to suggest that the theory of mind difficulties associated with ASD posed a significant problem in their relationships with their children, at least not from the parents' perspectives.

Finally, whilst the quantitative studies mostly focus on difficulties in parenting, the qualitative accounts highlight the immense range of experiences of parenthood, from joyful, mundane to painful. Although these experiences arguably reflect the reality of being a parent, whether on the autistic spectrum or not, as outlined above there appears to be factors unique to being a parent on the autistic spectrum. This warrants further research into the experiences and needs of this group of parents.

Limitations

There are several significant limitations to this review. Despite the thorough search strategy, only ten studies relevant to the topic of the review were identified. Two of the studies were identified from reviewing the reference list of included papers, which makes it possible that other relevant studies were not captured from the database search. The limited number of studies, alongside the heterogeneity in the methodology between the studies, make it difficult to draw definite conclusions from the synthesis. In addition, three of the qualitative studies explored the experiences of mothers during the perinatal period, focusing mostly on their experiences in the hospital environment. While similar themes emerged across these studies, they provide little information on what it is like to parent a child beyond that of a new-born.

The inclusion criteria for the review was kept intentionally broad due to the anticipated small number of studies in the area. This meant that there were factors that varied across the studies, which are likely to have impacted on parenting experience. This included whether the parent's children also had a diagnosis of ASD or not. Unsurprisingly, due to the heritable nature of ASD, a significant proportion of the parents in the studies had children with ASD, and for some studies this formed part of the inclusion/exclusion criteria. Parenting an autistic child will present unique challenges and it is difficult to compare findings across studies where the parents are reporting on their experience of parenting a child with an ASD diagnosis and those that are parenting a child without a diagnosis. While the findings from studies in this review allude to possible advantages of a shared diagnosis between parent and child, such as an increased understanding of their child's behaviours or traits relating to ASD, there are too few studies to draw conclusions.

The studies also varied in their inclusion criteria and how they assessed for ASD in participants. Six out of the ten studies did not specify that participants needed a clinical diagnosis of ASD to take part. While it is recognised that many people who identify as autistic do not seek a formal diagnosis for various reasons, this does challenge the validity of the findings. A recent meta-analyses has shown that autism studies are finding smaller and smaller differences between autistic and non-autistic participants, in areas typically associated with ASD, such as theory of mind and emotion recognition (Rødgaard, Jensen, Vergnes, Soulierès, & Mottron, 2019). The authors of the review acknowledge that autism is a continuum, and features of ASD occur to varying degrees in the general population. However, they question the validity of the diagnosis in some participants included in ASD research. Many of the studies in this current review use the Autism Quotient (AQ) to measure the degree of ASD traits. It is important to note that the researchers developed the AQ as a screening tool for ASD in adults, and state that it should not be used as a stand-alone diagnostic tool (Baron-Cohen et al., 2001).

One of the qualitative studies was a case study, which accounted for a significant proportion of the thematic synthesis. It is likely that the experiences of this individual may represent more extreme views, especially considering the researchers had initially planned to recruit multiple participants but had not managed to using their recruitment strategy (Rogers et al., 2017). In addition, two of the other qualitative studies, which provided most of the information on parenthood beyond the perinatal period, were unpublished Doctoral theses. While these studies did not fare any worse in the quality assessment than the published studies, they may not have been peer-reviewed to the same extent as published studies.

Another limitation of the review is the underrepresentation of fathers' experiences in the studies. Half of the studies only included mothers in their sample, and those that included both genders recruited significantly less fathers than mothers. This gender bias mirrors patterns in the parenting literature in general (Cassano, Adiran, Veits, & Zerman, 2006). Given that the findings in this review allude to possible gender differences in the experience of parenting for autistic mothers and fathers, the experiences of autistic mothers may not be representative of autistic fathers. Lastly, all the studies were conducted in Western countries, and therefore may provide less information on the experiences of autistic parents in non-Western cultures, where parenting practices and views around autism may be very different.

Implications for services

This review holds some implications for services supporting autistic parents or parents with similar needs. The findings suggest that some autistic parents may benefit from being offered support in targeted areas of parenting, such as managing the multi-tasking elements and supporting their children to socialise with others. Supporting parents with their own mental health needs is undoubtedly important and interventions aimed at improving psychological wellbeing for autistic parents may help to improve the satisfaction they get from parenthood. Professionals should be aware of potential barriers for autistic parents when seeking and accessing support for parenting and/or mental health difficulties. These include prior negative experiences of support, concerns about being judged as an incompetent parent, difficulties in communicating their needs to professionals, and having to navigate services that are not set-up in a way that meets the needs relating to ASD.

The findings from this review highlight the need for specific training in maternity services to develop staff knowledge of how ASD and pregnancy may interact. The qualitative synthesis provides suggestions on ways in which services and professionals can better support autistic mothers throughout their pregnancy, labour, and birth. While existing guidelines on supporting autistic individuals in healthcare settings provide some useful and relevant recommendations (NICE, 2012), there are some more unique to maternity care. This includes providing clear information prior to giving birth on how the stages of labour and birthing process may feel in the body and being aware that autistic women may find it difficult to communicate the degree of pain they are experiencing during labour. Professionals should hold in mind possible sensory sensitivities that could make the mothers' experience more challenging and ensure that they adequately prepare them for any medical procedures involving touch. A calm and low stimulating environment during birth is especially important for autistic women. These are consistent with recommendations summarised in Turner's (2017) paper, who highlights the lack of evidence-based guidelines for healthcare professionals supporting autistic women in UK maternity settings. Evidence-based guidelines and training around ASD in maternity services would hopefully help minimise the likelihood of autistic women having particularly distressing experiences during this pivotal stage of their life, as reported by many of the mothers in this review.

Future research

This review has many implications for future research. Firstly, it has clearly highlighted the scarcity of research that has been conducted in this area. This is surprising give the wealth of literature on the experiences of parenting a child with ASD and the heritable nature of the condition. The qualitative literature that is available has focused mostly on experiences around pregnancy and birth, so more research exploring the experiences of parenting across the child's lifespan would develop our understanding of autistic parents further. Given that a significant proportion of the mothers in these studies expressed that they would like support around their parenting, further research could help to identify areas for intervention and tailor current support being offered. In addition, despite ASD being more commonly diagnosed in men, the literature has mostly focused on autistic mothers' experiences. The findings from the limited research available suggests that autistic fathers may feel less confident in their parenting abilities and experience increased stress. Future research on the parenting experiences of fathers with ASD is warranted to explore this further.

Chapter 2 - Exploring the parenting experiences of autistic fathers

Abstract

Autism spectrum disorder (ASD) is a neurodevelopmental disorder which can have a significant impact on someone throughout their life. Given that ASD is a lifelong condition, it is important to consider how it may interact with the varying roles that adults take, including parental roles. Yet, there is very limited research into the experience of autistic parents, with fathers noticeably absent in the literature. This study aimed to develop our understanding of autistic fathers by exploring their experience of parenting using a qualitative methodology. Semi-structured interviews were carried out with nine fathers who had a clinical diagnosis of ASD and at least one child under the age of twenty-five. Interpretative Phenomenological Analysis (IPA) was used to analyse the data from the transcripts. Three superordinate themes were developed: 1) The interdependent relationship between autism and parenting; 2) The family system: a balancing act; and 3) Parenthood facilitating reflection and growth. The findings showed that the fathers were extremely dedicated to their children. Parenting could be challenging at times when there were conflicting needs, such as balancing their own sensory needs associated with ASD with their children's need for interaction. The fathers' partners had a significant impact on their experience and could affect how close they felt to their children. Receiving a diagnosis of ASD was helpful in aiding understanding across the family and highlights the importance of earlier diagnosis. Other implications from the findings include peer support being available for autistic parents and the need for fathers to be more meaningfully involved in parenting interventions. Suggestions for future research are outlined.

Introduction

Autistic Spectrum Disorder

Autistic Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder characterised by difficulties with social communication and interaction, and restrictive and repetitive interests or patterns of behaviour (APA, 2013). Common features of ASD include difficulties in understanding others' emotions and intentions, a need for predictability and routine, and atypical sensory experiences (Vannucchi et al., 2014). Over the last few decades there has been a significant increase in autism diagnoses, and it is now estimated that approximately 1% of the population meet criteria for an autistic spectrum condition (Brugha et al., 2011). There are likely to be several factors contributing to the rise in prevalence rates, including an increased awareness of ASD and the different ways in which it can present, as well as a broadening of the diagnostic criteria (Matson & Kozlowski, 2011).

Multiple theories have been developed to explain the social, cognitive, and sensory aspects associated with ASD (Rajendran & Mitchell, 2007). This includes the Theory of Mind Deficit, which proposes that people with ASD have a deficit or a delay in their ability to understand the mental states of themselves and others (Baron-Cohen, Leslie, & Frith, 1985). Another theory suggests that autism is a result of executive dysfunction, referring to an impairment in cognitive processes such as planning, switching attention, flexibility, and impulse control (Hill, 2004). While there is evidence that autistic individuals do have greater difficulty with tasks that require theory of mind (Baron-Cohen, 2000) and tasks that require executive functioning (Ozonoff, Pennington, & Rogers, 1991), neither of these theories can fully account for all the behaviours and traits associated with ASD.

Another criticism of these theories and the medical model of ASD is that the language used typically focuses on impairments and deficits in different areas of functioning. An alternative perspective is that autistic people have a different cognitive style termed ‘weak central coherence’ (Happé & Frith, 2006). This theory suggests that autistic individuals process information in a different way to the neurotypical population, showing a bias towards local i.e., detail-focused rather than global information processing. Weak central coherence can account for strengths as well as difficulties that autistic people may have, such as being able to recall specific details from complex or large amounts of information (Happé, 1999). Again, this theory is not conclusive, yet a shift in the discourse around autism to focus more on difference as opposed to deficits is welcomed by the autistic community (Bottema-Beutel, Kapp, Lester, Sasson, & Hand, 2020; Loftis, 2015).

Parenting and ASD

Given that ASD is a lifelong condition, it is important to consider how it may impact on the varying roles that adults take, including parental roles. For most parents, raising children is described as both a rewarding and challenging experience that requires significant adjustment. For autistic people, parenthood may bring additional challenges. The very nature of being a parent involves regular social interaction and an ability to understand the needs of another person, both areas in which autistic people can experience difficulties. The unpredictability of parenthood may also be more difficult to cope with as an autistic parent. In addition, executive functioning difficulties and sensory sensitivities could make it harder to manage the competing demands that accompany parenting (Pohl, Crockford, Blakemore, Allison, & Baron-Cohen, 2020).

While there has been plenty of research into the experience of parenting an autistic child, only in recent years have the experiences of autistic parents been explored in the literature. Ten studies exploring the parenting experiences of autistic parents have been identified

(Burton, 2016; Dissanayake, Richdale, Kolivas, & Pamment, 2020; Donovan, 2020; Gardner, Suplee, Bloch, & Lecks, 2016; Lau & Peterson, 2011; Lau, Peterson, Attwood, Garnett, & Kelley, 2016; Marriot, 2018; Pohl et al., 2020; Rogers, Lepherd, Ganguly, & Jacob-Rogers, 2017; van Steijn, Oerlemans, van Aken, Buitelaar, & Rommelse, 2014). Quantitative studies have mainly sought to compare aspects of parenting between autistic and non-autistic parents (Dissanayake et al., 2020; Lau & Peterson, 2011; Lau et al., 2016; Pohl et al., 2020; van Steijn et al., 2014), whereas qualitative studies have aimed to provide more in-depth accounts of individuals' lived experience of parenthood (Burton, 2016; Donovan, 2020; Gardner et al., 2016; Marriot, 2018; Rogers et al., 2017). While the findings highlighted some universal parenting experiences, they also suggested that some of the challenges that parents face may be compounded as an autistic parent. This included a clash between the parent's need for time alone and their children's need for interaction (Burton, 2016; Marriot, 2018), an exacerbation of sensory sensitivities due to certain experiences which accompany parenting (Burton, 2016; Gardner, Suplee, Block & Lecks, 2016) and difficulty coping with the multi-tasking elements of the parental role (Dissanayake et al., 2020; Pohl et al., 2020).

The review also highlighted negative experiences of health and social care services that autistic mothers had during and after their pregnancies. In the UK, the Autism Act (2009) was established to improve the provision of services for autistic people. Yet despite this existing legislation, the mothers in the UK-based studies reported feeling misunderstood by professionals and described how services were often set-up in a way that discriminated against autistic individuals (Burton, 2016; Pohl et al., 2020). The social model of disability can explain some of the difficulties that accompany autism (Oliver, 1983). This model proposes that a person is only disabled by systemic barriers, stigmatising attitudes, and exclusion by a society which does not accommodate difference (Oliver, 1983). In line with this concept, the autistic mothers felt that their communication and sensory processing difficulties were more pronounced because of the unaccommodating nature of the hospital environment and other services they encountered. Autistic mothers' interactions with services and perceived lack of appropriate support, appeared to make their experiences of pregnancy, childbirth, and early parenting more challenging.

Fatherhood and ASD

The roles that men take and the positions they hold in families are becoming increasingly fluid over time, especially in Western cultures (Dette-Hagenmeyer et al., 2014; Miller, 2010). In recent decades there has been a shift towards more 'involved fatherhood', with fathers being more directly involved in caregiving responsibilities (Miller, 2010; Schoppe-Sullivan & Fagan, 2020). While expectations and attitudes towards fatherhood may be changing, there are still gender differences in parenting practices. Fathers are often expected to, and are more likely to, engage in paid work (Warren, Pascall, & Fox, 2010; Miller, 2012). They tend to spend less time with their children on average compared to mothers and may take on different parental responsibilities, such as being more involved in the recreational and educational activities as opposed to the routine household chores or providing emotional support to their children (Bianchi, Sayer, Milkie, & Robinson, 2012; Miller, 2010).

Research has demonstrated how fathers' involvement and their approaches to parenting can significantly impact on their children's social and psychological development (Sarkadi, Kristiansson, Oberklaid, & Bremberg, 2008; Wilson & Prior, 2011). Paternal involvement is likely to be beneficial for fathers too; a large-scale international survey found that men report higher levels of family satisfaction when they engage in more childcare (Forste & Fox, 2014). UK social care policies, such as the Care Act (2014), now place greater emphasis on the need for services to take a whole family approach, considering the strengths and needs of both parents. Yet despite changes in how men are viewed within the family and increased recognition of the importance of the father-child relationship, fathers are often underrepresented in literature on parenthood and child development (Cassano, Adrian, Veits, & Zeman, 2006). Research into autistic parenthood mirrors this observation. Only half of the few existing studies on autistic parents have included fathers as well as mothers in their sample (Dissanayake et al., 2020; Lau & Peterson, 2011; Lau et al., 2016; Marriot, 2018; van Steijn et al., 2014), and when fathers were included, they made up a minority of the overall sample. This is despite there being a sex bias in ASD, which is more commonly diagnosed in men (Loomes, Hull, & Mandy, 2017).

Two studies which have included fathers in their sample highlighted possible gender differences in experiences of parenting for men and women on the autistic spectrum. Van Steijn et al. (2014) found that a greater degree of self-reported autistic traits was correlated with increased parental stress in fathers but not mothers. Another study by Lau et al., (2016) found that autistic fathers reported significantly lower scores in parenting efficacy than autistic mothers and the non-autistic parents. These findings support one another; it is understandable that if a parent is feeling less confident in their role as a parent, then they are going to experience more stress, and vice versa. The authors speculate on why these findings were observed in autistic fathers and not mothers, considering the impact of gender roles within the family. As noted above, fathers tend to be more involved in the recreational activities as opposed to the daily running of the household (Miller, 2010). Van Steijn et al. (2014) hypothesise that the spontaneous nature of these activities may be more difficult for autistic fathers, hence leading to more stress. While spontaneous activities can be difficult for autistic people, this is unlikely to be the only factor contributing to increased stress in autistic fathers. Another potential factor contributing to fathers experiencing higher levels of parenting stress and feeling less able to cope could be related to social support. An increased amount of social support has been linked to more positive parenting experiences, including helping to reduce stress associated with parenting (Weiss, 2002). People on the autistic spectrum often have very limited support networks and autistic men in particular may have very little social support available to them (Chen, Bundy, Cordier, Chien, & Einfield, 2017).

In addition to these published studies, autistic fathers have provided qualitative accounts of their experiences of parenting through blog posts and other forms of social media. One father speaks about fears he experienced when he found out he was expecting a child, doubting his ability to connect with his son because of his autism (Martin, 2020). This is comparable to the ‘internalised stigma’ that Burton (2016) describes in her study of autistic mothers, where the mothers appear to have internalised messages around ASD being in some ways incompatible with parenthood. The parents sharing their experiences online comment on the lack of information around autistic parents, which perhaps perpetuates this narrative around autistic parents further (Martin, 2020; Rudy, 2020).

Fathers of autistic children

Given the heritable nature of ASD, it is likely that some autistic fathers have autistic children and that some fathers of autistic children have undiagnosed ASD or a high number of autistic traits (Rubenstein & Chawla, 2018). Indeed, there are a growing number of anecdotal accounts and research findings that suggest many autistic parents are receiving their diagnosis during or after their child has gone through the assessment process (Burton, 2016; Marriot, 2018; Rudy, 2020). The experiences and perspectives of fathers of autistic children are again underrepresented in the literature (Braunstein, Peniston, Perelman, & Cassano, 2013). This lack of paternal involvement also extends to clinical practice. Fathers are less likely to be included in parenting interventions for autistic children, despite their involvement being associated with better outcomes (Rankin, Paisley, Tomeny, & Eldred, 2019).

The existing literature on fathers of children with ASD suggests they experience greater parenting stress than parents of neurotypical children, although possibly less than mothers of autistic children (Flippin & Crais, 2011). This stress may be related to difficulties their child has in expressing their needs, as well as managing challenging behaviour in response to changes in their child's routines or sensory disturbances (Flippin & Crais, 2011). Even when there are significant challenges, qualitative research has shown that fathers of autistic children value the sense of purpose and meaning that they get from the experience, viewing parenthood as an opportunity to develop themselves (Lashewicz, Shipton, & Lien, 2019; Potter, 2016). There may also be benefits from a shared diagnosis between parent and child; autistic parents may be able to relate to their child's behaviours associated with ASD, which may in turn help them to understand how to respond (Marriot, 2018).

Limitations of the existing literature

There is a scarcity of research on autistic parents, with fathers being noticeably absent in the literature. Whilst quantitative studies have highlighted potential gender differences in parenting experience for autistic fathers (Lau et al., 2016; van Steijn et al., 2014), the methodologies do not allow for an in-depth insight and understanding of their personal experience of parenting. One qualitative study which included fathers in the sample, only recruited one father in a sample of eight (Marriot, 2018). This study, alongside others on experiences of autistic parents in the literature, did not require parents to have a clinical diagnosis of ASD, which may challenge the validity of the findings.

In addition, most of the research to date has not attempted to include people with lived experience of autism in the design of the research. This lack of inclusion of autistic individuals in the research design process is a pattern observed across autism studies (Pellicano, Dinsmore, & Charman, 2014). Yet there are clear benefits to more inclusive methodologies, including understanding the priorities of research for autistic individuals (Pellicano et al., 2014), re-distributing the power imbalance between neurotypical researchers and the autistic population (MacLeod, 2019), and helping to develop tools and questionnaires which better capture the experiences of autistic people (Carrington et al., 2016).

