Exploring Fathers’ Experiences of Parenting their Adolescent Daughters with Autism Spectrum Disorders

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Submitted in accordance with the requirements for the degree of

Doctor of Clinical Psychology (D.Clin.Psychol.)

The University of Leeds

School of Medicine

Division of Psychological and School Medicine

July 2021

Acknowledgements

Firstly, I would like to thank my participants as this research would not have been possible without you. I valued your openness, honesty, and vulnerability in sharing your experiences with me, it was a real privilege to be a part of.

I would also like to thank my parent consultant for taking the time from her busy life to contribute to this research in such a thorough and thoughtful way, you have been invaluable.

To my research supervisors, Dr Tracey Smith and Dr Tom Cliffe (Team 'T'nT'), I am beyond grateful for everything you have done to support me in conducting this research and I cannot thank you enough. I have laughed and cried, and you have ridden the rollercoaster with me!

To one of my favourite's, Becky Piclet. I feel so lucky to have been able to share this process with you through choosing the same supervisors, and a similar project. I have valued your golden nuggets of wisdom, your positivity, your silliness, and your kindness - thank you. I could not have imagined this journey without you.

A big thank you to my husband, Alexis, who is my biggest cheerleader. He has dedicated so much to support me throughout my training and career so far, with so much care, kindness and understanding. I am so grateful for you.

A final thanks to my mum, and to my dad who have also been an invaluable support. You are always there, encouraging me. Who would have thought I would have got where I am now!? – only you!

I would also like to acknowledge and dedicate this research to my Grandad who sadly passed away one week before submitting. It made the last few weeks so much harder, but an even greater achievement, which I know he would have been incredibly proud of!

Abstract

Introduction*:* Research capturing fathers’ parenting experiences is limited in the current literature and even more so with regards to parenting a child with additional needs. Additionally, adolescent females with autism spectrum disorders without a co-occurring intellectual disability are under-represented in the evidence-base and often not recognised or understood within the education and, health and social care system. This often leads these adolescents to receive a late diagnosis or diagnosed with a mental health difficulty first; both of which impacts on their mental health further. In turn, this also impacts parents' emotional wellbeing and support needs as they attempt to get their children's needs met by the professional support systems. As fathers' voices are limited in the evidence-base regarding their parenting and mental health needs, this study therefore aimed to explore fathers’ experiences of parenting their adolescent daughters with autism spectrum disorders.

Method: A sample of eight fathers were interviewed using a semi structured interview. The data was transcribed and then analysed using interpretative phenomenological analysis. Both individual and group analyses were conducted which led to the development of group level themes.

Results: Three superordinate themes and ten sub-ordinate themes developed to describe fathers’ experiences of parenting their adolescent daughters, and an overview of them was presented. The superordinate themes were: ‘*turmoil in understanding relationship with daughters*’, ‘*difficulties in processing own emotional adjustments to ASD*’ and feeling ‘*let down by the system’*.

Discussion: The key findings were presented and discussed in relation to the wider literature. This study contributes to the lack of literature on both fathers’ parenting and adolescent females with autism spectrum disorders. Strengths and limitations of the study are presented. Lastly, the implications of the study for stakeholders are outlined and areas for future research are presented.

As the current study uses abbreviations throughout, Table 1 captures acronyms included in the current study, including their meaning and where they are first mentioned.

Table 1. A list of acronyms, their meaning and where they are first mentioned in the current study.

Acronym	**Meaning**	**First mentioned**
ASD	Autism spectrum disorder	Page 11
TD	Typically developing	Page 13
GD	Gender dysphoria	Page 16
IPA	Interpretative Phenomenological Analysis	Page 29
CAMHS	Child and adolescent mental health service	Page 62

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Chapter One – Introduction

The current study is interested in exploring fathers' experiences of parenting their adolescent daughters with autism spectrum disorders (ASDs). To set the scene, this chapter will begin by outlining contextual factors for the literature, including a summary of ASD and the importance of the choice of terminology used. Then, the current evidence base surrounding parenting will be discussed, encompassing children across the age range and genders, and children with different needs, eventually discussing parents of children with ASD. This literature review leads to a rationale of the current research study, where the aims and research question will be presented.

Contextual factors to consider in the literature

Firstly, it is important to highlight a debate in the terminology used to describe individuals on the autistic spectrum. Both editions of the Diagnostic and Statistical Manual of Mental Disorders, the DSM-IV (APA, 2000) and the most recent DSM-V (APA, 2013), refer to a person as having ASD if they meet the diagnostic criteria. However, 'disorder' has been considered as stigmatising, whereas 'condition' has been seen to capture both the strengths and disabling aspects, which for a time, became the terminology used by mental health professionals and researchers (Baron-Cohen, 2009). The term, however, shifted back to 'disorder' when the most recent DSM-V was published (APA, 2013). Thus, professionals must align with the formalised guidance and current diagnostic criteria, and refer to individuals as having ASD, which this study will also do.

In addition, the DSM-IV (APA, 2000) previously described behaviours consistent with an ASD under the category of Pervasive Developmental Disorders (PDD). PDD included: Autistic disorder, Asperger's syndrome, PDD not otherwise specified (PDD-NOS), Rett's disorder and childhood disintegrative disorder. This is important to note because until 2013 when the 5th edition of the DSM was published, the literature described Autism and Asperger's as separate diagnoses. Asperger's syndrome featured similar characteristics as Autistic disorder but was differentiated by having no features of clinically significant delay in language, cognitive development, or age-appropriate skills (APA, 2000). Moreover, ASD without an intellectual disability (formerly known as Asperger's syndrome) is identified less frequently amongst parents and professionals due to the absence of cognitive delays. Due to this, there also appears to be less understood about children with ASD without an intellectual disability, particularly in adolescent females. Thus, the current study aims to develop this understanding further. A synopsis of the current evidence base surrounding this rationale will be summarised below.

Literature Review

ASD is a neurodevelopmental condition characterised by two core features: persistent deficits in social communication and interaction, and restrictive and repetitive patterns of behaviour (APA, 2013). The presentation and severity of difficulties vary considerably amongst individuals; hence the condition is referred to as a 'spectrum'. There is strong evidence for a hereditary component in the presentation of ASD, however, no consistent genetic variant has been identified (Campisi, Imran, Nazeer, Skokauskas & Azeem, 2018).

Generally, the rates of children being diagnosed with an ASD are increasing, whereby 1 – 2% of children in the UK now have an ASD diagnosis (Roman-Urrestarazu, Van Kessel, Allison & Matthews, 2021). A recent study conducted by Roman-Urrestarazu, Van Kessel, Allison and Matthews (2021) explored the prevalence of ASD, focussing on differences across different racial and ethnic groups. Strikingly, they found that the highest prevalence of ASD was found in Black children (2.11%) and the lowest in Roma/Irish Traveller families (0.85%).

Regarding differences in age of children, it has been identified that 0.9% of children aged 5 have an ASD, 1.7% have an ASD at the age of 7, and 3.5% are aged 11 (Dillenburger, Jordan, McKerr, Keenan, 2015). These figures highlight that generally children are not diagnosed until they are school aged even though parents are often aware of their child's developmental difficulties from approximately 18 months old (Brett, Warnell, McConachie & Parr, 2016).

Gender differences

The prevalence of ASDs are higher in boys than girls; with a male to female ratio of approximately 4.3:1 (Fombonne, 2009). The prevalence rates also change when acknowledging a child's intellect. Typically, children who have an ASD with average cognitive abilities are diagnosed at approximately age 11 (Howlin & Asgharian, 1999). This is much later than children who have an ASD with lower functioning abilities who are on average, diagnosed at 5.5 years of age (Howlin & Asgharian, 1999). Regarding differences in gender, females with average intellect are less commonly diagnosed with an ASD than males, with a male to female ratio of 10:1 (Fombonne, 2003). This same group of females are also diagnosed much later than their male counterparts (Begeer et al., 2013). Contributing factors for this will be explored later in the chapter.

The statistics highlight a clear difference in prevalence of ASDs between genders, with a larger difference when there is no intellectual disability present (Gould & Ashton-Smith, 2011). This has resulted in a gender disparity in the evidence-base as the research appears to be male focused (Kreiser & White, 2014).

Why adolescence?

There is a wealth of research investigating the presentation of ASDs and differences in gender, in infant and primary school children. Interestingly, clear differences in socialisation have been found in primary school children; whereby, girls with an ASD unconsciously learn to 'camouflage' or 'mask' their social difficulties and appear to socialise like typically developing (TD) girls (Dean, Harwood & Kasari, 2017). It is suggested that masking develops as a response to cope with social exclusion. Boys often withdraw from their peers (Wainscot et al., 2008), whereas girls rote learn social communication patterns to fit in with their female peers (Gould & Ashton-Smith, 2011). Examples of masking include making eye contact during conversation and copying other's behaviours and social scripts (Lai & Baron-Cohen, 2015). Although some males have been found to use masking as a coping strategy, the proportion is significantly less than in females (Lai et al., 2017). Boys also find it more difficult to access and maintain engagement in male dominated games (Dean et al., 2017). This means that they are often observed in the school playground as wandering alongside the games, rather than actively engaged in them.

However, there is much less evidence examining the presentation of ASDs in males and females during adolescence. Adolescence is known to be a challenging time for TD young people and their parents, which features changes in the development of their identity (Erikson 1968); without the added complexity of experiencing social difficulties.

Before exploring the literature on the presentation of ASDs in adolescent girls and boys, it is important to highlight adolescent development in TD children first and the potential challenges that parents typically face.