Current study

The present study therefore aimed to address the gap in the literature by exploring the parenting experiences of autistic fathers. The sample consisted of fathers diagnosed with ‘high-functioning’ autism, which means that they did not have an additional diagnosis of a learning disability. The study aimed to enhance the understanding of the needs and experiences of this population, and in turn provide insight for professionals and services on how to tailor support to these individuals. This is in keeping with the National Institute for Health and Care Excellence (NICE) guidelines which highlights the importance of providing support for autistic adults in caregiving roles (NICE, 2012), as well as social care policies which emphasise the need for a whole family approach. Given the scarcity of research in the area and the complex nature of the phenomenon being studied, a qualitative methodology was thought to be most appropriate.

The study aimed to answer the following question: *What are the parenting experiences of fathers with a diagnosis of Autistic Spectrum Disorder (ASD)?*

Method

Design

The study used a cross-sectional qualitative design. Interpretative Phenomenological Analysis (IPA) approach was used to analyse data from semi-structured interviews (Smith, Flowers, & Larkin, 2009).

Sample

Purposive sampling was used to recruit a total of nine participants to the study. Smith, Flowers & Larkin (2009) suggest a sample size of between 4-10 for IPA Doctorate projects. A smaller sample size is recommended so that participants' experiences can be explored in sufficient detail, consistent with the idiographic nature of IPA. Other IPA studies exploring the lived experience of autistic individuals have included a similar number of participants (MacLeod, 2019).

Inclusion criteria

Participant selection was based on the following inclusion criteria:

- All the participants had a formal diagnosis of ASD. This means they had previously received a comprehensive assessment at a diagnostic clinic including a clinical interview, and either an informant interview and/or formal assessment tool, such as the Autism Diagnostic Observation Schedule (ADOS) (NICE, 2012). While it is acknowledged that some people who identify as autistic may never seek a formal diagnosis, having a formal diagnosis was believed important to help maximise homogeneity amongst the sample.

- The sample consisted of fathers whose youngest child was aged twenty-five or below. This age limit was set because the study aimed to explore experiences of parenting from pregnancy onwards and if these experiences were a long time ago, it would have been more difficult for participants to recall in detail. It was also an attempt to keep the sample more homogeneous, consistent with the IPA approach.
- All participants had to have good spoken English to be able to fully engage in the interview process.

Exclusion criteria

Participants were excluded if:

- They were seeing a psychiatrist for an active mental health problem at the time of data collection or had a history of significant mental health difficulties, such as psychotic illness. This was to try to avoid comorbid diagnoses having a significant influence on participants' accounts of parenting.
- They had a diagnosis of a global learning disability.
- They lacked capacity to be able to give consent according to the Mental Capacity Act (2005).

Recruitment

Participants were recruited from two specialist NHS adult autism services and from social groups run by third sector ASD organisations. Group facilitators and clinicians working in the NHS services were provided with written information about the study and a link to the study advert on Qualtrics online survey platform (Appendix D). They then circulated the study information and advert to group members or service users who might have met the criteria for the study.

Any men who showed interest in being involved in the study were screened over the phone by the researcher to ascertain if they met the eligibility criteria for the study. Those that appeared eligible for the study after screening were provided with a link to the participant information sheet on Qualtrics which provided detailed information about the study (Appendix E). Participants then completed a consent form which they signed digitally (Appendix F). After obtaining consent, demographic information was collected from participants (Appendix G). The researcher then arranged a time to complete an interview with each participant. Please see Appendix H for a diagram depicting the recruitment process through to participation in the interview.

Interviews

Initially the researcher had planned to conduct the interviews face-to-face at the NHS services where participants were recruited from or facilities where social groups were held. However, due to government recommendations regarding the Covid-19 pandemic, the interviews all took place remotely. Therefore, semi-structured interviews were carried out with each participant over MS Teams video conferencing platform (see Appendix I for interview schedule). Interviews lasted on average 68 minutes (ranging between 56 and 87 minutes). Participants were paid £10 for participation in the study, with a choice to receive £10 in cash or an Amazon voucher.

To help make the interview schedule more sensitive and accessible to the population being studied, an individual with lived experience of ASD provided consultation. This included providing feedback on the phrasing of the questions being asked and help identifying follow-up prompts to support participants to elaborate on their answers. While the IPA approach requires the questions to be open-ended, the interview schedule also had to consider the communication needs which are a feature of ASD. In line with other qualitative research which has explored the experiences of autistic people, the semi-structured interview included more scaffolding and prompts than might typically be used with IPA (Howard, Katsos & Gibson, 2019). This was believed to be important to help elicit more detail from participants about their experiences.

Ethical considerations

Prior to taking part in the study, participants were given an information sheet detailing the nature and purpose of the research. They were informed that participation was voluntary, and they could withdraw at any stage up until two weeks after their interview had taken place. Written consent was obtained to participate in the study and all participants were deemed to have mental capacity to give informed consent. Given the potentially sensitive nature of some of the interview questions, participants were reminded at the beginning of the interview that they could pause or end the interview at any time. Participants were also provided with relevant support agencies at the end of the interview, including their GP, local mental health, and crisis teams. Participants were informed prior to participating that the researcher had a duty to seek help if the interview revealed significant concerns.

Ethical approval

Initially ethical approval was obtained by Royal Holloway University of London College Ethics Committee in August 2020 (Appendix J). This enabled the researcher to recruit from third-sector organisations. Due to limited uptake of participants using this method of recruitment, NHS ethical approval was sought to widen the pool of potential participants. Brighton and Sussex NHS Research Ethics Committee approved the study in January 2021 (Appendix K-L). Local approval from the participating NHS Trusts was obtained in February 2021.

Data analysis

The data from the interviews were analysed using IPA guidelines outlined by Smith, Flowers & Larkin (2009). Analysis involved several stages. Firstly, all interviews were transcribed verbatim including any notable non-verbal utterances and significant pauses or hesitations. Each transcript was re-read multiple times and line-by-line comments made at the descriptive, linguistic, and conceptual level. Using these comments, emergent themes were developed for each individual transcript (Appendix M). These were then clustered into subordinate themes across the cases, based on connections and patterns identified by the researcher (Appendix N). Further synthesis enabled the subordinate themes to be re-organised into higher-level superordinate themes.

Rationale for IPA

IPA enables a detailed analysis of how individuals make sense of their personal and social experiences (Smith, Flowers & Larkin, 2009). In contrast to approaches such as thematic analysis which looks mostly for trends across cases, the idiographic nature of IPA commits to exploring detailed individual experiences prior to identifying collective experiences. This was thought to be important given the nature of the phenomenon of interest. Grounded theory, a qualitative approach which aims to identify theoretical processes that account for the phenomena being studied (Charmaz & Belgrave, 2007), was also considered for the study.

However, it was believed to be more helpful to gain an understanding first of the nature of the lived experience of autistic fathers before attempting to formulate a theory.

IPA recognises that the analysis includes not only the participants' interpretation of their experiences but also the researcher's interpretation of the participant's account of their experience. This is known as the 'double hermeneutic' (Smith, Flowers & Larkin, 2009). Therefore, the researcher is required to reflect on their own experiences, biases, and assumptions, and how they might impact on the research. It has been argued that this reflexivity helps equalise the power balance between autistic participants and non-autistic researchers (Howard, Katsos & Gibson, 2019). In this sense, IPA was considered a suitable approach to capture the lived experience and perspectives of autistic individuals.

It is also important to consider the ontological stance of the researcher which will inevitably influence their approach to research and the analysis of the data. The current researcher is informed by a critical realist perspective, which is compatible with the philosophical underpinnings of IPA. Critical realism assumes that a 'true' reality can only ever be partially accessed as knowledge is influenced by culture, history, and other social factors (Bhaskar & Hartwig, 2010).

Quality measures

To maintain quality standards, Elliott, Fischer, and Rennie's (1999) publishability guidelines for qualitative research were followed (as outlined in Appendix O). This included the researcher keeping an ongoing reflective journal to help identify assumptions and biases that might influence the research process and analysis (Appendix P). An audit trail was also kept to maintain transparency of the analytic process. Credibility checks included regular consultations with the project supervisors, both who have experience in qualitative analysis and one who works in an adult autism setting. The initial comments and emergent themes for multiple transcripts were checked and discussed with them, included parallel analysis for one excerpt.

Reflexivity statement

The primary researcher is a White British female Trainee Clinical Psychologist with long-standing interests in the experiences of adults with autism and learning disabilities. At the time of conducting the research she was working in an NHS adult autism service primarily providing autism diagnostic assessments and post-diagnostic support. Although the researcher's clinical experience gave her some understanding of the experiences of people with ASD, she was mindful to consider how this experience might influence her objectivity towards the research. Additionally, the researcher is not a parent herself nor on the autistic spectrum. She was careful to reflect on how the differences between herself and the participants in the study could influence the research process and interpretations during the analysis. This reflection was aided by use of the reflective journal and regular discussions with the researcher supervisors.

Contextualising the sample

Nine participants were recruited from third-sector organisations across England (n=4) and NHS adult autism services in London (n=5). Demographic characteristics for participants can be found in Table 6. Six participants were of White British ethnicity, two White Other and one Mixed Asian ethnicity. Five participants were in a heterosexual relationship with their child's partner, one participant was in a same-sex relationship, and the other three participants were divorced or separated. Eight participants lived with at least one of their children either full or part-time.

Table 6: Demographic characteristics of participants

Pseudonym	**Age range**	**Ethnicity**	**Relationship status**	**Age of child(ren)**	**ASD diagnosis in child**
David	51–60	White British	Married	24, 28	No
Martin	51-60	White British	Married	16, 19	Yes
Paul	51-60	White British	Divorced / separated	16, 21, 24, 27, 35 & 38	Suspected but not formally diagnosed
Tony	51-60	White British	Divorced / separated	15, 19	No
Michael	51-60	White British	Married	10	Yes
Stephan	51-60	White Other	Married	12, 35	Currently being assessed
Alex	31-40	Mixed White Asian	Civil partnership	6, 6	No
Markus	31-40	White Other	Married	5, 7	No
Tom	31-40	White British	Divorced / separated	11	Yes

Results

Table 7 outlines the three superordinate themes, made up from twelve subthemes, which were developed from the analysis. The representation of the themes across the participants can be found in Appendix Q with further quotes for each subtheme illustrated in Appendix R.

Table 7: Superordinate themes and subthemes

Superordinate themes	Subthemes
1) The interdependent relationship between autism and parenting	1.1. Parenthood as a catalyst for seeking diagnosis 1.2 Diagnosis enabling understanding and positive change 1.3 Challenging societal narratives 1.4 Family response to ASD: a contrast to the outside world 1.5 The value of shared experiences
2) The family system: a balancing act	2.1 Accommodating conflicting needs 2.2 Parenting together: cohesion and conflict 2.3 Evolving family dynamics
3) Parenthood facilitating reflection and growth	3.1 Impact of own experience of being parented 3.2 Being pushed outside of comfort zone 3.3 Dedication to the parental role 3.4 Rejecting the idealistic image of parenthood

1. The interdependent relationship between autism and parenting

This superordinate theme reflects the fathers' experiences that were specific to being an autistic parent and demonstrates the complex and circular interaction between autism and parenting. Throughout the interviews, fathers made sense of how being autistic may have influenced their experience of parenting and how parenthood interacted with being autistic.

1.1 Parenthood as a catalyst for seeking diagnosis

Six participants reported that the experience of being a parent, or the prospect of becoming a parent, was the reason for considering they might be autistic or provided motivation to seek a formal diagnosis. For three of the fathers their child going through the autism assessment process prompted their own exploration into the diagnosis. They described identifying with traits and behaviours in their child and resonating with information they gathered about autism during this time. For Alex and Markus, the change that having children brought into their lives was initially experienced as distressing. They reported finding it difficult to cope with the increased sensory stimulation and demand for interaction, which led them to consider they might be autistic and provided motivation for them to seek an assessment.

> "*And the reason why I asked for the whole diagnosis was actually the experience of being a father. Because I have a seven and a five-year-old. And they are, err, very lively. And it's just, err, my experience of being so overwhelmed by just the general chatter and, um, shouting and giggling. And, um, I thought this is completely normal for children to behave like that. And there's nothing wrong with that. But I still somehow felt like overwhelmed so many times, like I had to keep leaving the room, and I had to keep asking the children to keep it down. And then I started to think a bit more about it and look a bit more into it. And then I was doing like different, kind of, psychological tests online. And then they all kind of pointed towards autism." (Markus)*

1.2 Diagnosis enabling understanding and positive change

While receiving a diagnosis later in life was often accompanied with mixed emotions, most of the fathers described feeling a sense of relief. The assessment process and subsequent diagnosis had prompted reflection for all participants and helped them to make sense of experiences throughout their lives. For many of the fathers, being diagnosed as autistic enabled a better understanding of why they found some aspects of parenthood challenging. Having a formal diagnosis appeared to empower some of the fathers to acknowledge and make efforts to meet their own needs, which in turn had a positive impact on their wellbeing.

> *"Because before I kind of missed this, sort of, like, excuse to say something. It kind of felt in a way unreasonable to ask the children not to be loud. But now, knowing that, that's why I might be upset and like really like… I mean earlier, I guess I still do it, I take myself out of the situation. And I'd see it as being completely out of control, err, but now it makes me feel a bit more empowered to do, at least smaller, accommodations." (Markus)*
>
> *"I'm just a lot happier, now that I know why this is happening. And what I can do to look after myself." (Alex)*

Two fathers, Tony and Paul, shared feelings of disappointment that they had not been aware they were autistic when their children were younger. Paul wondered if being on the spectrum may have contributed to difficulties in understanding his children's intentions and behaviours, which had been a source of conflict during their adolescent years. While expressing regret at some of his past interactions with his children, Paul had been able to use what he had learned through reflection following his autism diagnosis to make changes in the way he interacted with his grandchildren.

> *"I can't rewrite time, but I try now in my later years as a grandparent not to lose my temper. It's just taken me a long time to realise that my behaviour is not as acceptable as I thought they were." (Paul)*

1.3 Challenging societal narratives

Several fathers commented on how they felt that narratives around autistic people lacking empathy were wrong or too simplistic, sharing examples where they have been emotionally in-tune with their children. Yet at the same time they discussed difficulties in struggling to read others' emotions and portray their own, often attributing this to being autistic.

> *"Lorna is a much warmer, err, person than I am. More emotional projection. Um, I don't do so much emotional projection. Probably because I'm autistic [laughs]." (Martin)*

The inconsistency in their individual accounts suggests an inner conflict for the men in terms of how they viewed themselves in the context of societal narratives around autism. Some fathers spoke about other autistic parents and the compatibility between parenting and being autistic. Markus felt it was necessary to justify that autistic people can make good parents, suggesting that he perceived stigma around parenting on the autistic spectrum.

> *"…if autistic people feel like they want to have children, they shouldn't talk themselves out of it. Because I think a lot of people might do that. And think like oh I will not be able to be a good parent. But I think if people feel like doing it then they should." (Markus)*

1.4 Family response to ASD: a contrast to the outside world

Participants discussed their families' attitude towards ASD and neurodiversity more generally. Most of the fathers described how behaviours or quirks related to their autism were viewed as "*not a big deal"* (Stephan) to their children and were just seen as part of who they are.

> *"Um, I can certainly remember, err, there was an awful lot of good humour about it, in a sense. They knew their father for goodness knows how long, they knew my ways of doing things, my quirks. So, in essence, it was not surprise to them. They certainly didn't say 'Oh my god we have an autistic father, run for the hills!' [laughs]. Um, that definitely wasn't the case. It was more the case, that we looked back at other events that occurred and smiled." (David)*

David's comment about *"running for the hills"* reflects the light-hearted attitude which he valued his daughters having towards neurodiversity. Humour also seemed to serve a function for David in assuaging the stigma associated with autism outside of the family context. Later in the interview, David revealed that a family friend, upon hearing that he had been diagnosed with ASD, suggested to his wife that she divorce him once his daughters left home. Other fathers also shared examples of ignorance and discrimination they had experienced from others outside of the family.

Interestingly, the communication difficulties the fathers experienced with others outside of the family did not feel as apparent with their children. Some of the fathers described a natural ease in the relationships with their children, which contrasted with other relationships where they felt the need to *"perform"* (Alex) or *"read between the lines"* (Markus).

1.5 The value of shared experiences

The fathers who had autistic children described an ability to relate to and understand their children's behaviour. For Michael this helped facilitate connection with his daughter and was different to experiences with others where he had felt unable to relate.

> *"Um, well, I mean particularly with Aoife, actually the autism is a strength because there are occasions where I can relate to what she's doing. Or something she's experiencing. Um, and that was, you know, kind of unexpected. Because unbeknownst to me I had it, there's a reason why I found it difficult to relate quite often to people. You know. Or the experience they were having. And I'd be like 'I don't really get why you feel like this'. Um, so, it was nice to be able to connect quite easily with Aoife about some things." (Michael)*

Martin described how being autistic enabled him to make helpful adaptations to parenting his children who are also on the spectrum.

> *"Because I know being autistic myself, that subtlety is not the answer. If you want to transmit something to a fellow autistic person, I've realised that you have to, as it were, overplay it. So, if I am pleased with the children, I go over the top with congratulating them and um, whatever. I mean it, I would never do it dishonestly! But I know that, um, over-expressing tends to get the message across." (Martin)*

Several fathers also highlighted the value of connecting with other autistic parents, or, for those with children on the spectrum, with other parents of autistic children. This was perceived as valuable as it both normalised their experiences and provided a platform for sharing advice.

> *"Having this peer support is very useful, in a way it kind of removes some of the pressure of why am I not able to deal with this. So, to see that other people are*

> *struggling with that as well. But also, here are some tips how to cope with it." (Markus)*

However, peer support was perceived as less helpful when personal circumstances were unique. Tom, who was separated from the mother of his autistic child, described feeling alone with his struggles despite being connected to other autistic parents and parents with autistic children.

> *"Um, but in all honesty, I don't have, err, that extended network of, you know, other families with similar problems to mine. Because actually I don't know anyone with, um, the sort of, family set-up like mine." (Tom)*

2. The family system: a balancing act

This superordinate theme relates to the interconnectedness of the family system, highlighting that the fathers' experience of parenting cannot be isolated from the context of the whole family. The fathers discussed the challenges of balancing needs and relationships between family members, and how patterns of interacting with one another tended to evolve over time.

2.1 Accommodating conflicting needs

All participants spoke about the difficulty of finding a balance between meeting their family's needs without neglecting their own. For some fathers, their children's innate need for social interaction conflicted with their own sensory processing needs or desire for time alone. This meant that prioritising their children's needs sometimes came as a detriment to the father's mental health. Tom described finding the multiple demands from his son as "*triggering"* and Markus reported that his children's desire to play and socialise with him could be *"overwhelming*". Alex experienced the level of eye contact sought by his children as *"physically painful"*, however had learned to overcome this sensation. Stephan also described having to *"override"* physical discomfort in response to his daughter's affection.

> *"But there are times when I find the physical contact difficult. Like Georgie is demonstrative. And she will want to jump on me or sit on me when we are watching TV. And there are times when I just don't want to have the physical closeness. Which I find perplexing and difficult, but I tend to override it." (Stephan)*

Participants shared strategies that helped them to cope with the increased demand for interaction. Five of the fathers highlighted the importance of having dedicated and regular breaks away from the family setting, which enabled them to be more present when spending time with their children and helped *"prevent meltdown"* (Markus). The fathers also discussed other creative strategies and family routines which accommodated everyone's needs.

> *"We always have dinner together, all of us at the table. But I need to… I can do it for like twenty minutes, and then I have a bean bag just next to the table. So, Papa can go just go and lie down. So, I finish eating for me, and then I lie down next to the table. So, I just need to not look at them. So, I will look outside or at the ceiling, but I'm still there very much. So that's what we do, and they are all absolutely fine with that." (Alex)*

2.2 Parenting together: cohesion and conflict

Unsurprisingly, their partners, or former partners in some cases, had a significant influence on participants' experience of parenting. Several fathers reported that their partners helped them to understand their children better, describing situations where their partners pointed out the, often unintentional, impact of their actions on their children. Their advice was mostly welcomed and could help minimise conflict, although did not always lead to behaviour change.

> *"Erm, because basically if I had a point, I would continually push it push it push it. I didn't really know when to stop. So, Mum would know, she would say, stop, change the subject. And I just, I just wouldn't. Found that difficult." (David)*

Some of the fathers spoke about how their partners' approach to parenting complemented their own, meaning they were able to fulfil different needs for their children e.g., spontaneous vs. directive activities. Most of the fathers reported that they felt less able to provide emotional support to their children compared to their partners, describing a preference to *"want to fix problems straight away"* (Tony) or show care through more tangible means such as cooking. Some of the fathers attributed this to being on the autistic spectrum, whereas for others it appeared to be related to internalised narratives around traditional gender roles within the family.

> *"And, possibly due to my age, but she's a mother and she's naturally better at it (providing emotional support) because she's female." (Paul)*

When approaches to parenting differed significantly to their partners, this could cause conflict and emotional distress. Tom, who separated from his son's mother before his son was born, described how powerless he felt when he disagreed with his former wife's actions towards his son.

> *"And I made some suggestions, but they were quickly dismissed. So, it's not my place to, to tell her. Or to suggest things anymore. So, I don't do it anymore." (Tom)*

2.3 Evolving family dynamics

The fathers discussed relationships between family members and how they changed over time. Those in heterosexual relationships commented on differences they perceived between the mother-child relationship and father-child relationship. Michael described feeling *“outside of the situation”* when reflecting on the first year following the birth of his daughter, conveying a sense of feeling excluded. Paul stated that his children would *“naturally go to their mother because the first thing they learned is Mum”,* suggesting he experienced the bond between mother and child as inevitably superior. In Tom’s case the fraught relationship he had with his former wife appeared to mediate the relationship he had with son.

> *“And that relationship that we had also meant that my relationship with my son was a little bit difficult. And it was things like when am I able to see him. The things that I can do with him. Feeling constantly like I’m being scrutinised for the things that I do with my son” (Tom)*

The fathers also reflected on the uniqueness of their relationships with their children and factors that affected the closeness of the relationship. Participating in activities that were based on shared values seemed to help bring them closer. Physical contact also appeared to facilitate connection and many of the fathers described enjoying moments of physical affection with their children, even if they did not usually enjoy physical contact with others.

> *“Um, I loved the fact that she was so relaxed that she could fall asleep on me. Erm, yeah and I’ve always loved cuddling Lorna and the children. I don’t like to be touched or to be cuddled by other people – but Lorna and the children are different.” (Martin)*

3. Parenthood facilitating reflection and growth

This superordinate theme relates to parenthood being a life-changing experience for all participants, which facilitated on-going reflection and growth as a person.

3.1 Impact of own experience of being parented

Many of the fathers reflected on their own upbringing and the impact it had on their experience of being a parent. For some participants, parenting brought up painful memories of their own childhood including feeling misunderstood by their parents or, in Martin's case, seen as a *"shameful child"*. Having a difficult or distant relationship with their own parents provided motivation for some fathers to actively create a different experience for their children.

> *"….and my Dad was quite distant, not distant distant. But everything around the kids was around my mum. Um, he was sort of there and bringing the money in and doing his job. Um, so yeah, I didn't want to be that I suppose." (Tony)*

In contrast, some of the fathers described modelling their parenting on observations of their own parents. For Paul this felt inevitable, "*you become your parents to a certain extent…",* conveying a perceived lack of agency over his actions.

3.2 Being pushed outside of comfort zone

Most of the fathers described having predictable and comfortable lives prior to children and discussed how parenting had placed them in situations where they felt completely out of their comfort zone. The experiences associated with parenthood could be stressful but were also perceived to develop the fathers' characters in a positive way. Participants described becoming more patient, leaning how to connect to their emotions, and developing their ability to recognise what someone else might need or might be thinking.

> *"But with children there is no question – you have to look after them. It's just, it's non-negotiable. And that is pushing my comfort zone a lot but at the same time, by being pushed there, I slowly built up this ability to, to care. And I think that is really nice to build that side." (Markus)*

3.3 Dedication to the parental role

All participants conveyed how dedicated they were to their children and role as a father. When discussing their strengths as a parent, the fathers spoke about *"absolute commitment"* (Stephan) and how they will *"always be there if they need something"* (David). Martin described a sense of *"duty"* towards his family, the repetition of the word many times throughout the interview highlighting how seriously he took this role.

The focus on their children could also come as a detriment to other aspects of their lives. Tom described how *"it felt like my freedom was taken away"*, suggesting he felt trapped by the responsibility of being a parent. Michael described the impact it had on his relationship with his wife, appearing to find it difficult to integrate the roles of father and husband.

> *"Making space for the couple isn't always something we've found easy. And I expect I haven't always prioritised that in retrospect perhaps as much as I should. I'm not great on putting myself in different roles, if you like, at the same time. So, I probably dropped into being Dad and a bit out of being husband." (Michael)*

3.4 Rejecting the idealistic image of parenthood

Almost all the fathers spoke about how they had come to realise that there is no such thing as a perfect parent or experience of parenthood. For Tom, this realisation initially evoked feelings of disappointment and guilt.

> *"Um, I, you know, very quickly into the parenthood I realised that parenthood isn't that image I had in my mind. The, you know, happy family with the child, and even if the parents aren't together, you can work it. And I felt very disappointed. Because I felt like parenthood was a constant struggle. And I felt very dismayed." (Tom)*

Despite Tom's personal circumstances remaining difficult, he later describes feeling more settled in his role as a father and experiencing pleasure from the growing connection he has with his son. Other fathers also appeared to have adjusted their expectations around parenthood, resulting in a level of acceptance for the range of emotional experiences that accompany parenting.

> *"Err, so it's fantastic, it's fun, it's difficult, it's upsetting. You know, it's a whole mixture of things. It's perplexing. It can be a struggle to find what the right thing to do is, um, sometimes. It seems like you can't do the right thing quite often. Eventually you realise it's not worth worrying so much about that." (Michael)*

When asked what advice they might give to other autistic fathers, almost all participants highlighted the importance of self-compassion. Many of the fathers expressed an appreciation for diverse parenting approaches and styles, perhaps reflecting their own experience of feeling different from other parents.

> *"Because it is different for everybody. There are no two autistic people who are alike. And there are no two parents who are alike. The main thing is to have in your heart, the best of intentions, and the most love for your children. You will make mistakes, you will have successes, that is natural, that is human." (Martin)*

Discussion

This study aimed to provide insight into the lived experiences of autistic fathers, whose voices until this point had been mostly neglected in the research literature. The themes highlighted both universal parenting experiences as well as experiences more unique to being an autistic father.

While not part of the inclusion criteria, the sample ultimately comprised of men who had received their ASD diagnosis later in life, most of whom had sought an assessment because of experiences related to being a parent. Receiving an adult autism diagnosis has been shown to evoke mixed feelings. People often describe a sense of relief as some of their experiences begin to make sense, as well as sadness and loss at having missed opportunities to understand themselves or have others understand them better (Huang, Arnold, Foley, & Trollor, 2020). This range of emotional responses to the diagnosis was mirrored in the fathers' narratives. Their accounts also showed how receiving a diagnosis could help improve relationships within the family and create a more positive experience of parenting, consistent with the experiences of the autistic parents in Burton (2016) and Marriott's (2018) studies. When the diagnosis led to positive change, this appeared to be mediated by multiple factors. Firstly, the diagnosis helped the fathers to understand some of their challenges with parenthood and therefore be less critical of themselves. Secondly, it helped to improve their partners/co-parents understanding of their behaviours and responses to situations, which may have previously been perceived as “*difficult”* (Alex) or *“cold”* (Stephan). This enhanced understanding then enabled strategies to be developed which balanced the fathers’ needs with their family’s needs. Comparatively, those who did not receive a diagnosis until their children reached adolescence, reported more challenges in their parenting experience and relationship with their co-parent. It appears that the diagnostic label was necessary to provide justification for accommodations to be made to meet their needs.

Even when fathers reported better insight into their ASD, they experienced challenges trying to balance conflicting needs in the family. Having to prioritise children’s needs above one’s own is a common experience for parents and is usually assumed to be an inevitable part of parenthood (Lind, Westerling, Sparrman & Dannesboe, 2016). The findings suggest this may have been compounded by the fathers’ ASD. In particular, the men with younger children spoke about the difficulties of managing their own sensory processing difficulties while parenting loud, lively, and physical children. This is comparable to the experiences of autistic mothers, who reported having to supress their own sensory needs to prioritise their children’s (Burton, 2016; Marriot, 2018). Some of the fathers in the study had developed creative strategies that met their children’s need for interaction and physical affection while accommodating their own needs. This is likely to be important for the parent-child attachment and may reduce the likelihood of meltdown or ‘burn out’ occurring for parents (Burton, 2016).

This clash between the fathers’ needs and child’s needs may partially explain why autistic parents report more parenting difficulties than non-autistic parents (Dissanayake et al., 2020; Pohl et al., 2020). Dissanayake et al. (2020) also hypothesise that the difference in reported parenting difficulties could be related to the theory of mind deficit, which might make it harder for autistic parents to instinctively understand and respond to their children.

There was some evidence of theory of mind difficulties in the fathers' accounts of parenting in this study. For example, Paul, reported finding it difficult to comprehend why his children could not remember things that he knew he had told them previously, which could lead to frustration and conflict. Other participants discussed how their partner helped them recognise the impact of their behaviour on their children, suggesting that they were struggling to understand the mental states of their children at times.

On the other hand, many of the fathers actively resisted the idea that they could not empathise with their children. This was consistent with findings from studies on autistic mothers (Burton, 2016). It might be that theory of mind difficulties are less present when parenting due to the familiarity within the parent-child relationship, making it easier for autistic parents to be attuned with their child. Additionally, children's needs may be less complex to recognise and understand, at least when the children are younger. The fathers' comments may also be a response to societal narratives around ASD. The discourse around ASD and empathy is often simplified, with theory of mind difficulties being harmfully misconstrued as an inability to form emotional connections with other people (Loftis, 2015). By questioning the association with ASD and a lack of empathy, the autistic parents may be attempting to challenge messages around autism affecting parenting competence. Several fathers in the study emphasised that autistic people could make 'good parents', suggesting that they were aware of perspectives suggesting otherwise. This is comparable to literature on parents with intellectual disabilities and serious mental illness, which has shown that these parents often feel pressure to prove themselves as competent parents in a society which presumes incompetence (Boursnell, 2007; Symonds et al., 2021; Theodore et al., 2018). Fears of stigma can be a barrier for parents to seek help or disclose parenting concerns (Ackerson, 2003; Boursnell, 2007), so this may need to be a consideration for those working with autistic fathers.

While fathers spoke about stigmatising attitudes from others outside the family, only two fathers shared negative experiences with services. This is a contrast to findings from the studies of autistic mothers, where an overarching theme related to discrimination and stigma they experienced when receiving support from services (Burton, 2016; Marriot, 2018; Pohl et al., 2020; Rogers et al., 2017). An explanation for this difference could simply be that mothers have more contact with services, such as during pregnancy and childbirth, and therefore more direct experience to reflect on. Gender could also factor into their experiences. There is arguably more societal pressure and expectations on mothers to be the "perfect mother" and those who go slightly against the norm may be perceived less favourably (Miller & Tina, 2005). Demographic factors of the sample in this study may also have played a role. Most of the men were from middle class backgrounds and well-educated. One father reflected on his ability to *"navigate the institutional systems"* compared to parents from less privileged backgrounds, highlighting how intersectionality will play a role in people's experiences of parenting and services.

Despite some of the challenges that being autistic brought into their lives, the fathers conveyed acceptance and celebration of their differences. Those with autistic children spoke about their children's behaviours and quirks mostly with fondness and acceptance. They discussed how they could understand and relate to some of their child's more unusual behaviour, consistent with findings in Marriot (2018)'s study which specifically explored the experiences of autistic parents raising autistic children. While accounts of acceptance and appreciation are found in the literature of parents of autistic children in general (Lashewicz, Shipton, & Lien, 2019; Potter, 2016), it may be that having a shared diagnosis strengthened the fathers' ability to empathise with their children above and beyond that of a neurotypical parent. This 'similarity-fit' has also been reported in studies of parents with greater number of ADHD symptoms who have a child with ADHD (Johnston, Williamson, Noyes, Stewart, & Weiss, 2016).

The value of shared experiences was also evident when the fathers discussed support they had received for parenting. The NHS service where five of the fathers were recruited from had set up a peer support group for autistic parents. This is a relatively unique group and is not a usual component of autism services across the UK, whose main priority is to provide assessment and diagnosis (NICE, 2012). All bar one of these fathers commented on how valuable they experienced this support, which helped normalise challenges they were experiences and provided a platform to share coping strategies. In addition, participants reported connecting with other autistic adults via online forums. Given that autistic individuals often report feeling misunderstood or even at times 'on a different planet' to neurotypical people (Müller, Schuler & Yates, 2008, p.179), it is unsurprising that the fathers sought a community of people they can relate to. Peer support seemed to help the fathers to feel less isolated, which may be especially important for those newer to parenting, given that the adjustment to fatherhood can be an isolating experience (Chin, Hall, & Daiches, 2010).

The findings also highlighted the significant influence of the father's partner/co-parent on their parenting experience. According to Bowen's family systems theory (cited in Brown, 2013), an individual cannot be understood in isolation but rather in the context of their family, whose experiences and behaviours are all interconnected. The interconnectedness of the family network was evident in the fathers' accounts of parenting. For the fathers who reported difficult relationships with their partners/co-parents, this impacted negatively on their mental health and could subsequently influence the closeness they experienced in their relationships with their children. When partners were understanding and accommodating to their needs, this improved the father’s psychological wellbeing and made family life a more rewarding experience for them.

The fathers discussed their roles and position within the family. Most of the fathers shared examples of providing hands-on care for their children and expressed a desire for equality in parental duties, consistent with more modern views around fatherhood (Miller, 2010; Schoppe-Sullivan & Fagan, 2020). Some of the fathers spoke about a natural division in responsibilities that had come about between them and their partners, which factored in their strengths and needs associated with ASD. It is possible that societal beliefs and expectations around gender roles may have also contributed to the separation of responsibilities. Interestingly, the narrative around being worse at providing emotional support appeared less present in the interviews with Stephan and Tom, who both had experience of raising their children as a single parent, and with Alex, who was in a same-sex relationship. Providing emotional support is traditionally associated with motherhood (Miller, 2005), so perhaps without a female parent present to provide this support the fathers felt more able to fulfil this role for their children.

For some of the fathers, societal constructions around gender roles could have a negative impact. One father, Tom, described the emotional turmoil he experienced when he was unsure how much contact he would be able to have with his son upon separating with his son’s mother. He reported feeling dismissed when he shared concerns to social services about the parenting practices of his former wife. Tom’s narrative resonates with accounts from fathers with learning disabilities (Dugdale & Symonds, 2017) and fathers with serious mental illness (Reupet & Maybery, 2009), suggesting that there are biases held by professionals and services which assume that the mother is the ‘primary caregiver’.

While there were differences in the approaches that participants took to parenting, a key theme that was evident throughout the fathers' accounts of parenting was a sense of duty and commitment to their children. The literature on fatherhood suggests that a fathers' desire to "be there" for his child is universal, transcending ethnicity, class, culture, and age (Miller, 2010). This dedication could lead to distress for some of the fathers when they felt unable to fulfil this role. It also provided motivation for the fathers to approach situations they would usually avoid if they felt it would benefit their child. This demonstrates the fathers' commitment to parenting and highlights the importance of services adapting their practice to meaningfully include fathers in parenting interventions.

Strengths and limitations

To the best of the author's knowledge, this was the first study to specifically explore the experience of parenting from the perspective of autistic fathers. The approach chosen (IPA) may be considered particularly suitable to elicit in-depth information about this novel topic. Milton (2012) argues that the way that autistic people communicate, experience emotions, form relationships and make sense of the world, is so different to non-autistic people that it can make it difficult for either to truly understand one another. He terms this the 'double empathy problem' and discusses the issues that can occur when non-autistic people conduct research on the autistic population. IPA is thought to address the double empathy problem somewhat, as the concept of the double hermeneutic openly acknowledges the limitations in trying to fully understand the inner world of another (MacLeod, 2019). Having an autistic man involved in the development of the interview questions may have also mitigated some of the challenges in understanding and helped participants to communicate their experiences.

There are also some limitations to the study. While the 'outsider' position of the researcher as a neurotypical woman without children may have enabled more objectivity at times, it could also have meant that some of what the participants were communicating about their experiences was misunderstood or interpreted inaccurately. Credibility checks with some of the men who partook in the study had been planned to help to mitigate this, however ultimately time constraints on the study meant this did not happen.

Furthermore, the sample size for the study was small which makes it difficult to generalise the findings. While it is estimated that approximately half of autistic people will have a comorbid learning disability (Centers for Disease Control and Prevention, 2014), fathers with learning disabilities were not included in the study. This was because it was anticipated that a comorbid learning disability could affect the experience of parenthood significantly. Unfortunately, this means that the findings may not be as applicable to this population of autistic fathers. In addition, the sample was made up of predominantly middle-class Caucasian men which limits the generalisation of the findings outside of this population, as the cultural context of participants will inevitably influence their accounts of fatherhood.

The upper age limit for the participants' children was set as twenty-five aiming to balance the need for parenting experiences to be relatively recent with the accessibility of participants. However, this meant that the ages of participants' children varied quite significantly therefore challenging the homogeneity required for IPA. While themes that developed individually were not drastically different depending on the children's age, it may have been more difficult for participants with children in their twenties to accurately recall experiences of parenting a younger child. There are also likely to be experiences unique to parenting a teenager which the fathers with younger children would not be able to comment on. Additionally, some of the participants were raising autistic children and others were not. While the heritable nature of ASD means that the sample is representative of autistic fathers’ context, caring for an autistic child comes with unique experiences and challenges.

Implications for clinical practice

The findings from the study have several implications for services and professionals working with this population. Firstly, they emphasise the need for increased recognition of ASD in parents and earlier diagnosis in general. This could improve autistic parents’ understanding of themselves and understanding from their partners/co-parent, thereby improving relationships within the family. Earlier diagnosis may also help parents to access appropriate support before difficulties arise or escalate.