Typically developing adolescents

Adolescence is a stage in early life where the exact age bounds vary by expert or study, however, is generally considered to be the second decade of life (Pearce, Hayward, Chassin & Curran, 2018). Moreover, it is the time period from the onset of puberty to the beginning of adult roles (Steinberg, 2016)

Erikson (1968) proposed that TD children pass through a series of psychosocial stages of development in which they begin to explore their identity and their social world. He described that each psychosocial stage involves having a crisis period, triggering a transition onto the next stage of development. If this crisis is not resolved, it can interfere with the person progressing onto their next developmental stage. According to Erikson (1968), the stages of early adolescence (approximately 11 – 18 years old) are in the 'identity vs role confusion' stage of development. Erikson described that this stage is firstly recognised by the start of puberty where the adolescent experiences physical, social and emotional changes. They become primarily concerned with others' views of them which affects their perception of themselves and their sense of achievement. Moreover, they become confused about their social roles as their identity evolves. Identity development occurs when young people develop several identities, including their gender identity. Gender identity has been described as “the extent to which a person experiences oneself to be like others of one gender…and provides an important basis for their interactions with others” (Steensma, Kreukels, de Vries & Cohen-Kettenis, 2013, p.289). Steensma and colleagues (2013) also highlight that specifically during adolescence, teenagers experience gender intensification. The gender intensification hypothesis proposed by Hill and Lynch (1983), suggests that adolescents experience an increased pressure to conform to social gender roles. Part of this may involve adolescents developing cliques with their peers and seeking independence and responsibilities from their parents. Erikson described this stage as being vital for identity formation as they begin to challenge previously accepted issues and look for ideals. However, when young people fail to successfully develop their identity through these avenues; perhaps due to a lack of ability to manage different social circumstances, the adolescents may feel a sense of not knowing who they are (Erikson, 1968).

Moreover, Erikson (1968) described that a female’s identity is acquired by seeking closeness and connection to others. Whereas, a male’s identity develops through detaching themselves from others. This supports later findings which suggests that an adolescent’s relationship with their parents is more important for females than males (Geuzaine, Debry & Liesens, 2000). Erikson (1968) also described that an adolescent male’s identity would be fully established by the end of adolescence, whereas a female’s is achieved when married with a family. Berzoff (1989) described that Erikson’s (1968) theory was accurate suggesting that a female’s identity is relationally focused, however, it also narrowly describes the traditional female roles of his time and so is therefore outdated.

Generally, research has supported Erikson’s theory, but critics have suggested that instead, the core period of identity development is in late adolescence into early adulthood (Steinberg & Morris, 2001). Moreover, Steinberg and Morris (2001) suggest that adolescence is now less about identity development and more about the development of their self-concept, specifically, beliefs about themselves. In this way, adolescents evaluate themselves in different aspects of their lives such as their academic attainment, their social relations, and their appearance (Masten et al., 1995).

Furthermore, the gender intensification hypothesis has also been critiqued. Priess and colleagues (2009) conducted a longitudinal study and found that adolescents did not become more gender stereotyped in their behaviours because in our current society adolescent males are encouraged to be more expressive than historically, and females, more independent. Additionally, the changes that young people experience in adolescence will naturally bring about changes in their relationship with their parents. Evidence suggests there is a mild increase in conflict in the parent-adolescent relationship characterised by an increase in bickering; arguments about trivial matters (Holmbeck 1996). More specifically, this has been found to increase around the onset of puberty, especially with mothers (Steinberg & Morris, 2001). Moreover, Steinberg & Morris (2001) suggests that the parent-adolescent relationship becomes more equal leading the young person to become autonomous in the family and begin contributing to family decisions. Due to the increased interest in friendships and being with their peers, adolescents also tend to spend less time with their parents; all of which decreases parents' feelings of closeness to their child (Larsons & Richard, 1991). In turn, this can also impact on the mental health of parents as they struggle to adjust to their young person's autonomy (Silverberg & Steinberg, 1990).

The construction of gender, and gender dysphoria in adolescents with ASDs

Whilst the development of gender identity has been summarised in relation to TD adolescents, it remains important to also discuss gender, and gender identity in adolescents with ASDs. This is because, as outlined above, a person's gender is an important factor in their identity and development. As such, this section will first begin by deconstructing gender, and then a further discussion on gender dysphoria and its prevalence in adolescents with ASDs compared to TD adolescents. Thus, highlighting their increased needs.

The construction of gender

Much social science research is related to participants' gender, yet it is often not carefully operationalised. Hegarty, Ansara and Baker (2018) discussed gender as being a complex construct which is “culturally and historically specific…and amenable to change” (p.59). The construction of gender as binary (two categories) is common, particularly in older research. For example, when an item in a questionnaire is assessed as a dichotomous variable with only two options, likely, male/female or masculine/feminine (Ansara & Hegarty, 2014). This exemplifies how researchers and people in general, by use of language, make implicit assumptions which conflates sex with gender. Therefore the binary construction of gender is maintained. However, Lindqvist, Senden and Renstrom (2020) outlines that gender is generally constructed by four facets: a person’s sex, their gender identity, legal gender and gender expression. They specifically note that these aspects of gender are not fixed and can change over time depending on external impacts, such as society (Resinder et al., 2015).

Firstly, a person’s sex refers to the physiological aspects of their body such as their genitalia, chromosomes and bodily attributes (Forhard-Dourlent et al, 2017). Lindqvist, Senden and Renstrom (2020) note that it is incorrect to assume that a person’s sex precedes and determines their gender alone (Bittner & Goodyear-Grant, 2017).

A person’s gender identity can be fluid, changing over time and contexts. For some, gender identity is stable throughout life and context, whereas for others it varies throughout their life. Therefore, a binary classification of gender excludes those who are gender fluid or do not identify with a gender at all (Nowatzki & Grant, 2011).

The term ‘legal gender’ or ‘assigned gender at birth’ is where an individual is categorised as female or male at birth, based on their genitalia, and then documented on birth certificates and passports (Fausto-Sterling, Coll & Lamarre, 2012). This term acknowledges that individuals who identify or express their gender do not have to correspond to their assigned gender at birth.

Gender expression, however, refers to how an individual sees themselves in relation to society’s norms, regarding their behaviour and appearance. As with gender identity, this may be fluid, changing over time and contexts depending on external influences.

These constructions of gender are therefore important in the consideration of adolescents, during a pivotal time in the development of their gender identity. Gender dysphoria will now be discussed, whereby individuals experience distress in relation to their gender. This is important to consider as it has been identified as particularly prevalent in adolescents with ASDs.

Gender dysphoria

Gender dysphoria is characterised by distress which accompanies an incongruence between experienced or expressed gender and gender assigned at birth (American Psychological Association, 2013). Moreover, the DSM-5 suggests that people living with gender dysphoria often want to change their appearance and/or bodily features to be more congruent with their gender identity. As such, they may undertake a ‘transition’ process which may vary between transitioning socially to gender-affirming surgery (American Psychological Association, 2013). The experience of gender dysphoria can cause clinically significant distress across different facets in the individuals functioning (American Psychological Association, 2013).

Kaltiala-Heino, Bergman, Työläjärvi and Frisén (2018) highlight in their paper exploring gender dysphoria in adolescence, some prevalence rates. They summarised surveys conducted in 2017 which found that 0.5% of adults in the general population identify as transgender (Zucker, 2017; Crissman, Berger, Graham & Dalton, 2017). More specifically, studies using a short self-report measure of gender identity found that 0.17% - 1.3% of adolescents and young adults identify as transgender (Zucker, 2017; Connolly, Zervos, Barone, Johnson & Joseph, 2016). Furthermore, a school-based survey which elicits gender experiences (and is commonly used in gender identity services) found that 1.3% of 16-19 years olds potentially had clinically significant gender dysphoria (Sumia, Lindberg, Tyolajarvi & Kaltiala-Heino, 2017). These statistics do not decipher between TD adolescents and those with ASDs but provides a helpful contextual framework for further understanding gender dysphoria in adolescence.

Gender dysphoria is important to discuss in relation to adolescents with ASDs, as there is a small but growing evidence base identifying that, individuals with ASDs have a significantly higher co-occurrence of gender dysphoria than TD individuals. More specifically, Coleman-Smith, Smith, Milne and Thompson (2020) highlighted evidence which suggested that 6.4% of children and 9.4% of adolescents referred to a gender identity disorder (GID) clinic showed clinically significant levels of autistic traits (Pasterski et al., 2014).

Currently, there is limited research in understanding the co-occurrence of gender dysphoria with ASD (Coleman-Smith et al., 2020). The studies which have examined the relationship between gender dysphoria and ASD have been criticised for being dismissive, seeing gender dysphoria as a ‘symptom’ of ASD and not as a distinct experience of their gender identity (Kraemer, Delsignore, Gundelfinger, Schnyder & Hepp, 2005).

However, the co-occurrence of gender dysphoria needs to be understood in the context of ASD in adolescence as it presents some significant challenges as identified by Strang and colleagues (2016) in the development of their clinical guidelines for ASD and gender dysphoria in adolescence. The authors found that these individuals are at risk of victimisation for several reasons. Some young people with ASD struggle in their gender transition, making them less likely to ‘pass’ as their affirmed gender. Moreover, their ASD makes it more challenging for adolescents to consider the safety of social and romantic interactions. Thus, a combination of victimisation, poor coping strategies and social difficulties linked with ASD, and inflexible thinking can contribute to increased mental health difficulties for these adolescents.

Strang et al., (2016) also found that adolescents with ASD and gender dysphoria may have more challenges at school due to experiences of stigma. Alongside this, they may also find it difficult to navigate their gender presentation and appear less aware of the potential safety risks and how others perceive them. Additionally, they may have more trouble managing social relationships in school due to the added complexity of navigating their gender identity alongside their social differences.

As such, these factors of adolescent development in individuals with ASDs are important in the consideration of the young person’s diverse experience of adolescence.

Parenting

This section will present some recent statistical data highlighting the diversity and context of current family life which is not often stated or represented in the literature on parenting. This evidence will be discussed alongside a traditional model of parenting, to consider experiences of parent-adolescent relationships.