The findings hold implications for post-diagnostic support offered to fathers following an autism diagnosis in adulthood. For autistic fathers who are struggling to cope with some of the demands associated with parenthood, post-diagnostic support could be used to explore how ASD interacts with their parenting and to develop strategies to manage when there are conflicting needs. It may be beneficial for partners to be involved in these sessions, as the accounts from participants show how partners’ responses are crucial in supporting positive changes within the family.

The value of peer support for autistic parents is clear from this study. NHS autism services or third sector ASD organisations could offer this type of support in a formalised manner i.e., facilitated peer support groups, or by simply providing a means for autistic parents to connect. Given that autistic people, including most of the fathers in this study, report finding it hard to maintain long-term relationships with others, it may be helpful for services to support ongoing contact.

Lastly, in line with current guidance which emphasises a whole family approach, the findings of this study highlight the importance of ensuring fathers’ voices are equally heard in discussions regarding their children’s care. Health and social care services working with children with autistic fathers should adapt interventions to meaningfully involve the fathers, considering their strengths and needs.

Future research

Considering one of the limitations to the current research included the varied ages of the fathers’ children, future research may wish to include autistic fathers with children of a similar age. It may be useful to focus on fathers’ experiences of parenting younger children and the transition to parenthood, seeing as the findings from this study suggest that this could be a more challenging time for autistic fathers. Additionally, the findings have highlighted how family members’ experiences are all interconnected. It may therefore be helpful to explore the perspectives of other family members when there is an autistic parent in the family, such as the partner or child themselves. This could provide further information for services providing support to these families. Finally, larger-scale quantitative research may also be useful to map the population of autistic parents in the UK, considering this information is unknown at present.

Conclusion

This study provides important insight into the lived experience of autistic fathers. Throughout the interviews the fathers demonstrated how much they valued their role as a father and how dedicated they were to their children. For some fathers, being autistic appeared to make aspects of parenthood more challenging, such as balancing their sensory needs with their children's need for interaction. The fathers' partners or co-parents were an important factor in their experience and could mediate the closeness of the fathers' relationship with their children. Receiving a diagnosis of ASD was found to improve understanding and enable accommodations to be made across the family, highlighting the importance of increased recognition of ASD in parents. Other implications from the study include the importance of peer support being accessible for autistic parents and a need for services to better involve fathers in parenting interventions. Future research could include focusing on autistic fathers' experience of transition to parenthood. It may also be helpful to explore the perspectives of other family members, such as partners or children.

Chapter 3. Integration, Impact and Dissemination

This chapter presents an integration of the findings from the systematic review and empirical study, discusses the potential real-world impact of the research, and outlines steps to disseminate the findings. It also includes further reflections on the development and implementation of the research.

Integration

Research interests and choice of topic

My interest in the topic of autistic fathers initially grew from an interest in the experiences of people with learning disabilities and autism, having worked in this area prior to starting my training in Clinical Psychology. I also have a general interest in parenting and attachment, specifically the experiences of parents from marginalised groups. My field supervisor, Dr Elizabeth Kock, informed me she had observed a growing number of parents being referred to her service, an adult autism assessment and diagnostic clinic in London. As part of the service provision, those who receive a positive diagnosis are offered post-diagnostic support which includes signposting to relevant resources considering their personal context. For the parents who were subsequently diagnosed with ASD, Dr Kock said she had been struck by how little information or resources there was available on parenting for those on the autistic spectrum. Knowing that there was a clinical need encouraged me to explore the research literature. While I could find an abundance of information on the experiences of parents of autistic children, I was also struck by how little research there was on parents who had a diagnosis of autism themselves. I was aware of the heritable nature of ASD and wondered why these parents' voices were not being heard in the literature. I also noticed a gender bias in the limited research on the topic, with fathers being noticeably absent from around half of the studies. I therefore thought that exploring the experiences of autistic fathers would both contribute to the literature base and hopefully have some clinical implications for services who work with these parents.

In terms of selecting a topic for my systematic review, it felt like an obvious choice to establish what the existing literature could tell us about the experiences of autistic parents. I knew from my initial literature searches that there was likely a limited number of studies, which is why I chose to include studies on both mothers' and fathers' experiences. The lack of research available also influenced my decision to include both qualitative and quantitative designs in the review.

Choice and development of study design

As a trainee clinical psychologist, I am naturally curious about how people make sense of their personal and social experiences. Qualitative approaches interest me as they enable richer insight into someone's inner world than quantitative approaches typically allow. Reading about 'the double empathy problem' by Milton (2012) made me reflect on how many of the tools used in autism research have been developed by neurotypical researchers. Given that autistic people are believed to experience the world in a very different way (Loftis, 2015; Milton, 2012), I started to wonder how accurately some of the tools used in quantitative research can capture the experiences of autistic individuals or how much information they truly provide about their experiences. I felt that a qualitative approach had more capacity to enable the voices of autistic people to be heard without making assumptions about their experiences. I also felt that this was particularly important given the scarcity of research out there on autistic fathers.

Prior to this study, I had limited experience in conducting qualitative research, having only previously used thematic analysis (Braun & Clarke, 2006). Upon learning more about the theoretical underpinnings of both approaches, I could see some similarities between thematic analysis and Interpretative Phenomenological Analysis (IPA). Both approaches are informed by critical realism (Bhaskar & Hartwig, 2010), which resonates with my own ontological position. Yet, I was intrigued by the higher-level of interpretation and attention to detailed accounts of individual cases that IPA offers. I felt that IPA was compatible with the aims of my research and that the idiographic nature of the approach would be beneficial given that ASD can affect people in a varied way.

While I was aware of the possible advantages of IPA to shed light on the personal experiences of autistic individuals (MacLeod, 2019), there were some aspects to the approach that I felt worked less well with this population. When I initially consulted with an Expert by Experience, an autistic man, his main feedback regarding the interview schedule was that some of my participants may find the open nature of the questions difficult to answer. IPA requires questions to be open and non-leading (Smith, Flowers & Larkin, 2009), so I had to consider carefully how to balance the communication needs of my participants with the principles of the approach. Given what I had read about the limitations of autism research and the use of inappropriate or inaccessible methods of data collection (MacLeod, 2019), I felt it was important to adapt my interview schedule to be as accessible as possible. The Expert by Experience helped me to identify follow-up prompts to questions, which I could use to support participants to elaborate on their answers or steer them back on track if they went off-tangent from topic. I was very grateful for his input into the interview schedule as the prompts elicited details that I would not have been able to get from participants otherwise.

Challenges and reflections

The main challenge of conducting a mixed-method review was trying to meaningfully integrate the findings from the qualitative and quantitative studies. I found this difficult as parenting is a broad concept with many different elements that factor into the experience. There were also some benefits from the review being mixed methods. The themes which emerged from the qualitative studies could offer potential explanations for findings from the quantitative studies, for example why autistic parents scored higher in parenting difficulties than non-autistic parents. Additionally, some of the findings in the larger-scale quantitative studies appeared to back-up the detailed experiences in the qualitative studies, such as the increased likelihood of negative experiences of healthcare services for autistic mothers. The findings from the review also strengthened the rationale for my empirical study, considering how few studies were identified, the underrepresentation of fathers, and the observation of possible gender differences in parenting experiences between autistic mothers and fathers (Lau et al., 2016; Van Steijn et al., 2014).

Given that the topic of the systematic review and the empirical study are directly linked, I tried to be mindful that the findings from the review did not influence the way that I analysed the fathers' interviews. While the double hermeneutic in IPA acknowledges that the researcher will inevitability influence the data, it is still important to attempt to 'bracket' one's own assumptions and biases during the analysis (Smith, Flowers & Larkin, 2006). Keeping a reflective journal helped me to notice when I was making assumptions or leaps from the data, based on the findings from the systematic review.

As the systematic review included studies on both mothers and fathers, there were some findings from the review that were gender-specific and therefore less relevant or applicable to the population in my study. There were also many commonalities across the findings from the systematic review and empirical study. I was particularly intrigued by the fathers' resistance to the idea that they could not empathise with their children, which resonated with the mothers' accounts in the qualitative studies in the review. This challenged some of my assumptions around autism and parenting, as I had anticipated that difficulties in recognising and understanding others' feelings and intentions associated with ASD would extend to the parent-child relationship. It also made me reflect on societal narratives and misconceptions around autism and the impact that this may have on autistic individuals. I am, however, aware the studies are only exploring the perspectives of the autistic parents and it is possible that findings may be different if other family members shared their experiences.

While the participants all shared the unique phenomenon of being autistic and a father, there was significant variation in their accounts of parenting. A challenge that I experienced when developing the superordinate themes in the empirical study was trying to meaningfully synthesise the diverse experiences of the fathers, without neglecting important individual experiences. Reading examples and illustrations of the analytic process in Smith, Flower and Larkin's (2009) book on IPA helped me understand how connections across themes could occur in different ways, such as searching for similarities in the function of behaviours/thoughts or noticing oppositional relationships. I found that as the analytic process went on, I started to notice more connections and patterns across the individual transcripts and then across cases, which may have been initially difficult to recognise. What I learned from attending a workshop on IPA was also extremely valuable during this analysis stage.

Throughout the research process, I reflected on my own position as a researcher and on the differences between myself and participants. The main differences aligned with the phenomenon I was studying. My participants were all male, autistic, and a parent, whereas I am female, I am not autistic, and I am not a parent. I viewed these differences as both an advantage and a disadvantage. On one hand I wondered if I might be more objective during the analysis as my own lived experience of the phenomenon could not bias the interpretations. On the other hand, I wondered if I might be misunderstanding the intention of what the fathers were saying or attributing some of their experiences to being autistic when they were a common experience of being a parent/father. I found that writing the reflective journal and meeting with my supervisors to discuss the initial coding of some of the transcripts was helpful in exploring these issues. Reading literature on masculinity and fatherhood helped me to better understand differences in societal expectations between men and women and their roles within families.

Additionally, while I was conducting this research, I was on placement in an adult autism assessment and diagnostic clinic. While I had worked clinically with autistic individuals prior to this placement, most of this experience had been in learning disability settings. This experience on placement was helpful for my research as I developed a better understanding of ‘high-functioning’ ASD beyond the theoretical knowledge I held about ASD. I also felt more confident at adapting my communication to elicit information from people with different communication needs, which was useful for conducting the interviews. I was however aware that the autism assessment and diagnostic process is influenced heavily by the medical model, and that I was being trained to focus on the negative impact that ASD can have on someone’s life as opposed to more of a holistic picture. I tried to ensure my biases and assumptions that may have arisen from working in this setting did not influence the interview and analysis process.

Impact of Covid-19

I anticipated that autistic fathers might be a difficult population to reach, so I initially planned to recruit from third-sector organisations and NHS autism services. When the Covid-19 pandemic started to significantly affect the UK in March 2020, I changed my plan and decided to recruit solely from the third sector. My supervisor and I made this decision as we were aware that NHS research ethics committees were understandably prioritising Covid-19 related studies and believed that it would be better to focus the recruitment strategy elsewhere. While recruitment from the third sector appeared initially successful, with four fathers getting in contact immediately after I had circulated the advert to group facilitators, the recruitment came to a quick halt. Further attempts to advertise through the third-sector were unsuccessful, so I decided to apply for NHS ethics as I was concerned that I would not reach my proposed sample size. This meant that recruitment was delayed and the time schedule for the project had to be pushed back. Unfortunately, this had a knock-on effect and, due to time constraints, I was not able to consult with participants about the themes that had been developed from my analysis, which I had initially planned to do as part of the credibility checks. Credibility checks are important to help improve the quality of qualitative research (Elliot, Fischer, & Rennie, 1999). While my supervisors provided credibility checks, it would have been advantageous to have the input of autistic fathers, especially given my own position of being a neurotypical female researcher without children.

Covid-19 also meant I had to change my interviews from being conducted face-to-face to remotely via video call. Initially I was concerned that this would affect the rapport I could build with participants which may in turn affect the richness of the data. However, I felt that the interviews ran smoothly, other than a few connection issues, and that participants were able to share their experiences in sufficient detail. I also wonder whether it may have been beneficial for some participants to do the interview in the familiarity of their own home, given that autistic people can find novel social situations anxiety-provoking (Robertson et al., 2018).

Impact

The 2014 Research Excellence Framework defines impact as “An effect on, change or benefit to the economy, society, culture, public policy or services, health, the environment or quality of life, beyond academia” (Penfield, Baker, Scoble, & Wykes, 2014). Prior to and throughout completing this research, I considered the potential academic impact and real-world implications of the findings. Harper, Maden and Dickson’s (2020) Evidence of Impact Model outlines five levels across the societal system in which qualitative research can have an impact (Figure 2). I will use this model as a framework to discuss the potential implications of the systematic review and empirical study across the different levels.

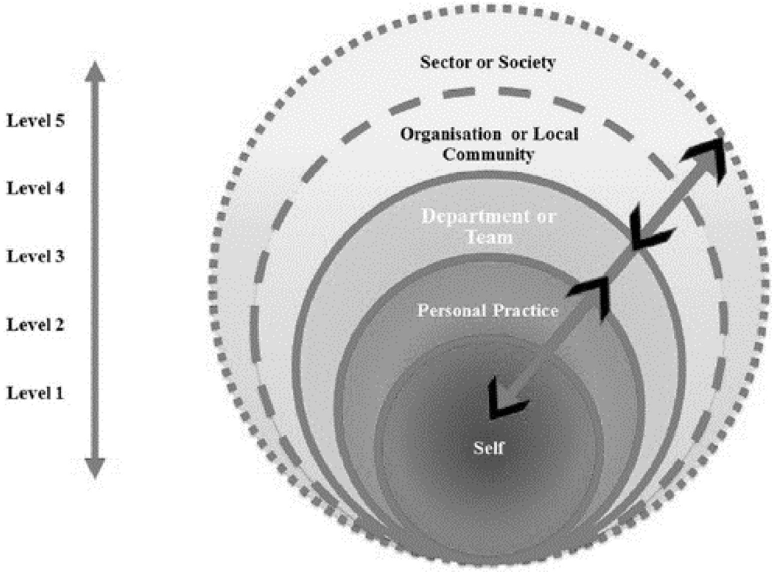

Figure 2: A visual representation of The Evidence of Impact Model (Harper, Maden & Dickson, 2019)

Level 1 & 2 – Self and Personal Practice

Levels 1 and 2 of the model relate to the impact of research at the microlevel of individuals. One of my main motivations for conducting the study originated from the few accounts from autistic parents about their experience of parenting. These parents appeared to interpret the lack of information and resources for autistic parents as a sign that parenthood is somehow incompatible with autism, and reported feeling isolated with their experiences (Grant, 2015; Martin, 2020; Rudy, 2020). On an individual level, I hope that the findings from the review and from the study can demonstrate to autistic parents that they are not alone and help to normalise some of their experiences. The findings from the empirical study showed how the fathers' experiences and attitudes towards parenthood changed over time, often for the better, which may provide reassurance and hope to autistic fathers who are finding aspects of parenthood challenging. I also hope that the findings can provide information and reassurance to autistic men who are considering becoming parents, or those who are about to become new parents.

The findings may also be of use to autistic fathers' support networks, including partners and co-parents, by providing understanding and insight into the fathers' experiences of parenting and more generally family life. The fathers' accounts in the study showed that better understanding from partners/co-parents could help to facilitate positive changes in how the family relates to one another, so this could benefit all family members.

Levels 3 & 4 – Department or Team, and Organisation or Local Community

Levels 3 and 4 of the model are concerned with the impact of research at the meso level i.e. the implications for the teams, organisations and local communities that surround the individual. The findings from both papers offer helpful knowledge for a range of health and social care professionals and services working with autistic parents. This includes practical recommendations for maternity services on how they could improve the care they offer to expectant autistic mothers as well as considerations for those implementing parenting interventions when one of the parents has autism.

The findings also provide insight for professionals working in autism diagnostic services. They highlight the importance of exploring the interaction between autism and parenting after parents are diagnosed with ASD. I also hope that this research will encourage professionals working in adult autism services to think more systemically and consider inviting partners/co-parents to post-diagnostic support sessions. Furthermore, the findings from the empirical study have demonstrated the value of peer support for autistic parents. Hopefully, this can provide further justification for NHS services and ASD organisations, such as the National Autistic Society, to offer this type of support. Peer support or self-advocacy groups may help to address some of the internalised stigma some autistic parents feel. Peer support may also be beneficial for services as it is often more sustainable long-term and less resource-heavy than other interventions (Solomon, 2004).

Finally, the findings from both the systematic review and empirical study clearly emphasise a need for earlier recognition of ASD. At Levels 3 & 4, this would mean health and social care professionals having a greater awareness of how high-functioning ASD can present and feeling confident enough to broach the subject of a referral for an autism assessment with service users they think could be on the spectrum. This may be particularly important for professionals working with autistic children, given the known genetic link and the accounts from parents in the systematic review and empirical paper who sought their own diagnosis after their child was diagnosed.

Level 5 – Sector or Society

Level 5 relates to the impact at the macro level which considers how research can influence the wider society. Findings from both the systematic review and empirical study have the potential to inform professional guidelines and national policies, as well as societal and cultural attitudes towards ASD and parenting. Currently the NICE guidelines (2012) relating to the diagnosis and management of autism spectrum disorder in adults state that “local care pathways should promote access to services for all adults with autism, including parents with autism” (NICE, 2012, p.34). The findings from the two papers provide information on how local care pathways may be able to improve the accessibility of services for autistic parents, which is also in keeping with current legislation such as The Autism Act 2009 and The Equality Act 2010. This is likely to include access to specialist training and education for professionals who work with autistic parents.

Regarding wider societal implications, the findings from both papers indicate that more needs to be done to reduce stigma associated with ASD. This research may contribute to reducing stigma by improving awareness of autistic parents’ experiences and challenging misconceptions around the ability of autistic individuals to form strong emotional connections with others (Loftis, 2015). Reducing stigma could encourage autistic parents to seek help with parenting concerns earlier, which may reduce the impact on services in the long-term. Tackling stigma at a societal level requires societal and cultural attitudes around ASD and neurodiversity to shift. This could be achieved through media channels including campaigns and better representation of autistic people, including autistic parents, in the media. Media representation may also help with earlier recognition and diagnosis of autism, by improving public awareness.

Dissemination

For research to have an impact, it is important that the findings are effectively disseminated. This includes reaching and engaging the audiences which may benefit from the research. I am currently in the early stages of dissemination of the project. So far, the findings from the empirical study have been shared with staff and students at Royal Holloway, University of London via remote presentations. Discussion that followed this presentation was helpful in considering the limitations of the study as well as possible clinical implications.

I have plans to disseminate the findings of the study further. Firstly, participants will be sent a copy of the lay summary of the findings. As outlined in my proposal, one or two of the participants that expressed interest in being involved in consultation for the project will be asked to provide feedback on the lay summary. This will hopefully help to improve the accessibility of the summary to the autistic population, including the target audience of autistic fathers. This may include making the summary more visual and concise i.e., identifying the key messages.

I will share the updated lay summary with the peer support group for autistic parents facilitated by one of the NHS services. I hope that the parents may have further ideas on where to disseminate the findings to reach a wider audience, specifically other autistic parents. This may include sharing a link to the summary on social media platforms, such as Twitter, and online communities for autistic adults. I also plan to post a link to the summary on the research forum on the National Autistic Society website. I believe that reaching other autistic parents is particularly important given that many of the existing blogs or accounts from autistic parents highlight that they cannot find much information about the topic online.