Alongside adolescent development, Friedman (1957) suggested that parents also progress through their own stages of development. These stages include: ‘learning the child’s cues’, ‘learning to accept growth and development’, ‘learning to separate’ and lastly, ‘learning to build a new life’ when the child reaches adolescence. Friedman (1957) suggested that Erikson’s developmental stage (1968) ‘identity vs role confusion’ occurs simultaneously alongside ‘learning to build a new life’. Friedman (1957) stressed that having an adolescent means that parents can re-build their lives as their adolescents’ independence grows. He proposed that the more parents can do this, the more tolerant they may become of their adolescents’ behaviour. Additionally, it is suggested that parents who actively engage in this developmental stage will not interfere with their adolescents’ development and experiences, and instead, will remain quietly in the background for support if needed. Friedman’s (1957) theory is the only identified theory to date that has explicitly explored a parent’s development.

However, Friedman’s (1957) developmental stages assumes a traditional nuclear family. This is a family which contains a married mother and father who live together, with their biological children. This is a long-assumed standard in which other types of families are often compared to (Smith, 1993; Powell et al., 2010). Researchers have suggested that this traditional family set-up is changing and is likely due to a rise in unmarried women having children and an increase in divorce rates (Kennedy & Ruggles, 2014; Curtin, Ventura & Martinez, 2014).

Recent evidence collated from the 2020 UK Census supports this and captures data highlighting that out of the 1.1 million families living in the UK with children, only 61% are married opposite sex couples (National Office of Statistics, 2021). Instead, families today are more diverse whereby 13% of families are opposite sex and unmarried, and 26% are lone parent families. Out of the lone parent families, 22% are mothers and 4% are fathers. Additionally, 0.1% of families are same-sex couples; both married and unmarried. However, the data recorded for same sex couples only highlights dependent children rather than both dependent and non-dependent children. Therefore, the statistic for same-sex couples may be higher (National Office of Statistics, 2021).

These statistics suggest that although opposite sex married couples remain the most common families in the UK, the data captured by the UK 2021 Census outlines that this is gradually changing as opposite sex non-married, lone-parent and single sex parents are rising. Therefore, whilst traditional models of parenting are a useful framework in which to base ideas, they should be considered tentatively as they do not offer inclusivity of experience. Thus, the current research must consider inclusive experiences of parenting rather than just traditional notions.

Alongside the discussion of parenting, the parent-adolescent relationship will be explored. This exploration will offer a distinct separation of mothering and fathering experiences in its recognition that these will likely differ.

Parent-adolescent relationship

As is well known, attachment theory focuses on the quality of the parent-child relationship; characterised by the parent's presence and emotional availability to their child (Bowlby, 1965 Lamb, 1997). Attachment theory proposes that a consistent and responsive caregiver leads to a healthy parent-child relationship. Later attachment research found that the quality of the early parent-child relationship determines later relationships through the development of the child's internal working model; the individual's representation of their self and their relationships (Bowlby, 1982). Coley (2003) summarised that as the adolescent experiences' changes in their development, parents play a vital role of supporting their child. Moreover, a positive correlation has been found between a healthy parent-adolescent relationship and good psychological and behavioural outcomes in young people (Kenny & Gallagher, 2002). Thus, it may be hypothesised that these crises in development, as proposed by Erikson (1986), are more likely to be resolved if the parent-child relationship is of good quality and they are emotionally available to support them.

Much of the research to date has focused on examining the adolescent-mother relationship or on the parents together rather than individually (Kerns & Stevens, 1996). However, adult and infant attachment studies have found that attachment relationships are unique to individuals suggesting that an infant will have a different attachment to different figures, typically, their mother and father (Ainsworth, 1982). Studies exploring parent-adolescent relationships have found both similarities (McCormick & Kennedy, 1994) and differences (Paterson, Field & Pryor, 1994) in relation to the quality of the relationship amongst genders of the parent and the adolescent. Although similarities and differences were identified, possible reasons that account for their findings were not discussed.

Buist, Decovik, Meeus & Van Aken (2001) used a Linear Growth Model, a longitudinal analysis to measure growth over time, to examine the developmental attachment patterns in adolescents in mothers and fathers separately. They found that adolescents reported a deterioration in the quality of both parental relationships, supporting evidence from previous studies (Papini, Roggman & Anderson, 1991). The authors also found that patterns of developmental change confirmed gender differences indicating that same-sex attachments were of higher quality than different-sex attachments during adolescence. Girls' quality of attachment slowly decreased with their mothers, and boys likewise with their fathers. The authors proposed that these findings can be explained by psychoanalytic theory. They suggested that adolescence is characterised by the occurrence of de-idealisation of their parents (Steinberg, 2001) in order to develop an autonomous identity. However, they still require their parents, particularly the same-sex parent, to guide significant life choices; all of which may create ruptures and distance in their parent relationships. Interestingly, the quality of the attachment to the different-sex parent is characterised by a non-linear developmental pattern, highlighting periods of closeness and distance.

Regarding the roles of parenting, Day and Padilla-Walker (2009) summarised that mothers and fathers approach parenting their adolescents differently (Steinberg & Silk, 2002). Furthermore, approaches to parenting are often dependent on the gender of the adolescents. For example, Stolz, Barber & Olsen (2005) found that fathers played a more pivotal role in parenting when their daughters had depression, and similarly, mothers did when their sons were exhibiting anti-social behaviours. Due to these differences in findings in TD adolescents, researchers appear to be moving away from general parenting and moving towards unique factors in mothering and fathering, which seem to be impacted by the gender of the adolescent (Day & Padilla-Walker, 2009). Day and Padilla-Walker (2009) used a series of questionnaires to examine mothers and fathers’ connectedness and involvement with their early adolescent children, and found using a hierarchical regression, that mothers parenting is focused on building relationships with their young person, whereas fathers are more centred on norm-compliance, namely, a focus on the unspoken rules and expectations of how they should behave (Lamb, 2004). Moreover, the authors predicted that the notion of parenting ‘involvement’ would be father specific, and ‘connectedness’ would be mother specific; however, they found that both variables were equally as important for both parents. Importantly, this study supported Stolz et al’s., (2005) findings which suggested fathers nurtured their children’s internalising behaviours more, such as depression, and mothers played a pivotal role in having hope for their children.

The evidence clearly suggests that adolescent males and females are likely to experience different relationships with their mothers and fathers separately. However, before exploring the experiences of parents of an adolescent with an ASD, it is crucial to examine the experiences of parenting adolescents with other developmental disabilities, in order to highlight possible similarities and differences contextually.

Experiences of parenting adolescents with other disabilities

It is well known that adolescents with a developmental disability are at higher risk of developing behavioural, psychological and social difficulties compared to their TD peers. Hamilton, Mazzucchelli & Sanders (2015) highlight that typically, adolescents who have a disability are less likely to have reciprocal relationships with their age-related peers than TD children (Skar, 2003). Similarly, relationships with parents have been found to be overprotective (Skar, 2003).

Skar (2003) used focus groups to investigate parents and practitioners’ perspectives on parenting their adolescent child with an intellectual disability or an ASD. Skar (2003) used Grounded Theory (Glaser & Strauss, 1967) and found that both parents and practitioners were concerned about the young peoples’ transition to adulthood. Their primary concern was regarding the adolescents’ desire to be more independent but having limited skills to do so. Other factors discussed included: vulnerability in relationships, society’s response to challenging behaviour in adolescence, managing sexual urges and development appropriately, personal hygiene and difficulties in communicating their needs effectively. Lastly, parents spoke about their feelings of grief for their child. For example, one parent described their adolescent as having to come “to the reality that they will not get a job, go to university…they may never get married, have a house or money” (Skar, 2003, p. 1670). Lastly, practitioners described feeling that parents with adolescents who have a disability were more isolated and described the importance of connecting to others.

It is important to note that only mothers participated in this study, therefore these findings cannot be generalised to fathers. Additionally, the authors highlighted that the sample included a range of difficulties and family backgrounds, though these were not explicitly described; therefore, although this captures a range of differences, the reader is unaware of what the differences are, which would be useful for clinical implications. Moreover, the study appears to capture a range of intellectual and cognitive abilities. This is a potential problem as individuals with ASDs and intellectual disabilities unlikely present with the same difficulties and therefore it would be useful to the reader to refine the groups with regards to their functional abilities.

Similarly, Wiener, Biondic, Grimbos and Herbert (2016) asked parents of adolescents with attention deficit hyperactivity disorder (ADHD) to complete a series of screening measures. ADHD is characterised by inattention and hyperactivity that is persistent across different situations and contexts (APA, 2013) and therefore challenges can present for parents. The authors found that both mothers and fathers experienced significantly higher levels of parenting stress compared with TD adolescents. Moreover, mothers of teenagers with ADHD also reported less satisfaction in their relationships with their child and others, and they reported feeling trapped in their role as a mother and feeling guilty because of this.

Marchal, van Oers, Maurice-Stam, Grootenhuis, van Trotsenburg and Haverman (2016) examined health-related quality of life and family functioning in Dutch mothers and fathers with young adolescents (aged 11-13) with down’s syndrome. Down’s syndrome is described as the most prevalent cause of an intellectual disability (De Graaf, 2011). The authors found that the health-related quality of life questionnaire did show statistically significant differences compared with parents of TD adolescents. However, both mothers and fathers had lower scores in several domains, notably, sexuality, cognition, social functioning, daily activities, vitality and sleep.

Additionally, the study also examined family functioning focusing on the domains of parenting, partner relation and social functioning. They found that mothers scores were not significantly different to TD controls, however, they identified that fathers reported more frequent elevated scores. This suggests that fathers of adolescents with DS may experience more difficulties in parenting domains compared to mothers. This study therefore highlights the pertinent need to investigate fathers’ experiences and their need for support, alongside mothers.

Helpfully, the authors highlighted that although the questionnaires outlined problems in these areas, the underlying mechanisms for these problems are unknown and only hypotheses can be made. Overall, it appears that fathers with adolescents with down's syndrome report similar problems to fathers with younger children with down's syndrome suggesting that their stressors likely remain a similar level throughout their development (Marchal, Maurice-Stam, Hatzmann, Van Trotsenburg & Grootenhuis, 2016).

Hartley, Seltzer, Head and Abbeduto (2013) examined fathers' psychological wellbeing in adolescents with an ASD, fragile x syndrome and down's syndrome. Fragile x syndrome is an inherited genetic condition that results in cognitive impairment leading to a learning disability and behavioural difficulties such as inattention and hyperactivity (Bailey, Raspa, Olmsted & Holiday, 2008). Their findings conclude that fathers of children with an ASD had more depressive symptoms than the other groups. Interestingly, fathers of children with down's syndrome and fragile x syndrome reported similar levels of stress. Additionally, fathers of adolescents with an ASD and fragile x syndrome reported experiencing more pessimism about their child's future than fathers of adolescents with down's syndrome. The authors hypothesise that these findings are likely associated with the type and seriousness of challenges that fathers manage when parenting their adolescent with an ASD. This supports evidence from their earlier study suggesting that the difficulties of parenting an adolescent with an ASD, and less so, fragile x syndrome are more stressful than the challenges that present when parenting an adolescent with down's syndrome (Abbeduto et al., 2004).

It may be hypothesised that a unique contributing factor to parental stress in having a child with an ASD is due to the social impairment that characterises the condition; unlike other disabilities that do not experience social impairments. This excludes fragile x syndrome as some young people present with ASD traits though may not meet the clinical criteria for a formal diagnosis. This hypothesis is supported by Smith, Oliver and Innocenti (2001) who found that when examining parenting stress in children with moderate to severe developmental delay, children's social skills were the highest predictor for parenting stress when comparing to adaptive behaviour difficulties, low cognitive abilities, delays in motor skills and communicative difficulties.

Overall, the literature suggests that mothers and fathers report experiencing higher level stressors in parenting their adolescents when they have additional needs, compared to TD adolescents. Moreover, the stressors that parents experience in adolescents with ASD compared to adolescents with DS and fragile x syndrome are unique, hypothesised to be due to the social impairments which characterise ASD. Furthermore, the literature suggests that mothers and fathers experience distinctively separate and different stressors with their adolescents. However, the differences between mothers and fathers' stressors are not clear in adolescents with ASDs. Therefore, more understanding of experiences is needed between mothers and fathers, and their male and female adolescents with ASD.

Gender differences in young people with ASDs

Interestingly, Cridland, Jones, Caputi and Magee (2014) describe adolescence as being a particularly difficult time for girls with an ASD compared to boys. The researchers summarise several reasons for this. Firstly, TD adolescent females' ways of relating become more complex and sophisticated, characterised by emotional reciprocity of sharing emotions and offering support (Gould, 2017). They also tend to engage in relational aggression involving gossiping, spreading rumours, laughing, and rolling their eyes at others (Nichols, Moravcik & Tetenbaum, 2009). TD girls also engage in faster paced conversations which girls with an ASD may take longer to process and comprehend. However, although adolescent girls with an ASD work harder to manage and understand these subtleties, and they get better at 'masking', it often occurs at the expense of experiencing significant cognitive fatigue, leading to exhaustion, anxiety and depression (Attwood, 2007). Evidence also suggests that girls with an ASD are more likely to internalise their difficulties, compared to boys, and focus their distress upon themselves (Mandy et al., 2012); overall contributing to poorer mental health. These reasons contribute to misdiagnosis in females, despite having characteristics of an ASD (Giarelli et al., 2010). Girls with an ASD also report more sexual problems than their male peers, and higher levels of sexual anxiety (Zamora et al., 2014).

These findings highlight significant distinctions between adolescent males and females with ASDs, regarding their presentation and the impact ASD has on their wellbeing. As above, these differences likely present specific challenges in parenting between mothers and fathers. The studies described indicate a need to capture adolescent girls experiences specifically, due to the long-term detrimental impact that ASD likely has on the young person and their parents. As such, an exploration of the literature on the differences between mothers and fathers in parenting sons and daughters is needed to understand the distinct rationale for the current study.

Mothers' experiences of parenting adolescent daughters with ASDs

Navot, Jorgenson and Webb (2017) described that little is known about the mother-daughter relationship in TD children, let alone in children with an ASD. Branje (2008) highlighted that, conflicts arise during early adolescence, and these conflicts are more likely to occur with daughters than with sons, and they typically occur first with mothers, then fathers (Laursen & Collins, 1994; Laursen, 1995). Furthermore, Kovar (2009) outlined that the quality of the relationship between a mother and daughter influences delinquency in adolescence (Hair, Moore, Garrett, Ling & Cleveland, 2008) and their educational achievement (Crosnoe & Trinitapoli, 2008). Moreover, a good quality mother-daughter relationship whereby the mother is emotionally available and empathic to her daughter's needs provides a good foundation for the development of the daughter's self-identity (Surrey, 1993). Compared to adolescent boys who unconsciously aim to separate their identity from their mother in order to identify as more masculine, girls do not separate their identities entirely from their mothers but instead aim to make changes that reflects their developmental changes (Coll, Surrey & Weingarten, 1999). Interestingly, in a study comparing the mother and father relationship in Mexican families (Updegraff, Delgado & Wheeler, 2009), the authors found that mothers of daughters spent more time with their adolescent daughters than their adolescent sons, specifically, five hours more per week. The study hypothesised that this could be due to the gender intensification hypothesis whereby mothers place more emphasis on socialising their same-gendered child (Hill & Lynch, 1983). Secondly, it could be due to mothers occupying a protective role and encouraging them to be family oriented (Azmitia & Brown, 2002). However, it must be noted that this study was conducted in Mexico where different cultural values are assumed.

Exploration of the mother-daughter relationship is valuable because evidence suggests that it is seen as unique and emotionally charged, with observed gender differences in the relationship between sons and daughters from birth (Keller, 2002). Additionally, raising a daughter with an ASD can present with unique challenges due to the juxtaposition of ASD behaviours and societal expectations of the development of female identity (Kreiser & White, 2014).

Cridland et al., (2014) examined the experiences of adolescent girls with an ASD from their own perspectives and their mothers combined. The researchers interviewed 5 girls aged from 12-17. Under the DSM-IV criteria (APA, 2000), three of the five girls had a diagnosis of Asperger's syndrome, one had Autistic disorder co-morbid with Epilepsy and one girl had a Pervasive Developmental Disorder – Not Otherwise Specified and a Learning Disorder.

A multiple case study approach was used to interview the mother-daughter dyads, with an IPA methodological analysis (Smith, Flowers & Larkin, 2009). As with the research outlined above, mothers described diagnostic issues for their daughters related to misdiagnosis and their social camouflaging strategy. Four out of the five mothers described the diagnostic process more challenging for their daughters than experiences they had heard from friends who had sons diagnosed.

The girls themselves discussed the 'feeling of being different' as they often shared a diagnosis with boys rather than girls, making it difficult for them to relate their experiences with others. However, some spoke about being friends with adolescent boys easier than girls as their relationships were often built on common interests.

Participants talked about their experience of high school being mixed; positive aspects included having a structured timetable, however challenges included making friends, managing large environments and finding the work difficult to do. Mothers raised negative aspects of feeling that teachers did not understand ASDs or have enough knowledge about it; for example, teachers were sending her daughter home for behaviours that were ASD related rather than misbehaving.

Both mothers and their daughters spoke about the complexity of building adolescent female relationships. The adolescents described attempting to socialise and relate to TD girls but found that they experienced relational aggression and bullying, and generally just a disinterest in relationships. The mothers described feeling that their daughters had more difficulty connecting to TD peers than boys did. They believed this was the case because boys typically build friendships on hobbies and girls' relationships are built on conversing with each other, thus adolescent girls rely more on their social skills than boys.

The onset of puberty and menstruation was mothers’ biggest area of concern for their daughters because they were worried about how their daughters would cope with it. However, mothers described being surprised about how their daughters managed, who took on a factual and logical attitude towards their menstruation. Mothers also reported feeling surprised about how open their daughters were talking about it because they are not embarrassed or attempting to cover up their feelings about it, like TD girls might do. Related to puberty, mothers also described having to support their daughter in hygiene routines, perhaps more than mothers of TD children. Moreover, romantic relationships and intimacy concerns were raised by mothers who described that their daughters were less interested than TD girls, they had the potential for misunderstanding personal boundaries and believed that they became confused over typical adolescent behaviour such as flirting.

Furthermore, mothers’ experiences were explored exclusively in the study. Overall, they spoke about the need for high involvement in their daughters’ daily activities and feeling isolated from other mothers as a result of this. However, this high involvement meant that they had a close relationship with their daughters, developed increased knowledge of ASDs, observed improvements in their daughters functioning as they developed and described feeling close to other family members who had an ASD. Cridland et al., (2014) related some of the experiences of mothers to that of ‘Ambiguous Loss’ (Boss, 1999; O’Brien, 2007) followed by a process of acceptance and positivity. Ambiguous Loss is the emotional experience in which the outcome of a stressor is uncertain or unpredictable. Similar to caring for a family member with Alzheimer’s, O’Brien (2007) suggests that ambiguous loss can also apply to a child with an ASD due to the physical presence of the child but a perceived psychological absence by the parent; perhaps due to the lack of reciprocity and feeling unable to build a loving relationship with their child (Çelik & Ekşi, 2018).