I have arranged to present the findings of the study in one of the monthly multi-disciplinary team meetings at the NHS autism service where I recruited some of my participants. I plan to use some of this time to explore with the team how the findings could be used to improve how services can support autistic parents, specifically those who may be struggling with aspects of parenthood. I anticipate that their expertise of the MDT will be particularly valuable when thinking about the clinical implications of the study. Following this meeting I plan on creating a document which includes these recommendations, which can then be disseminated to other services that come into contact with autistic fathers, including adult autism services as well as children's services.

I have also arranged to present the research findings at Central London Community Healthcare NHS Trust annual research conference, which will include an audience of academics and healthcare professionals.

So that the findings can be disseminated to an academic audience, the study will be prepared for publication and submitted to relevant journals. The journals will be selected based on their topic i.e. autism journals, their reputation and impact factor, and receptiveness to qualitative research. The journal which I will first attempt to publish with will be Research in Autism Spectrum Disorders.

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Appendices

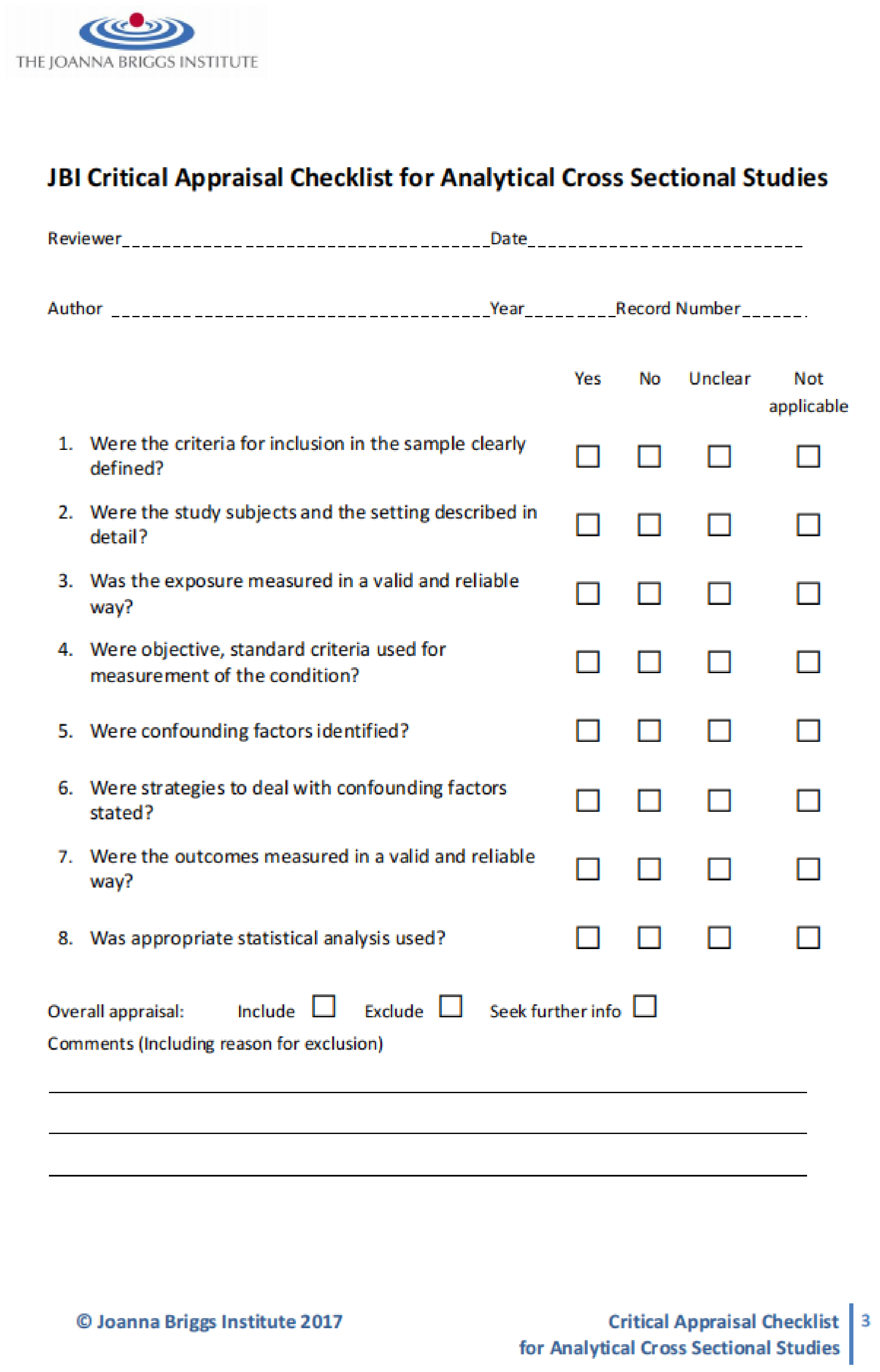
Appendix A: Search terms for literature search

(perinatal OR postnatal OR postpartum OR pregnan* OR childbearing OR parent* OR mother* OR father*)

AND

(autis* OR ASD OR asperger* OR neurodevelop*)

Appendix B: Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Analytical Cross-Sectional Studies



THE JOANNA BRIGGS INSTITUTE

JBI Critical Appraisal Checklist for Analytical Cross Sectional Studies

Reviewer______________________________________Date___________________________

Author ____________________________________Year_________Record Number______

	Yes	No	Unclear	Not applicable
1. Were the criteria for inclusion in the sample clearly defined?	☐	☐	☐	☐
2. Were the study subjects and the setting described in detail?	☐	☐	☐	☐
3. Was the exposure measured in a valid and reliable way?	☐	☐	☐	☐
4. Were objective, standard criteria used for measurement of the condition?	☐	☐	☐	☐
5. Were confounding factors identified?	☐	☐	☐	☐
6. Were strategies to deal with confounding factors stated?	☐	☐	☐	☐
7. Were the outcomes measured in a valid and reliable way?	☐	☐	☐	☐
8. Was appropriate statistical analysis used?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

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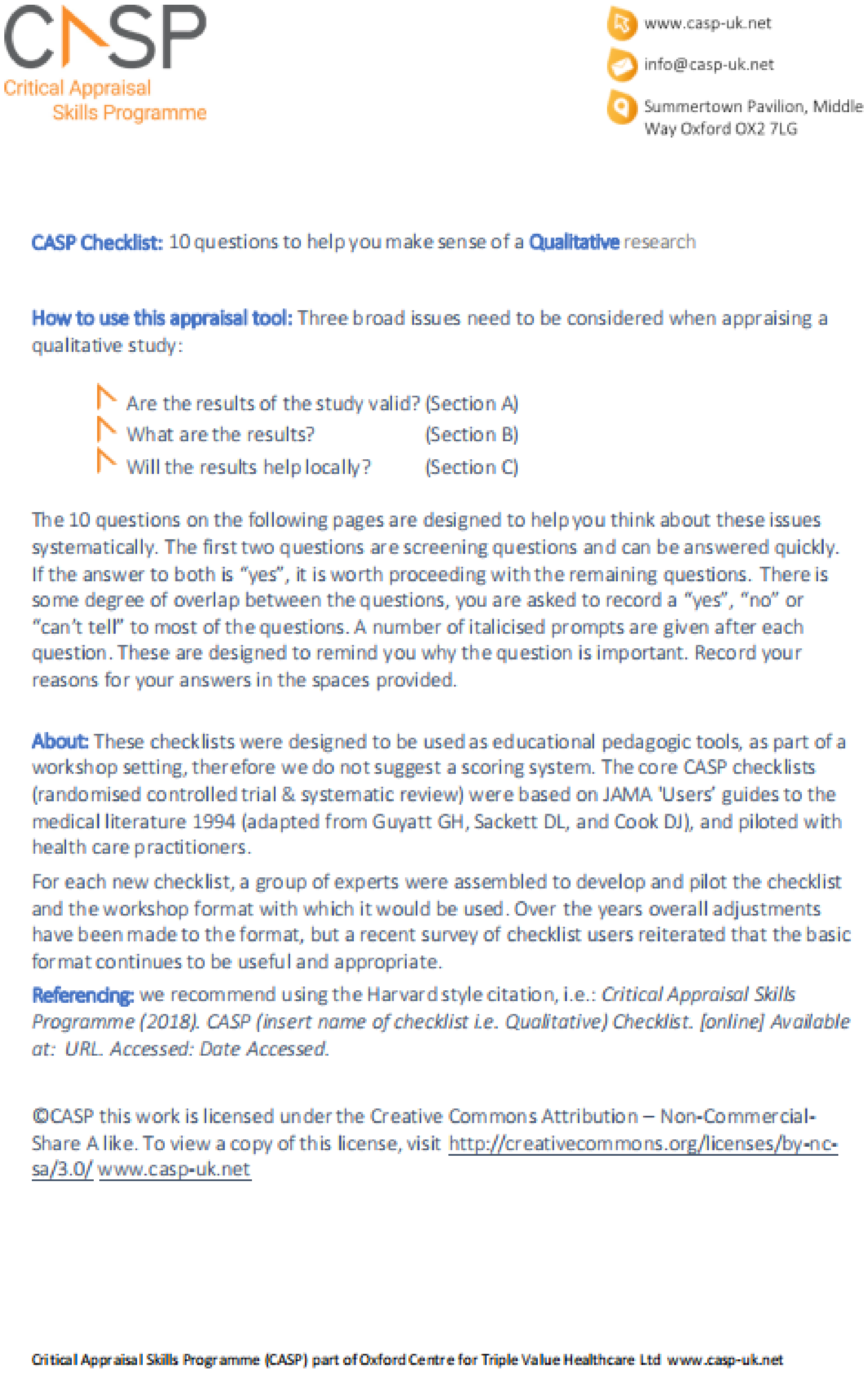
Critical Appraisal Checklist for Analytical Cross Sectional Studies | 3

Appendix C: Critical Appraisal Skills Programme (CASP) checklist



CASP
Critical Appraisal
Skills Programme

www.casp-uk.net
info@casp-uk.net
Summertown Pavilion, Middle
Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

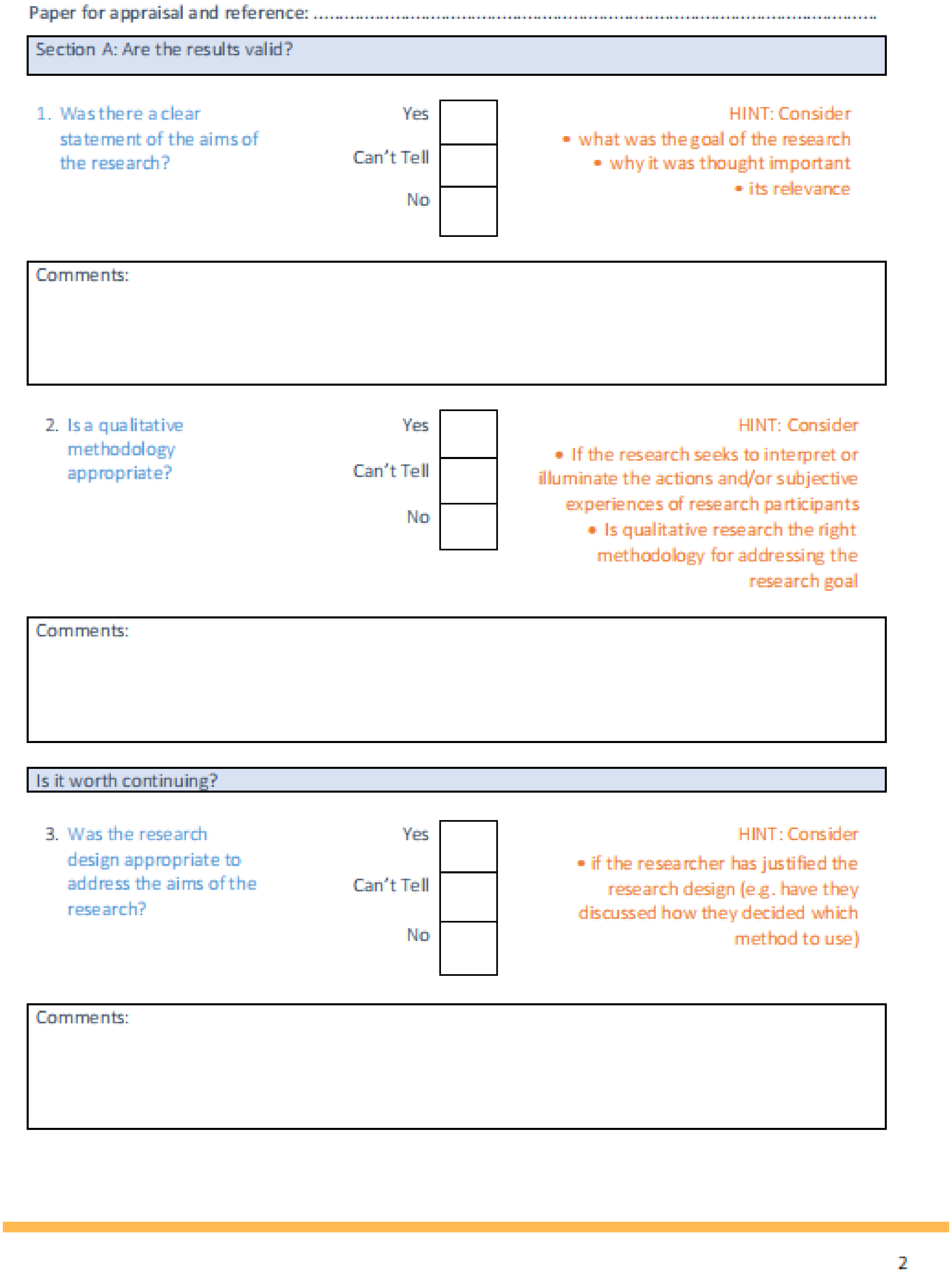
- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*



Paper for appraisal and reference: ……………………………………………………………………………………………

Section A: Are the results valid?

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

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

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

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

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

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider

- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:

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

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

Appendix D: Study advert

Are you a father with autism?

Would you like to share your experiences of parenting?

We are looking for autistic fathers to take part in a study exploring their experiences of parenting. This study is part of a Clinical Psychology Doctorate and has been reviewed and approved by the Department of Psychology Ethics Committee at Royal Holloway, University of London.

Who can take part in the study:

✓ People who are 18 years or older
✓ Someone who has had a comprehensive autism assessment and was given a clinical diagnosis of Autism Spectrum Disorder
✓ People who are a father to a child(ren) or young adult
✓ People from all backgrounds who can speak & read English

Who can't take part in the study:

✗ People who are currently under the care of a psychiatrist

What will taking part involve?

Taking part will involve an interview where you will be asked questions about your experience of being a parent. This will take about an hour and be over a video call. You will receive a £10 voucher for your time.

How can I be involved?

If you are interested in taking part and are happy for the researcher to contact you about the study, please leave your contact details below. The researcher will then arrange a time to answer any questions you have and ask a few screening questions to make sure you are eligible for the study. If you are not eligible, your contact details will be deleted.

Name: Phone number:
Email:
Preferred method of contact (email/phone):

If you have any questions or would like more information about the study, please contact the researcher:

Name: Amelia Turner, Trainee Clinical Psychologist Email: amelia.turner.2018@live.rhul.ac.uk

Thank you for your time.

Appendix E: Participant information sheet

Department of Psychology
Royal Holloway, University of London
Egham TW20 0EX
Tel: 01784 414012
Email: amelia.turner.2018@live.rhul.ac.uk
Web: https://www.royalholloway.ac.uk/

INFORMATION SHEET

Exploring the Parenting Experiences of Fathers with Autism

My name is Amelia Turner and I am a Doctoral student at Royal Holloway, University of London. I would like to invite you to take part in a research study. Before you decide, it is important you understand why we are doing this research and what taking part will involve.

What is the project about?

The research study is about the experiences of fathers who have a diagnosis of Autistic Spectrum Disorder (ASD). We are interested in hearing from autistic fathers about how they may experience different aspects of parenting. We hope that this research will help professionals to understand the experiences of autistic fathers better.

What will taking part involve?

If you decide to take part in the study, you will be directed to a page which will ask you to input some details about yourself. The researcher will then arrange a time to have an interview with you over Skype or MS teams. The interview will last about an hour. During the interview you will be asked about your experience of being a father and about your relationship with your child(ren). A tape recorder will be used to record the interview. You will be compensated £10 for your time, either in cash or an Amazon voucher.

What happens after the interview?

After 8-10 fathers have been interviewed, we will analyse the findings and write them up into a report. If you are interested in hearing about the findings, we will send you a summary of the findings.

How will my information stay confidential?

None of your information will be passed on to any of your friends, family or other professionals. Only the researcher and the project supervisor will know who you are. Audio recordings will be deleted as soon as the interview has been typed up. Your typed-up interview answers will be stored without your name on them. The interview transcripts and the demographic information you provide will be stored on a password-protected computer which only the researcher has access to.

The research is being conducted as part of a Doctorate in Clinical Psychology at Royal Holloway, University of London. We expect that information gathered from this study will be presented in scientific meetings and published in a journal. We will let people know some of what was said in the interviews, but not who said it. Your identity will be kept private and any names or recognisable information will be changed. Any personal details, such as your name and address, will be destroyed once we have fed back the findings of the study to you.

When might confidentiality be broken?

The only time where we may need to tell someone else what you said, such as another professional, is if we are worried that you or someone else might be at risk of serious harm. In this instance, we will let you know first if we need to speak to someone.

What are the advantages and disadvantages of taking part?

It is important to give you all the information you need so you can decide if you would like to take part. Here is a list of possible advantages and disadvantages of taking part.

Possible advantages: Some people find it enjoyable and useful to talk about their experiences with someone who is interested and good at listening. It is also an opportunity to contribute to research which may help other people, such as professionals, to understand the experiences of parents with ASD better.

Possible disadvantages: There are no physical risks from taking part, however we recognise that parenting can be a sensitive topic for some individuals. If you should become upset during the interview for any reason, you can ask to stop without giving a reason. If you need additional support, we can refer you to a relevant service.

Do I have to take part?

It is completely up to you to decide whether you would like to take part in the study. If you do agree to take part, you can change your mind at any time. You also have the right to withdraw your data up to one month after completing the interview. However, your data cannot be withdrawn once the doctoral thesis has been completed.

Who has reviewed the study?

Research Ethics Committees are independent groups of people who review research to protect those taking part. This study has been reviewed and given favourable opinion by

Brighton and Sussex NHS Research Ethics Committee and Royal Holloway's University Research Ethics Committee. Representatives from Royal Holloway's University Research Ethics Committee and regulatory authorities will continue to monitor the progress of the study throughout.

How will we use information about you?

We will need to use information from you for this research project. This information will include your name, contact details and some demographic information. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a pseudonym instead.

We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

You can find out more about how we use your information:

- At www.hra.nhs.uk/information-about-patients/
- Or by emailing the researcher: amelia.turner.2018@live.rhul.ac.uk

What if there is a problem?

If you have a concern about this study, you should speak to the researcher or project supervisors who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting Dr Gary Brown, Chair of the Research Committee at Royal Holloway, University of London on 01784 414330.

THANK YOU FOR YOU TIME

Thank you for taking the time to read through this information sheet. If you would still like to take part in the study, please press continue. You will then be directed to a consent form.

If you have any more questions about the study, please contact the researcher.