The themes found in Cridland et al's., (2014) study supported previous findings of parenting adolescent children (Mount & Dillon, 2012). A limitation of this study as described by the authors was regarding its homogeneity, although it focused on adolescence (between the ages of 12 and 17) the study could capture more specific ages ranges by categorising adolescents into early, middle and late adolescence. Additionally, there could be more consideration of the influence of other family dynamics and relationships, such as the age, gender and birth order of siblings. The authors also identified that the interview schedule was semi-structured and open-ended which encouraged mothers and daughters to speak freely about their experiences and fitted with the IPA methodological design. However, further research should consider the use of a more structured interview schedule in order to develop a holistic understanding of mother and daughter relationships alongside their described research study.

Navot et al., (2017) conducted a study that focused on adolescent daughters with an ASD, with average intelligence and functional verbal communication. This group of females appear to be particularly interesting to investigate because, as described above, they often experience longer delays in receiving a diagnosis, and higher rates of misdiagnosis because they appear to manage their social environment well at school (Rivet & Matson, 2011). Navot et al., (2017) used an interactive process (Erlandson et al., 1993) to explore the maternal experience of raising an adolescent daughter with an ASD, and its impact on the mother-daughter relationship. With regards to the mothers experience they found eight themes: scepticism and delayed diagnosis, disbelief from others, lack of information, increasing social demands with adolescence, struggling with puberty and hygiene, disappointment in physical appearance, sexuality and vulnerability in future relationship and worries about future functioning. The first three themes were regarding the difficulties mothers had accessing services for an ASD assessment, and then difficulties in learning about gender specific ASD presentations in females. Mothers described how school became harder for their daughters as they moved into adolescence due to increased expectations in social functioning. Moreover, they described challenges with puberty, specifically, supporting their daughters to manage their menstruation and hygiene. Mothers expressed concerns in their daughters' abilities to be a part of a romantic relationship, but also their ability to identify harmful predatory behaviour. Lastly, they spoke about a dilemma of wanting to support their daughter to balance typical adolescent behaviour of seeking independence, with having limited skills to manage complex social situations.

With regards to the impact of having a daughter with an ASD on the mother-daughter relationship, mothers described having an early positive vision and the desire to have a close relationship with their daughter. Furthermore, they described feeling guilt and grief in relation to their daughters delayed diagnosis. Mothers also described how their early expectations for closeness to their daughters were not fulfilled. Moreover, they reported having to adjust to their daughters needs by fulfilling ASD related challenges. Finally, mothers spoke about their expectations of having a different type of relationship to the one they initially expected.

This study is the first to provide insight into the mother-daughter adolescent relationship in a specific group of high functioning daughters with ASDs. However, it was conducted in the United States, therefore it would be interesting to explore the similarities and differences to UK mothers' experiences. Moreover, although the analysis of naturalistic enquiry through an interactive process requires the researcher to make meaning from the participants experiences, it does not involve a double hermeneutic process that Interpretative Phenomenological Analysis (IPA) does. This is when the researcher engages in a process of interpreting the participants interpretation of their experiences (Smith, et al., 2009), offering more in-depth reflections of experiences.

Senior (2019) conducted a doctoral thesis using IPA to explore parents understanding of their adolescent daughters ASD over time, capturing pre-diagnosis to post-diagnosis experiences. Senior (2019) aimed to interview both mothers and fathers but only recruited mothers. The researcher found that mothers described their experience of parenting their adolescent daughter as a journey from a position of powerlessness to an expert experience over time. Mothers also identified that social interaction is more difficult to navigate for girls, and lastly, the delay in diagnosis impacted on their daughters' sense of self. This study focused less on mothers' view of their relationship with their daughters, but more on how they perceived their daughters to experience adolescence alongside managing a diagnosis of ASDs. Senior (2019) recruited from online forums which suggests that mothers were either more involved in the upbringing of their daughter or it was mostly mothers who accessed online forums.

Interestingly, both Navot et al., (2017), and Senior's (2019) studies appear to focus on the challenges of parenting their daughters from a perspective of viewing the difficulty within their daughters, rather than within the socially constructed environment with which we live in. The

Social Model of Disability (SMD) challenges this by suggesting that the problems are in fact within society which creates barriers for people living with a difference (Oliver, 1996). This is in line with the premise that the SMD has been more successfully implemented for people living with physical disabilities than neurodevelopmental disabilities (Milton, Martin & Melham, 2016). Not only does this perpetuate ableism, but it also creates a wider gap in the social exclusion of young people with ASD which likely goes against researchers' aims (Campbell, 2008). This is a prominent critique throughout the literature to date and should be considered in the current study.

To summarise, there is a large amount of literature exploring mothers' experiences but very little looking at fathers' experiences. This will now be reviewed.

Fathers' experiences of parenting

As previously referred to, the experiences of fathers are far less researched compared to mothers' experiences, and the evidence-base in fathers parenting their TD adolescent child is limited. This may be because mothers have historically and traditionally been the primary caregiver, and due to their higher involvement may be more likely to experience parenting related stress compared to fathers (Nye & McLaughlin, 1976; Bristol & Schopler, 1983). It is suggested that due to more involvement in parenting and in their child's care, fathers are now more accessible to researchers who focus on the parenting experience. Historically, fathers were only studied if there was a paternal absence or overtly negative dynamics influenced by fathers (Layland, 1981). However, societal changes such as both parents having dual careers and the need for parent-role flexibility mean that parental roles have changed, and fathers are seen to have more equal parenting responsibilities (Diamond, 1998; Rodrigue, Morgan & Geffken, 1992).

A study exploring the experience of South-Asian immigrant fathers from the United States found from using focus groups that fathers of TD adolescents wanted to feel closer to their children and feel more involved in their daily activities. The findings suggest that fathers took on several fathering roles such as being a family provider, their child's teacher, supervisor and disciplinarian (Xiong & Detzner, 2006). However, this sample of fathers may show differing experiences of their roles if conducted with a UK sample.

Regarding reported differences in mothers and fathers in adolescent relationships, the mother is reported to provide a more care-giving role compared to fathers (Cauce & Domenech-Rodrigues, 2000; Updegraff et al., 2009). Mothers also described themselves as more accepting of their adolescent child (Updegraff et al., 2009).

Within the field of ASDs, the low proportion of father's contribution to research appears to be particularly surprising. For example, Cheuk and Lashewicz (2015) summarise that often, the difference in the ratio of participating mothers and fathers is 2:1 (e.g., Twoy et al., 2017). Silverstein and Phares (1996) reviewed dissertation abstracts from 1986 to 1994 for undergraduate, masters and doctoral psychology dissertations and found that fathers were only focused on significantly less (10.5%) in dissertations compared to mothers (59.5%) and both parents (30%). More specifically, fathers' experiences seemed to be particularly neglected in doctoral theses whereby only 10% of fathers were researched, and this focus tended to be on the topic of developmental psychology. Moreover, Zimmerman, Salem & Notaro (2000) supported this finding suggesting a clear lack of evidence exploring a father's perspective into parenting their TD adolescent child.

Furthermore, there also appears to be a difference in participation between mothers and fathers regarding the type of methodology used for data collection. For example, in Davis and Carter's (2008) study, generally, mothers preferred to engage in interviews and questionnaires, and fathers preferred questionnaires. Fabiano (2007) hypothesised that fathers of children with ASDs may not be interested to take part, or alternatively, may not be invited to participate. Interestingly, despite the societal changes in family roles, Cheuk and Lashewicz (2015) outlined that both men and women continued to identify the mother as the child's primary caregiver (Williams, 2008).

Fathers' experiences of parenting an adolescent son with an ASD

Axup (2012) conducted a UK doctoral thesis of fathers' experiences of raising sons with asperger's syndrome using IPA. This study recruited fathers of sons who were aged 11-19. The study identified themes of: self in time, self and identity, self and syndrome, self and family, and lastly, self and world, and parenting as an evolving practice. Axup (2012) found that fathers reflected on their own evaluations of their parenting and wondered about genetic links of asperger's syndrome, as all the fathers queried whether they had asperger's syndrome or carried the genes. Moreover, fathers reflected on their individual and parental developmental journeys. Interestingly, they described their sons as also having two journeys; a journey as an individual and a journey as an individual with asperger's syndrome. Fathers also spoke about their past, hopes and fears for the future for their sons. Regarding the theme of 'self and identity', fathers described that their sons with asperger's syndrome challenged their social identities of man, son, father, worker, and husband. Fathers described their identities as constantly changing in response to their sons' developmental paths, including feelings of masculinity as their idealised image of their father-son relationship had to be adapted to connect with their son. The 'self and syndrome' theme encompassed fathers' evolving relationship with their son's 'syndrome'. Fathers also spoke about themselves in relation to their family and ways of coping with parenting their son. Fathers described feelings of isolation in relation to their mothers enmeshed relationship with their sons. If fathers had other children, they described managing these difficult feelings by being more involved in their other children's lives and providing back up for their wives. Fathers described the siblings embodying a representation of normalcy, which was important for them. They were also concerned about the impact on their other children who they feared were neglected due to the higher needs that their son with asperger's syndrome presented with. In relation to the 'self and world' fathers described their values which were both strengthened and challenged by having a son with asperger's syndrome. Lastly, fathers reported that there was little advice available to support them in managing their sons challenging behaviour.

This study highlighted several limitations. The inclusion criteria involved fathers who lived in the family home. This criterion captures a distinct and traditional group of fathers who have the support of their partners/wives living alongside them. Moreover, the sample recruited were mainly white fathers from middle class background which was reflected in the data where they talked about their childhoods and how their experiences influenced their parenting. The study describes that although these findings are not generalisable, homogeneity of the data is the aim of IPA research. This study appears to be the only study to date that has explored fathers' experiences of parenting their adolescents with ASDs without an intellectual disability, but more specifically a son, using an IPA analysis.

Overall, Axup's (2012) study seems to be the first to use an IPA methodological design exploring fathers' experiences of sons with ASDs. However, there is not an identified study exploring mothers' experiences of parenting their adolescent sons with ASD, nor an exploration of fathers parenting their adolescent daughters with ASDs. Thus, due to limited evidence-base examining fathers in the parenting literature and the need to understand their parenting experiences in relation to their adolescent daughters, this will be the focus of the current study.

Summary of literature review

The prevalence rates of ASDs are much higher in boys than in girls. Additionally, the discrepancy gets larger when considering girls without an intellectual disability; increasing the rates to 6 males being diagnosed to every female (Fombonne, 2009). In addition, little research has explored the experience of adolescence in young people with an ASD. Adolescence is typically, a challenging time for both the young person and their parent, without the added complexities of having impairments in social functioning. Erikson (1967) describes the developmental stage of adolescence as being a time where young people manage psychosocial crises about their identity and roles. Simultaneously, Friedman (1957) proposed that parents have their own developmental trajectory; whereby they learn to build a new life when their child reaches adolescence but remain quietly in the background to support.

The changes that TD young people experience in adolescence will naturally bring about changes in their relationship with their parents. Evidence suggests there is a mild increase in conflict in the parent-adolescent relationship, especially with mothers (Holmbeck 1996). Thus, an examination of their relationship when managing an ASD is of interest during this time. As studies exploring TD parent-adolescent relationships have found both similarities (McCormick & Kennedy, 1994) and differences (Pateson, 1994) in the quality of the relationship amongst genders of the parent and the adolescent, it is useful to explore genders separately to capture unique experiences. Focusing on this high functioning group of adolescents with an ASD, Navot et al., (2017) explored the experiences of mothers raising their daughter and found two categories of findings emerged; the impact that they perceived having an ASD had on their daughter, and the impact of their daughter's ASD on their mother-daughter relationship. Overall, they found challenges and experiences that females with an ASD encompass that are likely to be unique to being a female with their condition, such as puberty and social relationships. Moreover, mothers described their relationship with their daughter to be different than initially expected but still felt able to fulfil a different type of connection and closeness to their daughter.

Lastly, another doctoral thesis explored the experience of fathers with adolescent sons who had a high functioning ASD, using IPA analysis (Axup, 2012). In summary, they found that fathers experiences were uniquely different to Navot et al's., (2017) findings about mothers. They described the impact of having a son with an ASD on their identity, feelings of isolation over their wives being overly involved with their son and the impact this has on their other children, and they also spoke about their values being strengthened and challenged parenting their son, alongside having little support or advice from professionals. This study interviewed fathers who lived with their wives and were from white middle-class homes, therefore encompassing fathers from this particular background.

Research aims

Taken together, these studies provide a better understanding of both parents' experiences, which appear to have some similarities and differences when parenting male and female adolescents. As mentioned previously, although there is a gap in the literature exploring mothers' experiences of parenting sons with ASDs, there is also a distinct gap on exploring fathers' experiences of parenting adolescent daughters with ASDs. A need for exploration of both areas has been highlighted by the literature, however, fathers' experiences will be prioritised. This is because fathers are under-represented in the parenting literature compared to mothers, despite, societal changes where fathers parent equally to mothers (Diamond, 1998). Additionally, there is an increasing focus on male mental health as highlighted by the parenting literature whereby fathers’ emotional support needs are being increasingly demonstrated. As explained previously, adolescent daughters with ASDs are also an under-represented group, leading their needs not being met by both researchers and mental health professionals.

Therefore, the current study aims to explore and better understanding the experiences of fathers in parenting their adolescent daughters with ASDs.

Research aims and question

The current study aims to explore fathers’ experiences of parenting their adolescent daughters with ASDs. This is considered by answering the following question:

What are fathers’ experiences of parenting their adolescent daughters with ASDs?

Chapter Two – Method

This chapter discusses the qualitative methodological approach used to conduct this research, Interpretative Phenomenological Analysis (IPA), its rationale and why other methodologies were deemed are less suited. It will also outline the design, sampling, and recruitment of the study. Finally, it will present the process of analysis, the ethical considerations, and the methodological quality checks undertaken.

Methodology

Qualitative methodological research is concerned with exploring meaning, specifically, how people experience the world and the sense they make from it (Willig, 2013). Whilst this group of approaches will explore human experience in different ways, all will see these elements of experiences as meaningful to peoples "complex" and "multi-layered social world" (Mason, 2002, p.3). Qualitative approaches use methods of data generation, such as interviews, which aims to capture a "rounded" and "rich" understanding of experiences (Mason, 2002, p.3). Unlike quantitative research, a qualitative approach does not search for a cause and effect through standardised methods of data collection such as questionnaires (Mason, 2002).

Within qualitative research, sample sizes are often small which has historically been an area of contention amongst quantitative researchers as this means the findings cannot be generalised to wider groups of people (Smith et al., 2009). However, generalising research findings is not the aim of qualitative research. Instead, it is concerned with exploring detailed, human phenomena, within a small, homogenous, sample of people (Smith et al., 2009).
As qualitative research is "time-consuming, labour-intensive and both imaginatively and emotionally demanding" (Smith, et al., 2009, p.42) it requires researchers to reflect throughout the process about their own responses and interpretation to the data. Thus, my own reflections as a researcher will be captured both in the 'reflexivity statement' in this chapter, but also throughout the research write-up.

A consideration of methodologies

As previously stated, qualitative methodologies encompass a group of related approaches and so, it is important to consider the methodologies which best fit the research question, as the various approaches will offer different views on what they seek to achieve (Smith et al., 2009). Two alternative qualitative methodologies will be considered: Grounded Theory and Discourse Analysis alongside a rationale for why they have not been chosen for this research question. Finally, an outline and justification for choosing IPA will be presented.

Grounded Theory (GT)

Grounded Theory (Glasser & Strauss, 1967) aims to generate a theoretical account of a particular phenomenon (Smith et al., 2009), and usually focusses on that phenomenon's social processes. There are similarities between GT and IPA whereby they both use a broadly inductive process (developing a theory from the data) rather than a deductive process (testing of a theory against the data) to understand the phenomenon. However, a GT study would typically use a larger sample than IPA and develop a more conceptual explanation of the social experience. As this study aims to explore the subjective individual experience rather than the social process of an experience, GT is not considered to be an appropriate methodological analysis in response to the research question.

Discourse Analysis (DA)

DA was also considered as a potential methodology. DA focusses on how individuals personally, socially and politically experience their world through language (Starks & Brown Trinidad, 2007). DA argues that language constructs and mediates our understanding of reality. From a cognitive perspective, it suggests that individuals' verbal expression of their views provides information about their cognitions. Thus, language provides an expression of "what is in their minds" (Willig, 2013, p. 339) and so, is a representation of their mental state.

As such, DA is considered an inappropriate methodology for the current research as it requires focusing on how discourses have influenced fathers' experiences, rather than how the father experiences the phenomena themselves. Moreover, as this topic area has not yet been investigated IPA is considered a more appropriate method as it seeks to explore fathers' experiences without a pre-defined criterion.

Interpretative Phenomenological Analysis (IPA)

IPA involves a detailed examination of lived human experience without any predefined categories (Smith et al., 2009). IPA researchers see 'experience' as occasions or moments in life which becomes significant for an individual (Smith et al., 2009). It aims to engage individuals in a level of reflection about their experience, its significance, and the sense they make of it (Smith et al., 2009). It also assumes that an individual's account of their experience is simultaneous to their thoughts and feelings about it (Smith, 2003). IPA focuses on a small group of people who share similar experiences, i.e., the sample aims to be homogenous. As such, IPA is most suited to this research in exploring fathers' experiences of parenting their adolescent daughters with ASDs. IPA is informed by three theoretical underpinnings: phenomenology, hermeneutics, and idiography (Smith et al., 2009). Although these underpinnings are interlinked in the descriptions already made about IPA, they will be discussed in more detail below to highlight a clearer distinction between the schools of thought.

Phenomenology

Phenomenological research is concerned with exploring human experience, i.e., a phenomenon. It acknowledges that individuals are impacted by their cultural experiences, relationships, and language and aims to understand these experiences more fully (Smith et al., 2009). However, IPA recognises that these experiences are not directly accessible to the researcher or entirely conscious for the participant (Langdridge, 2004). Thus, interpretation is an important co-construct within the analysis.

Hermeneutics

Hermeneutics is the ‘theory of interpretation’ within the analysis, as IPA acknowledges that the researcher is unable to gain direct access to a participant’s world due to the complexity of human experience. Thus, in order to understand an individual’s experience more fully, the researcher is required to reflect on their beliefs, biases, and experiences about their world, and reflect on how these in relation to the participant (Willig, 2013). Therefore, not only does IPA require the participant to reflect on their experience of the phenomena, but the researcher also “tries to make sense of the participant trying to make sense of what is happening to them” (Smith et al., 2009, p.3.). This level of reflexivity means that the researcher is engaging in a ‘double hermeneutic’ process. This illustrates the active role of the researcher whereby, the researcher is a human, like the participant, drawing on everyday experiences to make sense of the world. However, they also only have access to the participant’s experiences and their reports about it. This leaves the participant’s meaning-making as first order, and the researcher’s as second order (Smith et al., 2009).

Additionally, from a hermeneutic perspective, Smith et al., (2009) outline that IPA researchers should combine two stances: an empathic and questioning stance. An empathic stance requires the researcher to ‘stand in their shoes’ in order to see their perspective, but to also occupy a ‘questioning’ stance. This involves being alongside the participant and offering a sense of curiosity and questioning in the sense making process.

Idiography

IPA is idiographic in its focus on the ‘particular’ of lived experience. This means to develop a clearer understanding about the details and nuances of the phenomenon. This theoretical underpinning is the primary rationale for having a small sample size as it is concerned with the detail of an individual experience (Smith et al., 2009).