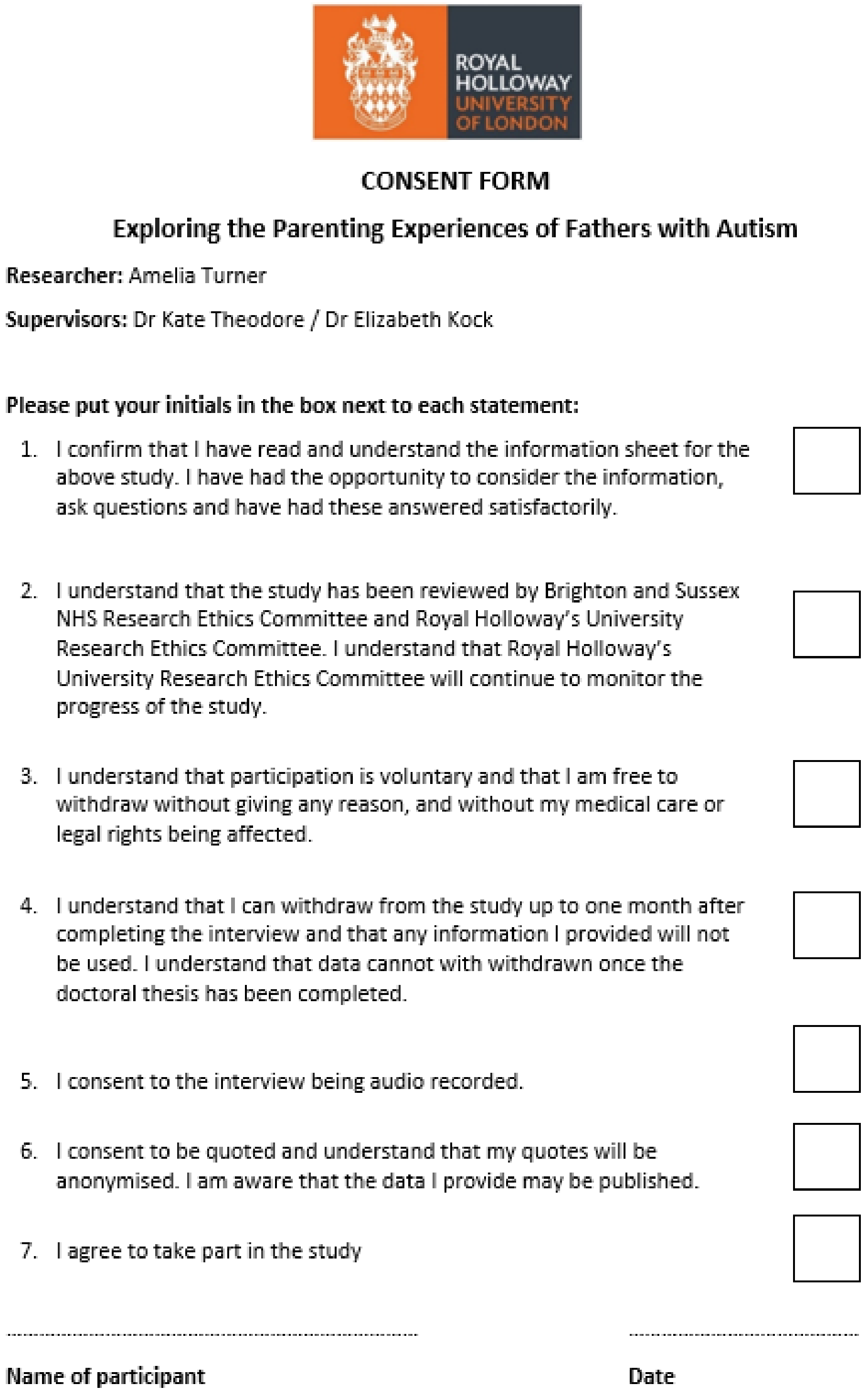
CONTACT INFORMATION

Name: Amelia Turner **Email: amelia.turner.2018@live.rhul.ac.uk**

Telephone: 01784 414012

Supervisor: Dr Kate Theodore (Clinical Tutor, Doctorate in Clinical Psychology Department of Royal Holloway, University of London)

Appendix F: Consent form



ROYAL HOLLOWAY UNIVERSITY OF LONDON

CONSENT FORM

Exploring the Parenting Experiences of Fathers with Autism

Researcher: Amelia Turner

Supervisors: Dr Kate Theodore / Dr Elizabeth Kock

Please put your initials in the box next to each statement:

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that the study has been reviewed by Brighton and Sussex NHS Research Ethics Committee and Royal Holloway's University Research Ethics Committee. I understand that Royal Holloway's University Research Ethics Committee will continue to monitor the progress of the study. ☐
3. I understand that participation is voluntary and that I am free to withdraw without giving any reason, and without my medical care or legal rights being affected. ☐
4. I understand that I can withdraw from the study up to one month after completing the interview and that any information I provided will not be used. I understand that data cannot with withdrawn once the doctoral thesis has been completed. ☐
5. I consent to the interview being audio recorded. ☐
6. I consent to be quoted and understand that my quotes will be anonymised. I am aware that the data I provide may be published. ☐
7. I agree to take part in the study ☐

....

Name of participant **Date**

Appendix G: Demographic questionnaire

PARTICIPANT DEMOGRAPHICS QUESTIONNAIRE
Exploring the Parenting Experiences of Fathers with Autism

Name:

Please state your age:

How old were you when you received your diagnosis of autism?

Please specify your ethnicity:

What is your employment status?
Full time employment
Part time employment
Unemployed / not looking for work
Unemployed / looking for work
Self employed
Student
Retired
Other (please specify):

What is your relationship status?
Single
Living with partner
Married
Divorced / separated
Other (please specify):

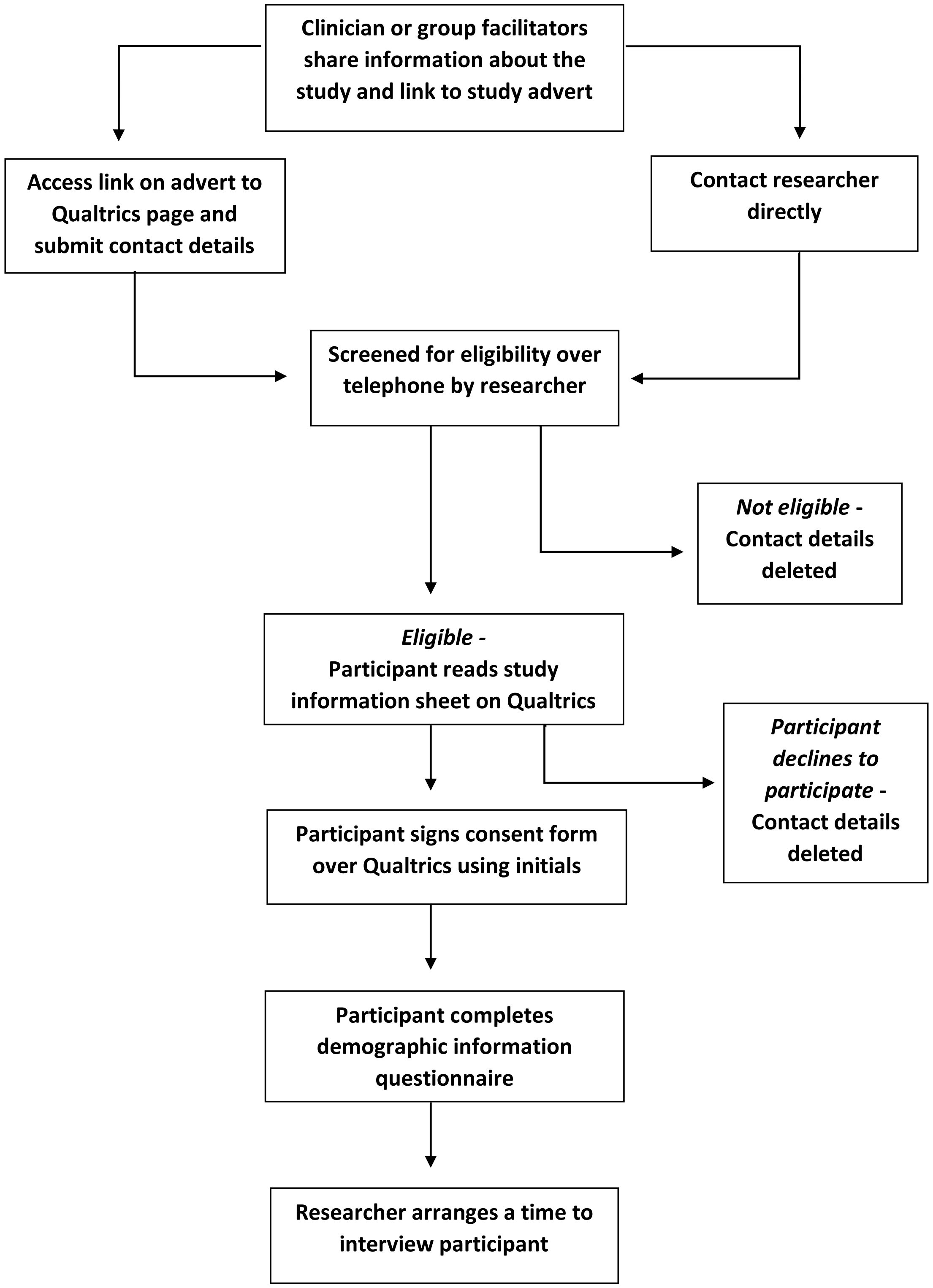
How many children do you have?

How old are your children?

Are you currently living with your child(ren)?

How many of your children (if any) have a diagnosis of Autism?

Appendix H: Participant recruitment pathway



Appendix I: Interview schedule

Introduction

Thank you very much for coming to speak with me today. Did you have any questions about anything on the information sheet?

Are you worried about talking with me today at all? *(If yes, explore concerns)*

Is there anything I can do to make you more comfortable?

It's important that you know that there are no right or wrong answers, this is simply to find out more about your experiences from your perspective. Please let me know if you would like to take a break or end the interview at any point.

Terminology

During this interview I will be asking you questions about being a father with autism. I have planned to use the word 'autism' in the questions, but some people prefer other terms like ASD/Autism Spectrum Disorder/Asperger's/Autistic. I wondered what term you like me to use to describe autism/being autistic? *(then use the participant's preferred term throughout the interview)*

Confidentiality

As explained in the information sheet everything that we discuss today will be treated confidentially. After the interview I will transcribe the interview and anonymise it. I may quote you when I write up the findings, but you won't be identifiable. The only time I would need to involve anyone else in our discussion today or tell anyone else anything that we talk about is if you told me that you, or someone else were at risk of harm. If that did happen, I would discuss it with you before talking to anyone else. Do you have any questions?

Interview

Diagnosis

I'm interested in your personal experience of receiving a diagnosis of autism *(or preferred term)* and your experience of becoming a father.

- Can you tell me a bit about your experience of receiving a diagnosis of autism *(or preferred term)*?

  Explore:

  When was it? *(establish whether it was before or after having children)*

  How did it come about?

  Did you seek out a diagnosis yourself, or did someone else suggest it?

What was it like getting the diagnosis?

Becoming a parent

I'm now going to ask you a few questions about your views before you had your child(ren).

- Have you always wanted to be a father?

  Explore:

  How did you know?

  What made you want to be a father/what made you apprehensive?

- How did you feel when you found out you were becoming a father?

  Explore:

  Was it planned?

  What was that like for you?

Parenting

I'm going to ask you a couple of questions about being a father.

- Can you tell me a bit about what it's like to be a father?
- What are some of the things you enjoy most about being a father?
- What are your strengths as a father?
- What are some of the things you find more difficult?

  Explore:

  Why do you think you find that harder?

- What impact, if any, do you think autism *(or preferred term)* has on your experience as a father?

  Prompt:

Relationship

I'm going to ask you some questions about your relationship with your children. Let's start from the beginning…

- What was it like when your child(ren) was born?

- What was your relationship with him/her/them like as they started to get older?

  Explore:

  When they were going to nursery/school/college?

  What was different about being a father to a child/teenager than when they were a baby/child?

  How did you find it?

- What do you enjoy doing together?

- What's it like spending time with your child(ren)?

- *(If multiple children)* Is that the same or different to your other children?

  Explore: how so?

Parenting with partner

(If there is another parent involved in child's care) Can I ask you about what it's like parenting with your partner/child(ren)'s mother.

- How do you find it?
  Explore:
  What is difficult about it?
  What do you like about it?
  Have they ever given you any feedback about your parenting? What was it?

- Do you take on any different parenting roles?

  Explore:

  How did they come about?

  Can you give me any examples?

Support

- Have you received any advice or other support around being a father?

  Explore:

  Have you received support from family/friends?

  Any support from professionals/services?

  (If yes) What was helpful/unhelpful?

- Is there any support you would have liked? What would that look like?

- Is there any advice you would give to other autistic fathers?

- Is there anything else you think we should know about your experience of being a father with autism *(or preferred term)*?

Ending

- What's it been like talking to me today?

Debrief

Thank you for taking the time to talk to me today. Just to let you know a bit about what happens next. I will be talking to several other people and asking them similar questions. I will listen to each interview and transcribe them. After I've done that, each recording will be deleted. The transcribed file will not have your name or any of your details on. I will analyse the written interviews, looking for themes and links. I will then write the findings up into a thesis for submission.

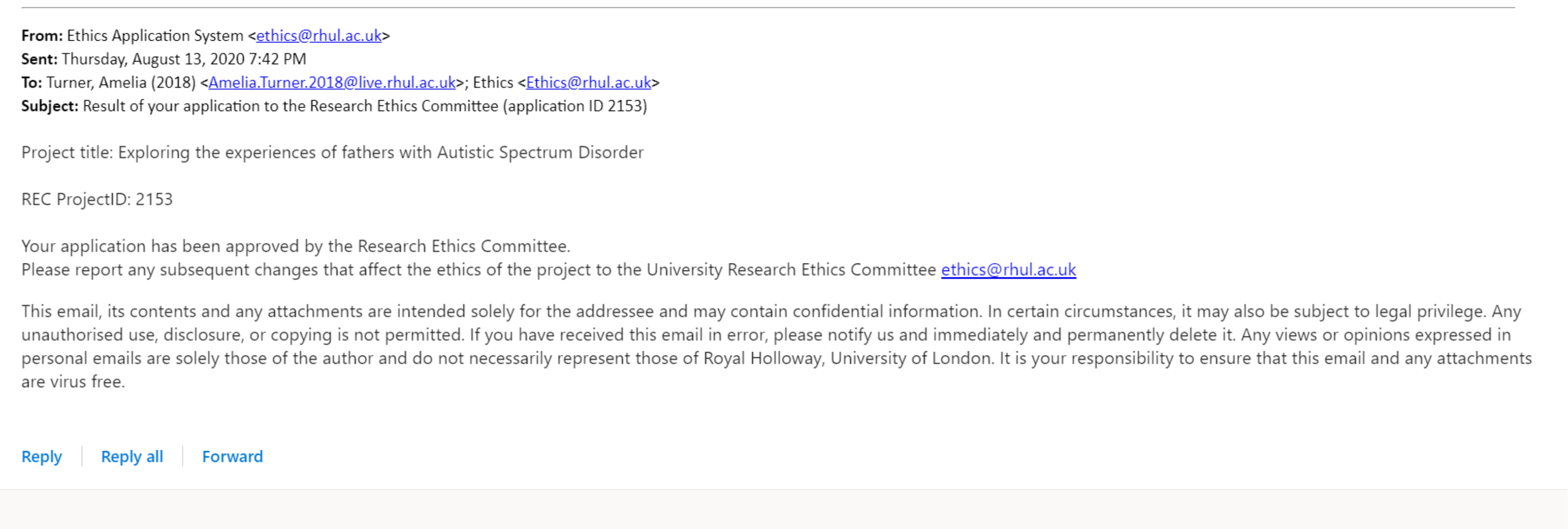
- Do you have any questions about anything that we have talked about or the study in general?
- Would you like to receive information about the study findings directly?
- Would you be interested in being involved in providing feedback on the themes and findings that have emerged from the interviews?

Other prompts

When giving examples of different situations/experiences:

- How did they (children) respond? What was that like for them at the time?
- How did that make you feel at the time?
- Did that affect your relationship with your son/daughter? How so? Did it bring you closer/further apart?
- What was the impact of that experience on your parenting?
- How does that impact your parenting now?
- Some parents find (parenting activity) difficult/challenging, what was your experience?
- When (son/daughter/partner) did that… how did it make you feel?

Appendix J: Royal Holloway, University of London ethical approval confirmation



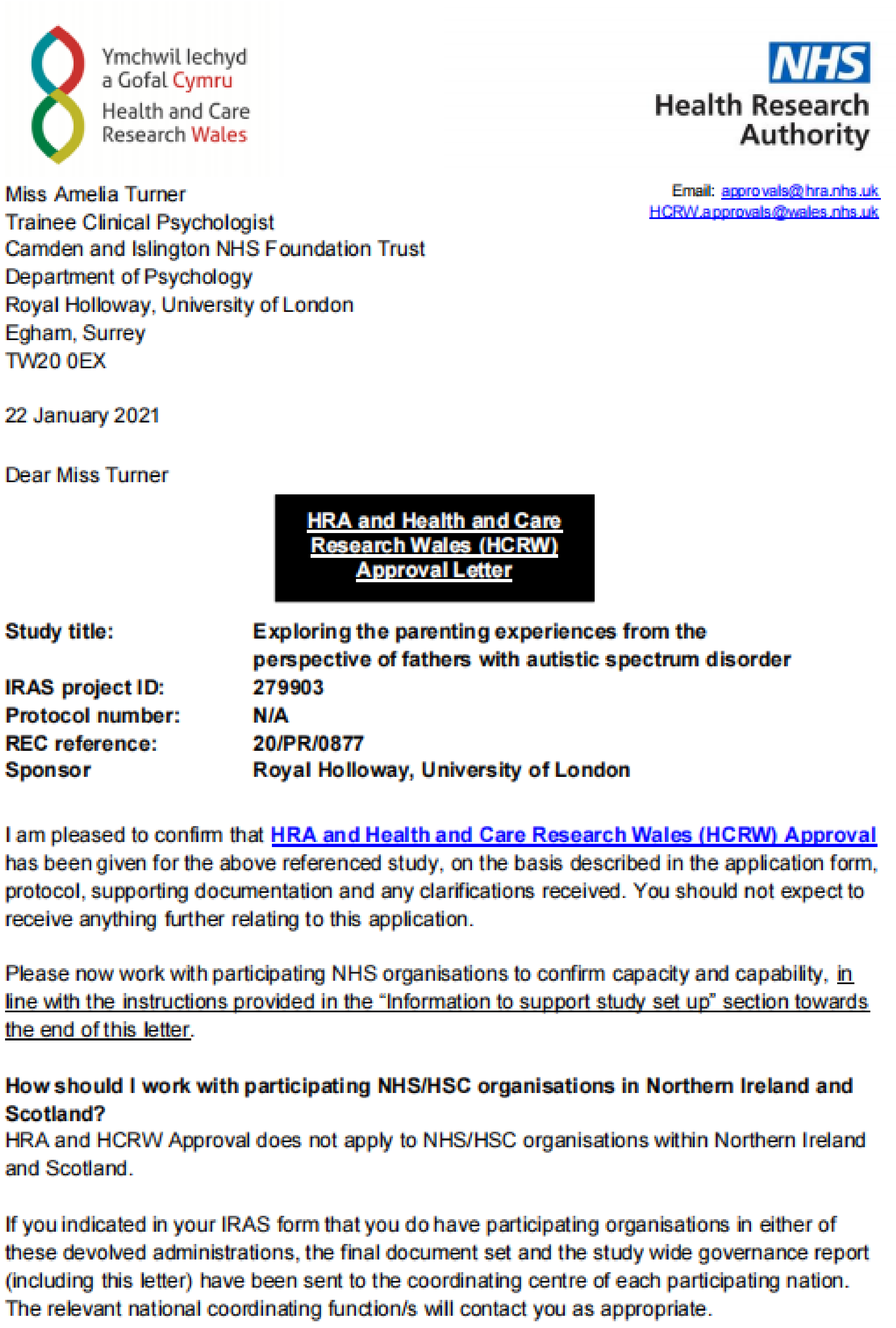
From: Ethics Application System <ethics@rhul.ac.uk>
Sent: Thursday, August 13, 2020 7:42 PM
To: Turner, Amelia (2018) <Amelia.Turner.2018@live.rhul.ac.uk>; Ethics <Ethics@rhul.ac.uk>
Subject: Result of your application to the Research Ethics Committee (application ID 2153)

Project title: Exploring the experiences of fathers with Autistic Spectrum Disorder

REC ProjectID: 2153

Your application has been approved by the Research Ethics Committee.
Please report any subsequent changes that affect the ethics of the project to the University Research Ethics Committee ethics@rhul.ac.uk

Appendix K: HRA approval letter



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

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

Miss Amelia Turner
Trainee Clinical Psychologist
Camden and Islington NHS Foundation Trust
Department of Psychology
Royal Holloway, University of London
Egham, Surrey
TW20 0EX

22 January 2021

Dear Miss Turner

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title: **Exploring the parenting experiences from the perspective of fathers with autistic spectrum disorder**
IRAS project ID: **279903**
Protocol number: **N/A**
REC reference: **20/PR/0877**
Sponsor **Royal Holloway, University of London**

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

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

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

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

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

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

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

What are my notification responsibilities during the study?