Methodological stance

Within qualitative methodologies, it is recognised that the researcher is implicated in the research process in some way. Thus, it is important for the researcher to recognise and describe their ontological and epistemological position within the research. Firstly, ontology is concerned with the "nature of the world" (Willig, 2013, p. 61) , i.e., 'what is there to know?' whereas epistemology questions 'how can we know?' (Willig, 2013). Both recognise that it is impossible not to make some assumptions about the world and thus it is important for researchers to state their position in order to understand their methodological stance more fully.

Not only did IPA fit with the explorative research question, but it also fit with my personal approach as an individual, and my professional approach as a psychologist. The epistemological position of IPA aligns with my personal values and professional position in understanding human experience without any preconceived ideas about what might be happening for a person. IPA also requires a significant level of reflection about human experience which the Clinical Psychology profession involves. Subsequently, I am in an advantaged position to understand and engage with the epistemology in order to conduct the analysis appropriately. Due to these reasons, IPA has become increasingly attractive for Psychologists generally (Willig, 2013). Additionally, the ontological position of IPA fits with the social constructionist approach as proposed by Burr (1995). This notion suggests that individuals interpret the same situation in different ways which is influenced by their cultural background history and language. Thus, proposing that there is no universal truth (Burr, 1995).

Data collection

Alongside the methodology, a suitable method of data collection must also be considered. To complement IPA, semi-structured interviews (SSI) were used in this research. A discussion of this method will be presented alongside a rationale about why it was chosen.

Smith and colleagues (2009) argued that IPA is best suited to a method which will invite participants to share rich, in-depth, and detailed accounts of their experiences. To allow for this, two primary methods are considered most appropriate in supporting participants to elicit their stories, thoughts, and feelings about their experiences.

Diaries

Diaries usefully enable participants to share experiences which may feel more difficult when face-to-face (Willig, 2008). However, keeping a diary likely impacts on a participant's daily routine and there is a risk of their shared experience being altered as a consequence. Additionally, studies who have used diaries have reported having poor recruitment and high attrition rates (Willig, 2008). Thus, diaries were not considered a suitable method for the research question and design.

Semi- structured interviews

Due to the level of depth and detail required for IPA, semi-structured, one-to-one interviews are the preferred method of data collection (Smith et al., 2009). Interviews allow for a rapport to be built which provides participants with a level of safety to share and reflect on their experiences. SSIs also align with and allows for the hermeneutic process to occur within the model of relationship required between researcher and participant for IPA (Smith et al., 2009).

A SSI is where the participant is asked a series of open-ended questions based on an interview guide (Smith et al., 2009). A semi-structured interview is preferred over a structured or unstructured interview as it allows for the researcher and participant to engage in a conversation in which the researcher can modify questions or thoughts within their framework, dependent on what the participant shares which other formats would not consider (Smith et al., 2009). The semi-structured nature of the interview allows for a good flow of dialogue between researcher and participant. This encourages a more natural but contained experience sharing of their story whilst having a clear framework about relevant topics of discussion. IPA interviews attempt to address the research question from an indirect or "sideways" perspective (Smith et al., 2009, p. 58). As such, the main research question of 'what are your experiences of having an autistic daughter?' will not be asked directly. Instead, a series of questions will lead the participant to consider and explore their experiences through relevant topics (such as their experience of early fatherhood, their daughter's diagnosis journey and current experience of fatherhood). This allows the question to be answered subsequently through the analysis (Smith et al., 2009). Lastly, as interviews aim to facilitate a dialogue for participants to share their experiences in their own words, much of the interview will require the participant to talk whilst the interviewer listens (Smith et al., 2009).

Method

Research Design

As outlined, this study is of a qualitative design using IPA as the methodological framework for analysing the data collected from semi-structured interviews.

Sampling

Smith et al., (2009) suggest that there is no 'right' sample size, and it often depends on several contextual factors such as the researchers' constraints and the level of richness in the data. They propose that a reasonable sample size for a doctorate project is between four and ten interviews. As this research is only interviewing participants once, this translates to recruiting between four and ten participants. This size is considered sufficient in developing meaningful similarities and differences between participants without the researcher becoming overwhelmed with the data (Smith et al., 2009). There is a risk that if the data set is too large, problems arise in meeting IPA's commitments. As such, I recruited eight participants. This number was considered sufficient within my time scales for the project and with regards to my level of interest by participants in the study.

Participants were recruited using purposeful sampling. Thus, the aim was to recruit a homogenous sample, as recommended by Smith et al., (2009). Homogeneity allows the sample to generate more meaning about their experience of fathering their autistic, adolescent daughters. Although the inclusion and exclusion criteria for the sample will be presented below, it is important to identify elements where homogeneity was challenged within this sample. Due to the timescale limits of the study and because participants were recruited during the COVID-19 global pandemic where families were forced to stay at home and therefore less available than fathers usually would be to have open conversations, it was decided important to invite fathers who have daughters within a wide age range of adolescence (aged 10 – 24) in order to avoid low levels of recruitment. Thus, this may introduce heterogeneity into the sample due to the different stages of adolescent development which occur within this age range. However, the age range of the sample was from 11 – 20 years old, with the majority of daughters being aged between 11 and 15. Therefore, it is felt that heterogeneity of the sample was not too stark. As IPA requires analysing individual participants' interview data first, before conducting a group analysis about similarities or difference amongst participants, any observations where heterogeneity has likely influenced the findings will be highlighted in the results.

Inclusion criteria

- Fathers of daughters who have been diagnosed with an ASD, made by a relevant professional, who do not also have a co-occurring intellectual disability.

  Rationale: ASD without an intellectual disability was firstly guided by the literature as presented in chapter one of this study, as the most recent literature focused on the exploration of experiences of mothers of daughters (Navot et al., 2017; Senior, 2019) and fathers of sons (Axup, 2012). Thus, fathers of daughters have not yet been investigated using an IPA methodology. Additionally, this group of young people are more likely to be misdiagnosed or diagnosed later than the typical age of 5.5 due to their good functional abilities (Howlin & Asgharian, 1999).

- Fathers who have been present during the identified concerns and diagnosis. Fathers do not need to be living with their daughters but should be actively involved in parenting her.

  Rationale: It was assumed that fathers who are not actively involved in parenting their daughter and who were not present during their daughter's diagnosis journey would not have sufficient experience or detail to contribute to an IPA study, where rich, in-depth detail is considered vital.

- Fathers who have daughters aged between 10 and 24.

  Rationale: The World Health Organisation's (WHO) definition of 'adolescence' refers to 10 – 24-year-olds as it aligns more closely with adolescent growth and development in today's society (Sawyer, Azzopardi Wickremarathne & Patton, 2018).

- Fathers where English is their first or second language.

  Rationale: Interpreters may impact on the quality of data collection.

- Additionally, although the definition of 'daughter' was not described prior to recruitment, 'daughter' refers to individuals who are assigned female at birth.

  Rationale: The differences in the presentation of ASD in males and females suggests a biological component, thus, daughters need to be assigned as female at birth.

Exclusion criteria:

- The fathers' daughter has a diagnosis of an intellectual disability or cognitive impairment.
- Mothers
- Daughters who are 9 years or below
- Daughters who are 25 years or above
- Daughters who identify as female but were not assigned as female at birth
- Non-English speakers

Parent Consultant

A parent of an autistic child was recruited as a parent consultant for the research. 'Victoria' is a mother to her 6-year-old daughter with ASD and sensory processing disorder. She was recruited from an email distribution list sent to all parents of special educational needs and disabilities children (SEND) in the Bristol region. This mailing list is managed by a colleague and the co-founder to SENDawelcome: a community promoting the inclusion of children with special educational needs and disabilities.

A mother, instead of a father was initially recruited to be a parent consultant as my initial research focus was exploring mothers' parenting experiences. However, although both mothers and fathers' experiences of parenting adolescent daughters with ASDs is limited in the current evidence-base, fathers were priotised as they are more under-represented in the parenting literature generally. Though, as I required a parent consultant to support me in shaping the research question, I had already recruited and consulted with Victoria before changing the focus. Thus, it would have been inappropriate to consider recruiting a father instead. We spoke together openly about the additional need for a father's perspective, and she agreed that she would hold her husband's experiences in mind, alongside hers as a way of managing the dilemma. Her husband also shared that he was happy to be consulted if helpful, too. As the research progressed, Victoria's husband was often unavailable to have direct conversations with, however, Victoria actively shared her thoughts in addition to her husband's experiences that he had spoken about with her.

Victoria agreed to support the study across four specific time points: 1) an initial discussion about the shaping of the research, including its outline and the proposed research question, 2) reviewing of research documents, 3) to engage in a pilot interview, 4) to discuss the findings of the study after participation has closed.

To thank Victoria for her participation across all four areas of development, she was given £75 from my research budget. This was a Bankers Automated Clearing Service (BACS) transfer into her bank account authorised by the University of Leeds.

Interview schedule

As discussed earlier, semi-structured interviews were conducted using a semi-structured interview schedule developed within the IPA methodological framework (Smith et al., 2009). An interview schedule (see Appendix A) was developed and shaped by a number of influences: through reading of pre-existing literature on relevant topics that had been found to be associated with experiences of parenting autistic children, through a consideration of the research question, through following Smith et al.'s., (2009) recommendations on building an interview schedule, through collaboration with both my research supervisors, my parent consultant and finally with an IPA consultant who facilitated a peer supervision group. This process of review included the continuous shaping and minor changes until it was finalised with a total of 7 questions. These questions were open-ended questions and included some prompts to support discussions and reflection about participants experience, if necessary, whilst also not trying to directly influence their thinking.