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

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

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

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

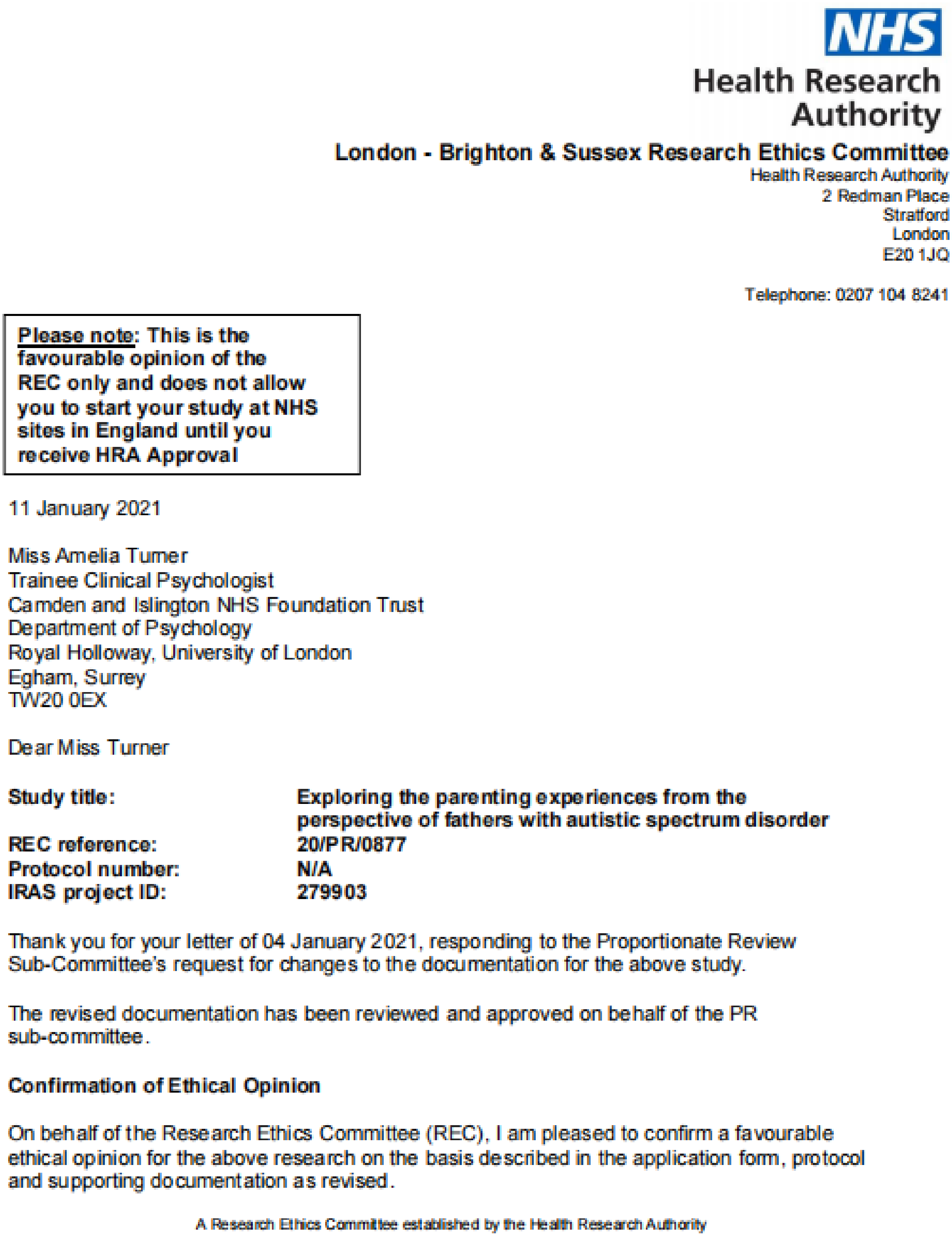
Your IRAS project ID is **279903**. Please quote this on all correspondence.

Yours sincerely,
Helen Penistone
Approvals Manager

Email: approvals@hra.nhs.uk

Copy to: *Mrs Leisha Wickham*

Appendix L: Brighton & Sussex REC favourable ethical opinion letter



NHS
Health Research
Authority

London - Brighton & Sussex Research Ethics Committee
Health Research Authority
2 Redman Place
Stratford
London
E20 1JQ

Telephone: 0207 104 8241

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

11 January 2021

Miss Amelia Turner
Trainee Clinical Psychologist
Camden and Islington NHS Foundation Trust
Department of Psychology
Royal Holloway, University of London
Egham, Surrey
TW20 0EX

Dear Miss Turner

Study title:	**Exploring the parenting experiences from the perspective of fathers with autistic spectrum disorder**
REC reference:	**20/PR/0877**
Protocol number:	**N/A**
IRAS project ID:	**279903**

Thank you for your letter of 04 January 2021, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved on behalf of the PR sub-committee.

Confirmation of Ethical Opinion

On behalf of the Research Ethics Committee (REC), I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Good Practice Principles and Responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the Favourable Opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Number	Conditions
1	The Committee acknowledged that there are still a few typographical errors in the Participant Information Sheet and requested this is re-read for accuracy.
2	The Committee identified that Dr Elizabeth Kock is still mentioned as a supervisor in the Participant Information Sheet and requested this is changed to "key collaborator" or omitted.
3	The Committee emphasised that it is very important the research is published and requested this is reflected in the Participant Information Sheet as it still states the research "may" be published.
4	The Committee commended the researchers for mentioning the Royal Holloway representatives in the Participant Information Sheet but requested "representatives of the regulatory authorities" are also mentioned.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

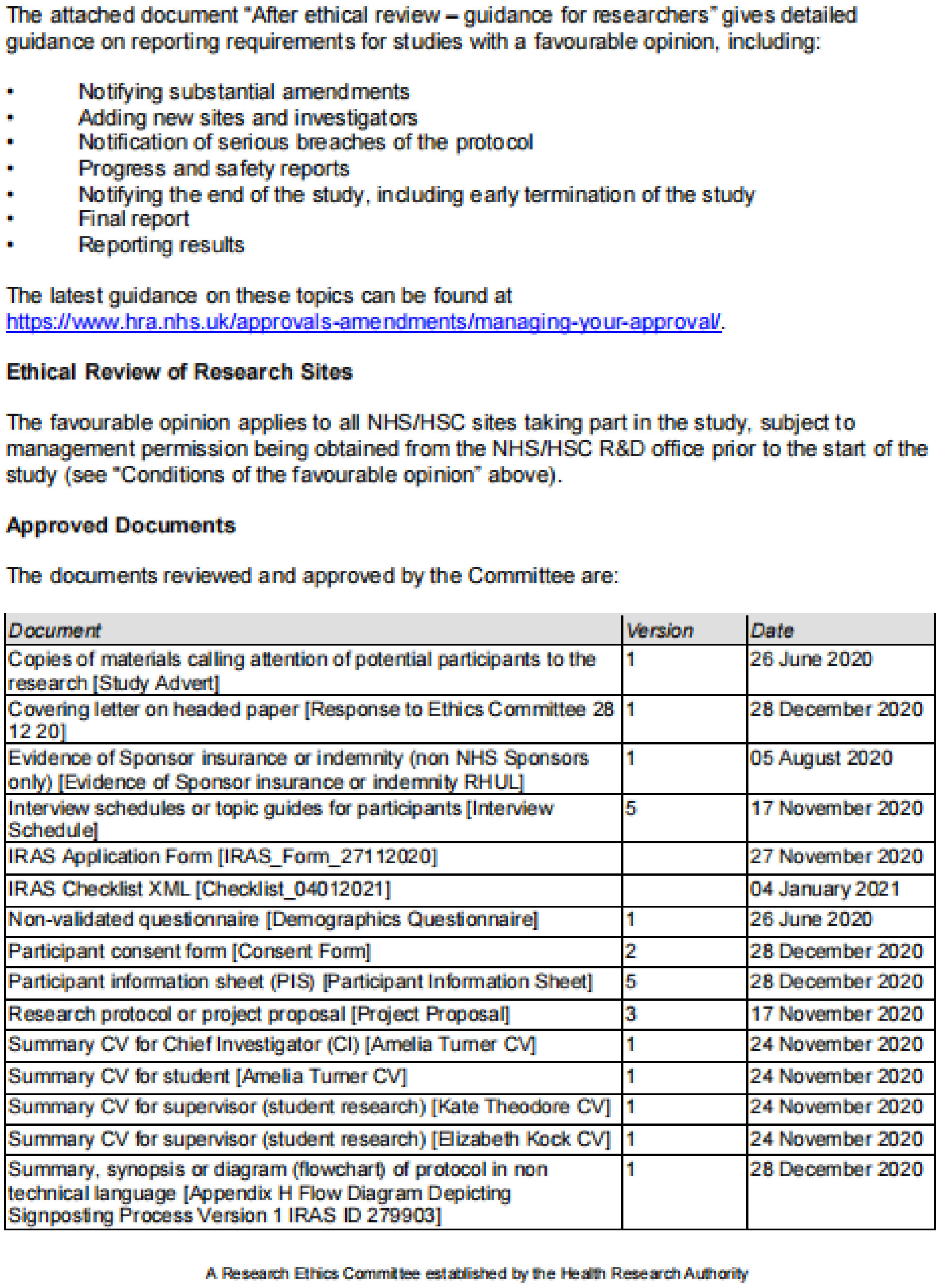
Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements



The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical Review of Research Sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved Documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Study Advert]	1	26 June 2020
Covering letter on headed paper [Response to Ethics Committee 28 12 20]	1	28 December 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor insurance or indemnity RHUL]	1	05 August 2020
Interview schedules or topic guides for participants [Interview Schedule]	5	17 November 2020
IRAS Application Form [IRAS_Form_27112020]		27 November 2020
IRAS Checklist XML [Checklist_04012021]		04 January 2021
Non-validated questionnaire [Demographics Questionnaire]	1	26 June 2020
Participant consent form [Consent Form]	2	28 December 2020
Participant information sheet (PIS) [Participant Information Sheet]	5	28 December 2020
Research protocol or project proposal [Project Proposal]	3	17 November 2020
Summary CV for Chief Investigator (CI) [Amelia Turner CV]	1	24 November 2020
Summary CV for student [Amelia Turner CV]	1	24 November 2020
Summary CV for supervisor (student research) [Kate Theodore CV]	1	24 November 2020
Summary CV for supervisor (student research) [Elizabeth Kock CV]	1	24 November 2020
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Appendix H Flow Diagram Depicting Signposting Process Version 1 IRAS ID 279903]	1	28 December 2020

Statement of Compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:
https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 279903	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

PP
Mrs Carrie Ridley
Chair

Email: brightonandsussex.rec@hra.nhs.uk

Copy to: Mrs Leisha Wickham

Appendix M: Example of line-by-line coding and development of themes

Extract from Alex's interview:

Emergent themes	**Original transcript**	**Exploratory comments**
	I: Maybe if we start, would you mind telling me a little bit about how you received your diagnosis. How did it come about?	
Need for time alone *Sensory needs* *Need for predictability* *Interaction between environment and ASD* *Contrast of life before and after children* *Children as catalyst for seeking diagnosis* *Parenthood as permanent social setting*	P: Err, yeah, so, um, well my partner and I have thought that… we've been together for a very long time. We've been together for, err, twenty, sixteen years. That I'm on the spectrum because I have worked alone, um, since I was 23, 24. And, um, I will often say I need time alone in the house. I don't like loud noises. I'm very particular about what I wear. I can eat the same food for days and days on end, and that doesn't bother me. And I have, err, a freakishly good memory for patterns. So, I analyse charts for financial markets. I remember Chinese characters very well. And, you know the classic things like plane schedules, maps, things like that. And, um, I was very comfortable with that kind of life, you know, sitting and staring at my computer screen for most of the day. Or, you know, studying Chinese for eight hours a day and writing, or do whatever else. Um, until the children came about. When by the very nature of it involves being around other people. A lot. Especially the	Familiarity between him and partner. Thought he was probably autistic but felt no real need to seek diagnosis before – behaviours/quirks viewed as just part of him, who he is. Has found ways of accommodating for ASD naturally throughout life e.g. working alone. Clearly associates ASD with needing time alone – his understanding of ASD is being quite solidarity? Need for predictability and routine. Describes ASD as a series of tangible behaviours, likes and dislikes. These are just part of him and the way he is. Life before children was comfortable, predictable. *ASD only problematic in context of environment.* Children changed his life completely – no longer comfortable and predictable. Having children equals a permanent social setting. Finds this very difficult. Can no longer have as much time alone. 'First few years of their life' – suggests a change in demand for social interaction over course of

Family interaction causing distress *Avoidance/ withdrawal as way of coping* *Coping with sensory overload* *Impact of coping strategies on family* *Need to withdraw* *Parenthood as catalyst for seeking diagnosis* *Shared experiences with others* *Sense of relief* *Diagnosis enabling understanding*	first few years of their life. And it just got extremely hard for me. So, I, err, I wanted to avoid and go into classic self-soothing behaviours. Isolation, sitting in the dark, humming loud. I listen to a lot of classical music so I would turn it on very loud. Basically, I became quite distressed, and William, my partner, said it was affecting him. And also the children. So, we didn't quite know… I would become quite unpredictable. So, I would sort of, be around, and then I'd just retreat. So, um, yeah, the GP made the referral to the autism service and I went through the three-step diagnostic process. And they told me that people often get the diagnosis just after children are born, or they change employment, or things like that. So yeah, children being born is apparently quite a big trigger for seeking out a diagnosis because it changes life so much. And, um, that's how it came about. I: OK. And how did you feel about it at the time? P: Err, both a sense of relief and, err, a lot of fear. Relief because, well I mean before the diagnosis, William would joke that in social situations I have, it's a forty-minute span that I would have. Like if we go to restaurants I would just sit down, order, then I'd want to leave straight away after I finish eating. Or at a dinner party, or any sort of party, I'd be involved for three quarters of an hour and then	children's life. Things get easier over time? 'Classic' self-soothing – is he relating to other people with ASD? Or does he mean these are typical ways of self-soothing for him. Being around his children all the time led to emotional distress. Uses avoidance/withdrawal as way of coping. Sitting in the dark and humming – *is this his way of coping with sensory overload from being around children?* Partner pointed out that his coping strategies were impacting the whole family. Possibility that he lacked awareness/insight into how his actions were affecting others? Is this a part of his ASD presentation perhaps. *'Retreat' - withdraw into safety/hiding away. Being a parent didn't feel safe?* The change that children brought to his life triggered process of seeking a diagnosis. Mentions that people on the spectrum often seek out diagnosis after big life changes - helps to normalise his experience? *Shared experiences* Mixed feelings around diagnosis. Fear and relief contrasting emotions. Is fear to do with stigma? 'Joke' implies that his ASD-related quirks/behaviours are viewed in good humour by partner – *acceptance within family?* Sense of relief related to a better understanding of himself and his experiences. Attributes certain behaviours of his to ASD. Having the diagnosis provides a framework for

Avoidance/ withdrawal as way of coping *Diagnosis providing justification to meet own needs* *Diagnosis facilitating reflection and growth*	I'd want to isolate. Or get quite drunk. Actually, that's another one of my coping strategies. Um, and, since the diagnosis I've found that I have been able to take a lot of greater care of myself. So, that I do take time away from people and social settings. I don't feel shy about going to sit by myself in the toilet for ten minutes. Which means that my alcohol consumption has fallen pretty much to zero. I'm just a lot happier, now that I know why this is happening. And what I can do to look after myself. Yeah.	others to understand his behaviours. Everything finally makes sense. Alcohol as another coping strategy, also functions as avoidance? Alcohol numbs/dampens down experiences. Makes social settings bearable Felt that he needed justification to be able to take himself away before. Perhaps felt social pressure to fit in? Having a label enables him to feel empowered to take care of his own needs. Change in coping strategies from unhelpful (alcohol) to more helpful (taking himself away) after diagnosis. Knowledge of why he feels and behaves in a certain way has improved his emotional wellbeing. *Value of diagnosis.*

Transformation of themes over time:

1. Emergent themes – family interactions causing distress, children as catalyst for seeking diagnosis, parenthood as permanent social setting, impact of coping strategies on family, diagnosis enabling understanding, diagnosis facilitating reflection and growth
2. Subordinate themes – parenthood as catalyst for diagnosis, diagnosis facilitating understanding and positive change
3. Superordinate theme – interaction between autism and parenthood
4. Superordinate theme revised: the interdependent relationship between parenting and autism

Extract from Markus' interview:

Emergent themes	**Original transcript**	**Exploratory comments**
	I: You've told me some already, but I was going to ask, are there particular roles that you and your partner take within the parenting?	
Balancing duties *Fulfilling different needs* *Internalised gender roles* *Working as team*	P: Yes, so I think there is, kind of, a slight imbalance in that sense. Like, my partner is doing most of the emotional support with the children and then I try to do the practical, err, things. Like, for example, in the past I have cooked dinner, remind my children to eat and finish their dinner. Then I kind of, wash them, get them to dress in their pyjamas, brush their teeth, and all that sort of stuff. And then their Mum takes over and sort of hugs them, um, helps them to wind down and fall asleep.	Imbalance implies unfair – sense that partner is doing more than him? Practical support vs. emotional support. Is this to do with strengths/difficulties relating to ASD or beliefs around gender roles in family. Cooking, dressing = tangible way of expressing care Working in partnership to meet children's needs. Difference between mother-child and father-child relationship. Possible internalised gender roles/narratives around ASD
	I: And how do you find parenting together with your partner?	
Complementary roles with partner *Working as team* *Pressure to be a good parent*	P: I think we, kind of, complement each other well. So, the children seen to be, kind of, developing ahead of their age, so it all seems to be working out well [laughs]. There is always a worry like, am I being a good enough parent. Like, are the children going to be healthy, are they going to be fine. And so far, just based on what we see and the feedback that we get from teachers, it's going very well. So that's very reassuring. A good thing.	Complementary roles. Work as team. Commitment to parental role. Feels pressure to be a 'good enough' parent. Anxiety that comes with parenting
	I: And what are some of the things you find more difficult with parenting? Whether that's in the past or now, with parenting.	

Conflicting needs *Prioritising children above own needs* *Family interactions causing distress* *Pushed out of comfort zone* *Balancing own needs and family needs* *Strive for balance/equality*	P: Hmm. I guess the hardest thing for me is, um, not really having that much time to just retreat into special interests and, kind of, have things my way. So that was, and still is, the hardest thing to cope with. I: mmm. How do you cope with that? P: I try to carve time out whenever I can. Or take a small break if I feel the situation is a bit too overwhelming. Um, so, the reason why I learned self-development and the stuff with computers is because that's my special interest. So, but it's also, by that it's also something that is quite comforting to retreat to. So, a lot of times when things become a bit too much, I try to at least for ten minutes hide in the bedroom and just read something on the computer or something like that. Which is comforting. But I would do that like most of my time. But this way I'm like, well there are all these things that I still need to do, at least, um, I take this little break now. And in a way kind of slice the time up. So, I do the things that are, kind of, difficult but necessary to do. Then I take a little break and that's sometimes very difficult to manage. And not to be stuck and be away from family responsibilities, because it's a bit unfair to everyone. So yeah, I guess the trick is to balance that.	Desire for time alone. Retreat into his safe comfortable place. Special interests – part of ASD presentation. Conflicting needs between him and children. Has to 'cope with' implies a struggle. He is prioritising children's needs above own. Adapted ways of managing within family context. Retreat and hide – being within family context can cause distress – sensory overload? Need time to recharge. Children pushing him out of comfort zone. Desire for things to be fair. Need to strike balance between his needs and family's/ children's needs

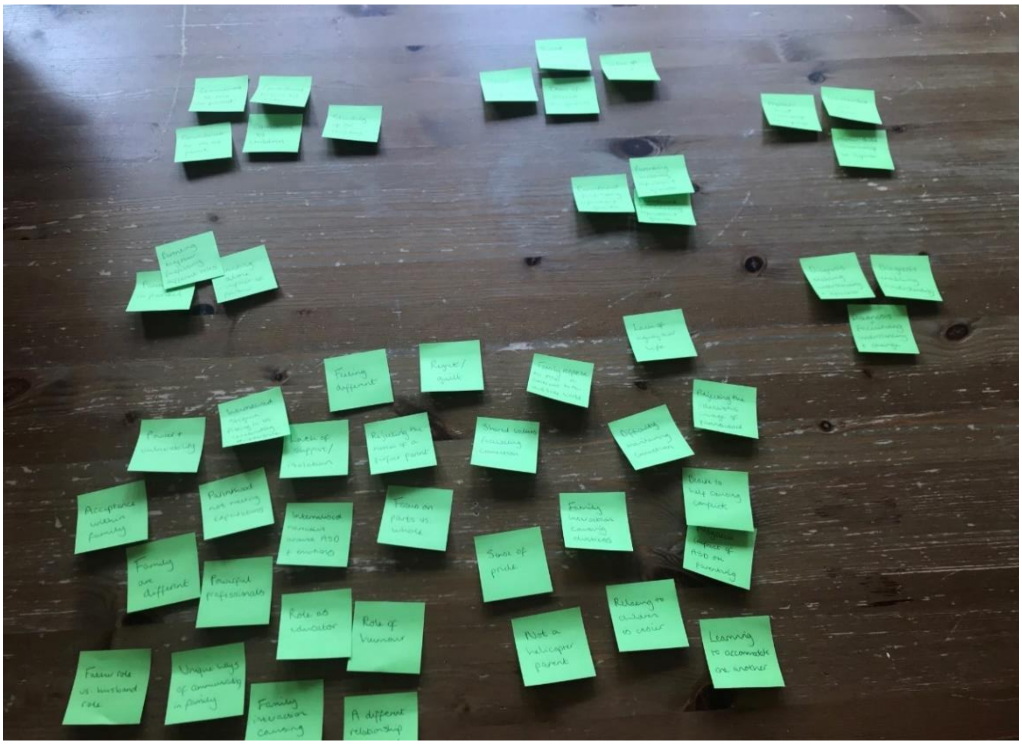
Transformation of themes over time:

1. Emergent themes – balancing duties, fulfilling different needs, internalised gender roles, complementary roles, working in partnership, conflicting needs, prioritising

children’s needs, family interactions causing distress, balancing own needs with family’s needs, striving for balance

2. Subordinate themes – accommodating conflicting needs, parenting together: cohesion and conflict
3. Superordinate theme – the family system
4. Superordinate theme revised: the family system: a balancing act

Appendix N: Photos illustrating development of themes across cases



Appendix O: Elliot, Fischer & Rennie's (1999) publishability guidelines

Publishability Guidelines Especially Pertinent to Qualitative Research	How I have tried to achieve this
1) Owning one's perspective	I have described and acknowledged my own position and experiences that may be relevant to the study.
2) Situating the sample	I have described relevant demographic characteristics of the participants and reflected on how these may have contributed to their experience.
3) Providing credibility checks	The research and field supervisor have been involved in checking the credibility of the analysis.
4) Coherence	I have presented an integrated summary of the analysis, including themes and subthemes, helping the reader to follow my thinking in identifying the themes.
5) Accomplishing general vs. specific research tasks	I recruited a relatively homogenous sample in line with the IPA approach and have been careful to ensure that the conclusions drawn from the study are only viewed as applicable to that population.
6) Resonating with feeders	Feedback from healthcare professionals and from experts by experience (participants from the study) will help to ensure the data is presented in a way that resonates with readers, including the autistic population.

Appendix P: Extracts from reflective journal

Reflections after interview 4

I found this interview more challenging than previous interviews. Some of this was due to poor internet connection and the participant speaking softly so it was difficult to hear him at times. The interview felt stilted, and he often gave short answers to my questions. I struggled to know how to phrase my questions to help him to provide more detail about his experiences. I was very grateful for the extra prompts I had in my interview schedule.

I am left feeling sad that he had not received support earlier or got a diagnosis earlier to help him make sense of some of the challenges he experienced throughout his life. I was not sure how much to explore the difficulties he has experienced as a parent – he seemed to feel a real sense of failure as a parent. I found I was having to resist the urge to normalise/validate some of his experiences during the interview which I might usually do in my role as a therapist. His account made me think about the idea that autistic people lack insight into how their behaviour affects others. He clearly had reflected on how he had behaved at times with his children while they were growing up. This included reflecting on his own upbringing and making some links between his ASD presentation i.e. difficulty understanding others' intentions and why he responded in certain ways. It seemed like it was perhaps more difficult for him to reflect on his parenting experiences and make changes when he was actively parenting at the time.

I also saw some parallels with the roles that he described and my own parenting i.e. the father helps with the practical problems and mother provides more of the emotional support. Themes of traditional gender roles were very apparent in this interview in general. As someone who identifies as a feminist, very rigid assumptions around gender roles would usually evoke a negative response in me. However, I did not find this was the case for some reason. I think he recognised to a certain extent that he was just following the model/framework of how he had been parented, but it had not worked out in that way that he had hoped or expected.

What I don't want to lose in analysis:

- Sense of sadness and regret at not having a better understanding of autism earlier on in his parenting journey. Desire to make changes now in his role as grandparent.
- Possible impact of theory of mind difficulties on parenting
- Internalised / traditional gender roles
- Following a framework of how he was parented – lack of agency?

Initial coding and emergent themes – participant two

While reading over the transcript to familiarise myself with the data I have noticed that there are times I encourage my participant to speak about experiences not directly related to his experience of parenting e.g. his experience of discrimination at work. As a psychologist we are trained to explore people's experiences and it was difficult not to follow-up on aspects of what he was saying – especially when they seemed important to him. However, I realise I need to hold in mind the aim of my research a bit more before asking follow-up questions. Luckily, I still have most of my participants to recruit and interview, so it is good for me to recognise this now.

My meeting with both supervisors to discuss the initial coding of one of the individual transcripts in-depth was useful to provide credibility checks for some of the interpretations I had made. My field supervisor helped me to notice possible links between the participant's account and theories/models to do with autism. I also realised that I was being too descriptive at times and finding it harder to make higher-level interpretations. I think this is a bit more challenging with my participants as they tend to speak in quite concrete/factual ways, which is often the case for autistic people. Going back to the IPA book and my notes from the workshop has helped me remember that there are multiple ways in which interpretations and connections can be made other than looking directly at the choice of language.

Cross case analysis

As I have started to look across cases I am surprised at how some of the emergent themes group together, even when I felt that the individual accounts were very different. It has been interesting to notice how inconsistencies in individual accounts also occur across cases e.g. participants stating they can easily empathise with their children however find it difficult to recognise emotions in others. At the same time, there are some themes that do not seem to belong anywhere, and I am worried about losing sight of participants' individual experiences. I plan to discuss this with my supervisors as I realise I am having difficulty prioritising what information to keep.

Development of superordinate themes

I found meeting with my supervisor to discuss the themes very helpful. I had not been sure about how well some of the subordinate themes fitted with the superordinate themes. We thought how the themes could be re-structured so that the superordinate themes capture the essence of the subthemes. For example, I realised that 'what it means to be a father' did not need to be a separate superordinate theme but could come under 'parenthood enabling reflection and growth'. I know that qualitative interviews often produce a lot of detailed and rich information and supervision has helped me accept that I need to prioritise information for the final paper.

Appendix Q: Endorsement of themes across participants

Superordinate theme	Subtheme	David	Martin	Paul	Tony	Michael	Stephan	Alex	Markus	Tom
Interdependent relationship between ASD and parenting	Parenthood as a catalyst for seeking diagnosis		✓	✓		✓		✓	✓	✓
	Diagnosis enabling understanding and positive change	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Challenging societal narratives		✓		✓	✓	✓	✓	✓	✓
	Family response to ASD: a contrast to the outside world	✓	✓	✓	✓		✓	✓	✓	✓
	The value of shared experiences	✓	✓		✓	✓	✓	✓	✓	✓
The family system: a balancing act	Accommodating conflicting needs		✓	✓		✓	✓	✓	✓	✓
	Parenting together: cohesion and conflict	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Evolving family dynamics	✓	✓	✓	✓	✓	✓	✓	✓	✓
Parenthood facilitating reflection and growth	Impact of own experience of being parented	✓	✓	✓	✓		✓			✓
	Being pushed outside of comfort zone		✓	✓		✓	✓	✓	✓	✓
	Dedication to the parental role	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Rejecting the idealistic image of parenthood		✓	✓		✓	✓	✓	✓	✓

Appendix R: Additional illustrative quotes

Superordinate theme	Subordinate theme	Quotes
The interaction between autism and parenting	Parenthood as a catalyst for seeking diagnosis	*"But something that struck me when myself and my wife went as part of my daughter's diagnosis, err, that the questions that were being asked 'does she do this? Does she do that?'. I'm like, yes but I do those things. And I would often find myself before my daughter was diagnosed, sometimes, sort of, um, trying to, not very consciously, but just responding perhaps to some concerns that my wife had about my daughter, by going, oh yeah but I was like that when I was a kid [laughs]. Um, so, then you realise that there's a reason for that." (Michael)* *"I would become quite unpredictable. So I would sort of, be around, and then I'd just retreat. So, um, yeah, the GP made the referral to the autism service and I went through the three-step diagnostic process. And they told me that people often get the diagnosis just after children are born, or they change employment, or things like that. So yeah, children being born is apparently quite a big trigger for seeking out a diagnosis because it changes life so much." (Alex)*
	Diagnosis enabling understanding and positive change	*"I think for Fran, my partner, it was helpful. Because there's been interesting things in our marriage I guess. And there's been aspects of our relationship that she's found difficult at times. And the diagnosis explains those." (Stephan)* *"But as I didn't know I was autistic until I was 57, I spent most of my parenting years as an autistic parent but not knowing I was autistic. It's only looking back over the last three years when it's like yes, that explains why I did that, or why I reacted in such a way." (Paul)* *"And, yeah, that that was when me and William had a big conversation and we thought actually maybe I need to get a proper diagnosis. Temper my exposure to outside life so I can be more present with the children. Which is what we do." (Alex)*

	Challenging societal narratives	*"And I see myself as having very strong feelings around, um, and wanting to be very much connected to people. While at the same time genuinely having social difficulties and sometimes doing daft things socially, um, but certainly not lacking empathy." (Stephan)* *"Um, so, when they're teenagers and they say they're alright and they are still just grunting at you. And you think hmm. Yeah, it is that sort of empathising with them, which of course autistic people aren't supposed to do. It's very much seeing myself in them, I suppose." (Tony)*
	Family response to ASD: a contrast to the outside world	*"So, she's aware that I've been through the process, I've read stuff about autism and we've spoken about it. So it's just part of the fabric of everyday life, it's not a big deal." (Stephan)* *"And then there are also parents - I don't know many because I don't hang out with them - who try and fix their children. Or they are just very confused about, um, why their children are a little bit different because of their spectrum traits." (Tom)*
	The value of shared experiences	*"Um, the thing that really has surprised me most, is the pleasure I get in working with, um, certainly younger children and their parents, um, when there is a case of autism in the family. And it always seems to put a smile on the parents' faces. Because everyone else I think just seems to say, oh the child's cute and quirky or whatever, I think they know behind the scenes what's going on and they are actually very very welcoming of someone who is prepared to say, err, 'I'm that as well'. (David)* *"Well the [NHS autism service] were fantastic. I mean they had a little workshop, a series of events for partners of autistic people. And William has… it was lovely for them, because, err… So, there were a batch of us that were diagnosed at roughly the same time, and their partners came along. And I suppose that for them it was very nice to see that… yeah, he found the partner meetings quite useful and helpful." (Alex)* *"And, um, something I liked about that, in retrospect, is that, was the other parents. I mean you weren't necessarily having huge group discussions about stuff. But you'd have a cup of coffee and you'd have a chat, and it was nice just to feel that shared, you know, we're facing the same thing here. We're asking the same questions." (Michael)*

The family system: a balancing act	Accommodating conflicting needs	*"Um, I still struggle with the, err, sort of frequent requests that come from my son. Like when he wants something. It feels a little bit triggering for me. And I don't know whether that's part of my autistic traits or whether that's maybe like another trait it's triggering, based on my childhood." (Tom)* *"And obviously they, from very early on, particularly from six months on, they really seek out eye contact and eyes. And, um, I have since taught myself to do very well and I enjoy it now. But it is quite, err, I'd say in many ways almost physically painful from the beginning process. It's err, it's like a very very, you know, finely grated thing inside your head that just moves and scrapes and it's quite uncomfortable." (Alex)* *"So, what I found really useful is, like, finding these little breaks to, um, take care of myself. To have more energy to take care of children. So rather than kind of trying to push on and carry on but being really depleted and kind of on the edge. It's less helpful than finding a little bit of time to let off the steam and regain a little bit of energy. And then you get back to the situation. I've found that makes a big difference – basically to stop before reaching meltdown stage." (Makrus)*
	Parenting together: cohesion and conflict	*[talking about parenting with his ex-partner] "Um, we have, not only a difficult relationship. It's also, um, we don't communicate much. I almost feel like we have a completely different like view of reality." (Tom)* *"Like, my partner is doing most of the emotional support with the children and then I try to do the practical, err, things. Like, for example, in the past I have cooked dinner, remind my children to eat and finish their dinner. Then I kind of, wash them, get them to dress in their pyjamas, brush their teeth, and all that sort of stuff. And then their Mum takes over and sort of hugs them, um, helps them to wind down and fall asleep." (Markus)* *"So, I have lovely little projects with them, umm. Err, but it is usually goal directed behaviour. Spontaneous, shared activities with me we just don't do. With William, they often cook together and that." (Alex)* *"…it would probably emphasise any differences in approach or different ways of doing things. Because it ends up becoming more of a, doing stuff on your own, lots of flexibility, to all of a sudden the workload goes up and responsibilities. And if you have different styles, they're likely to become much more obvious." (Tony)*

	Evolving family dynamics	*"They [my sons] are similar to me in terms of the weird going off on tangents. Random conversations. Which completely confused my wife. And we still do it now." (Tony)* *"So naturally, I feel he kind of comes to me a bit more then his Mum. Because he might feel a bit safer around me. Um, and the internal factors is things like, err, well me just understanding myself a bit better. And understanding my relationship with him. And realising I need to be a bit more patient, and mindful, and focused, and look after his needs but also my own needs. And to be very open about it. My son and I are also talk about boundaries a lot." (Tom)*
Parenthood facilitating reflection and growth	Impact of own experience of being parented	*"She [Martin's mother] projected the shame she felt, or the shame she had, outwards. Primarily at me. I tend to inwardly project shame. I am ashamed of myself. As a result of this, Lorna and I always wanted to make sure our children knew we were proud of them. And so, we have always tried to favour towards the things we are proud about in our children rather than the things that might be more negative." (Martin)* *"I think that the main one is, erm, my ability to be affectionate and vulnerable. And this probably comes from the way that I was brought up and raised." (Tom)*
	Being pushed outside of comfort zone	*"I live in fear of going to the school meetings, the school play, or the school parent night whatever. And I think about how I will negotiate meeting other parents and things. And what I might say and that sort of thing. So, um, so that's… but I would do those things." (Stephan)* *"I think it's like, um, doing the things that otherwise I wouldn't be doing myself. So, being exposed to things, experiences of going out to the park and like playing with things. I'm not very physical. So, like doing that sort of activities with children is great." (Markus)*
	Dedication to the parental role	*"The moment Rosie was born it was my duty to be there for Rosie. That's how they coached us, and I was very serious about carrying out these duties." (Martin)*

		"I will always support my kids, in a sense. They might not think so at times, and I may be too supportive at times, erm, I probably poke my nose in too much occasionally. But, um, if they need something, or I think they need something, I'll do it." (David) *"And I think there is real commitment. And I think I am prepared to put myself on the line as a parent. But that's definitely there. That's a real choice I made when Luke was young, so." (Stephan)*
	Rejecting the idealistic image of parenthood	*"I would say don't expect it to be easy, it will be difficult, and that's OK. It's OK that it will be difficult because it won't, you know, it doesn't matter if you don't get everything right, it doesn't matter if things don't work out the way you hoped things were going to, that you know, you think you're going to make your child happy and they don't enjoy this thing you planned, and all that sort of thing. That you can't make everything right." (Michael)* *"I learned to let go of the frustrations. And I learned to accept that things are the way they are sometimes. And there are some things that we can't change." (Tom)*