Pilot Interview

I completed a pilot interview with Victoria to ensure that my interview schedule covered the appropriate related topics and supported a dialogue about the participants' experiences. I specifically wanted to ensure that the questions asked were phrased in an appropriate, helpful way to elicit thoughts and reflections. I also aimed for the interview to last between 1 and 2 hours as this seemed sufficient for a participant to engage meaningfully in an interview about their experiences. The pilot interview lasted 1 hour, 24 minutes. Victoria provided helpful feedback about the phrasing of questions. Following this, I changed the wording of one question in the schedule regarding when fathers first had "concerns" about their daughter's development. Victoria told me that they may not have had concerns specifically, or other people in their daughter's life might have identified ASD. Therefore, following my pilot interview, I changed this question to, 'tell me about how your daughter's diagnosis came about?'.
This change created more room for different experiences and did not assume the ASD was a concern specifically.

Procedure

Recruitment

Out of the eight participants, two were recruited from local third-sector organisations who support young people with ASD, and the final six participants were recruited from a Facebook group for UK parents of daughters with autism. This involved emailing the organisation to ask them to share the study's poster on their social media page (see Appendix B for recruitment flyer). Additionally, the recruitment poster was shared by the researcher in the specific Facebook group. All participants contacted me via email to express interest in participating in the study. No participants were screened out during the initial email contact.

However, three participants expressed interest in an initial email but did not respond to a follow up email, sent as per the approved ethical procedure. Interestingly, these emails were from mothers on behalf of their daughter's fathers. Two further fathers were declined participation in the study as it was deemed to be fully recruited. These fathers were declined participation as a maximum sample size of eight participants was considered most appropriate in line with the time constraints of conducting the study. This was discussed and decided in collaboration with my research supervisors and the recommendation by Smith and colleagues (2009) who stated that a doctoral thesis should aim to recruit between 4 and 10 participants.

Participants

Eight fathers participated altogether from the described avenues of recruitment. The Facebook group described above generated significant interest where fifteen parents expressed interest for their daughters' fathers. This included mothers expressing an interest on fathers' behalf. However, following the expression of interest, eight fathers agreed to participate. Further detail about individual participants will be discussed in the pen portrait section of the results in chapter three.

Interviews

Planning for recruitment occurred prior to the COVID-19 global pandemic and so, this study was given ethical approval to conduct interviews both face-to-face and via video call. As the study was not limited to the Leeds area, ethical approval was granted for participants who lived further afield to participate in their interview via video call on a video platform such as Zoom. Participants who lived locally could attend a face-to-face interview at the University of Leeds or in their home. However, due to the global pandemic all participants were seen via video call on Zoom. The interviews lasted between 1 hour 19 minutes and 1 hour 48 minutes. All interviews were audio recorded.

Before the interviews started, I reminded participants about respect for their privacy. This is where if they felt uncomfortable in answering a particular question, they should inform me and we would move onto the next one. As the interviews were conducted remotely over video call, I reminded participants about confidentiality within this context, specifically, that their interview would not be overheard by anybody in my environment and to protect this within their environment. Similarly, if either of us were disturbed then the interview would pause, and we would resume when it is appropriate to. Additionally, if either of us experienced any technical difficulties and our internet connection failed, then we would try to re-connect. If this did not work, then I would have attempted to contact them via other means they had provided me (email or phone). I also checked their eligibility to participate in the study before starting. The interview schedule was constructed in such a way that contextual questions were asked at the beginning to gain an understanding of participants' backgrounds. This also aided rapport building. As mentioned previously, building rapport is vital for participants to feel safe and comfortable in sharing their personal experiences (Smith et al., 2009).

The interview schedule was followed but used flexibly in accordance with the participant's responses to the questions. Prompts were used to encourage further curiosity and sense making of an experience. Similarly, participants were also asked to elaborate if they provided brief answers.

Prior to, during and following the interview, I recorded my personal reflections in a reflexive log about my experience of the participant and their interview to aid my reflexive position. I then referred back to these reflections during analysis.

Transcription

All interviews were audio recorded and transcribed including all of the non-semantic content (e.g., sighs, pauses, laughs). I transcribed the first interview myself to engage with the process of transcribing and to familiarise myself with it. The remaining seven interviews were transcribed by a University approved transcriber. Any identifiable information from the interview was anonymized. Before conducting the individual analysis of each interview, I re-listened to the audio recording whilst reading the transcript to identify any errors and edit them accordingly.

Data Analysis

When conducting my IPA analysis, I followed the six stages as recommended by Smith et al., (2009). To support me with conducting the analysis, I attended IPA workshops with my peer group, offered by an IPA consultant at the University of Leeds which were facilitated throughout the project's different stages. I analysed each participant's interview individually and then conducted the group analysis. The six steps which made up the entire analysis are outlined below. It is important to note that whilst my confidence grew with the process of analysis, the steps began to merge more closely together. I will note how this occurred with each step within the descriptions of them below. Whilst conducting the analyses, I kept reflexive notes which will be presented in text boxes alongside the presentation of findings within the results chapter.

Step 1: Reading and re-reading – familiarising myself with the data

Prior to beginning the first step of the analysis I created a Microsoft Word document in which I copied the transcript into with wide margins both sides of the page in order to make notes about the data. I labelled one side of the page 'initial noting' and the other side 'emergent themes' to prepare myself for further steps in the analysis. I began each individual interview analysis by listening to the audio-recording of the interview whilst reading the transcript. This process allowed me to remind myself of tones or gestures which the participant may have used in line with the text, which I noted. I then read the transcript again and highlighted parts of text which stood out to me as being particularly interesting. During this stage, I also 'chunked' the data into sections which were divided into 'off topic' and 'on-topic' as a strategy for helping me to keep the research question in mind and to prevent feeling overwhelmed with the data. The 'off topic' chunks were used as contextual information for my pen portraits which I copied into a Word document and used as bullet points. The 'on topic' chunks were used specifically for my analysis. During this stage of analysis, I also made reflexive notes throughout which continued from my notes made before and immediately following the interviews. This was a particularly interesting process as I found that my reflections were often different and already more interpretative, as this stage allowed me to 'zoom out' from the interview more and see my initial reflective notes from a different angle.

Step 2: Initial noting and further immersion

This next step involves making initial, line-by-line notes after having familiarised myself with the text. As Smith et al., (2009) described however, steps 1 and 2 began to merge as I grew more confident with the process of analysis. This is where I began to make notes whilst reading and re-reading the text. As Smith et al., (2009) advised I initially made notes on the transcript using three focusses on the data: descriptive information (describing the content of what is being said), linguistic comments (focusing on the specific use of language) and conceptual comments (more interpretative comments about what the participant is saying). I used different coloured fonts to categorise the comments in my notes. An example of this can be seen in Appendix C. However, it should also be noted that this phase also developed more throughout the analyses as I made less descriptive notes, the more I became familiar with the process. This led me to focus more on the linguistic and conceptual notes, helping me to build interpretations from the text. This is because it became less helpful as I had already developed a good understanding of the data during the reading and re-reading step of the process. During this step I also highlighted quotes which stood out from the text which I could look back on for the later stages of analysis.

Steps 3 and 4: Developing emergent themes and searching for connections across them

This step involved re-reading the notes I have made and searching for connections between them to make up some emergent themes. I noted these themes by hand on paper as seen in Appendix D in order to help me separate from my conceptual note taking. During this stage I also copied my quotes into a Word document to help develop the themes and use as a reference point, see Appendix E. My emergent themes were re-defined several times to develop superordinate and subordinate themes. I also re-read the transcript holding the themes in mind to ensure it covered the data. This stage was frequently shared in supervision and was re-defined further after these conversations as at this stage, my supervisors helped me to ‘zoom out’ from the themes further and support interpretation. When the themes were finalised, I typed the superordinate and subordinate themes into a Word document and copied the quotes to support the rationale for the chosen themes. See Appendix F for an example of this stage of the analysis for individual interviews. I have not presented themes from each individual analysis of participants in the results chapter as there are overlaps in the group themes, but key individual experiences will be detailed in the pen portraits.

Step 5: Moving onto the next case

Here, I repeated the first 4 steps for each participant before finally moving onto the final stage of analysis where I searched more widely for connections across individual participant themes.

Step 6: Looking for patterns across individual participants' themes

This involved looking for patterns across individual participant cases. I conducted this stage by identifying patterns and putting them into an Excel table and considering which participants they applied to. This was a constantly evolving process and was revised with numerous re-visitings of the transcripts to capture group experiences as opposed to individual experiences. As part of this process, group theme names were changed several times in order to capture the essence of the experiences for all participants. Again, I shared this process several times with my supervisors who again, helped me to ‘zoom out’ and capture and name my interpretations of the data. I found the discussion of themes out loud helped me with this process and to see how confident I felt in their application to participants. See Appendix G for different versions of my superordinate and subordinate themes before they were finalised. These discussions also included reflections about the data which is captured in my results.

Ethics

Full ethical approval was granted from the University of Leeds School of Medicine Research Ethics Committee (SoMREC) on 14th August 2020 (MREC19-084) (see Appendix H). The ethical considerations for the study are outlined below.

Ethical considerations

Informed consent and confidentiality

On expression of interest via email, all eligible participants were forwarded the participant information sheet (PIS) (see Appendix I). When agreement for participation in the study was confirmed, verbal consent was sought prior to the interview starting in line with the University of Leeds verbal informed consent protocol for all interviews. Thus, the participant consent form was used as a reference only (see Appendix J). A script at the beginning of the interview schedule was used to seek verbal consent (see interview schedule in Appendix A).

Prior to the interview taking place, the participant was reminded of the key points from the participant information sheet to ensure they gave their informed consent. These were:

- The participant's personal information and interview was being kept strictly confidential. However, if they disclosed that they or others were at risk of harm, it is my duty of care to inform the appropriate services.
- Their interview was audio-recorded and was to be deleted following transcription of the data.
- The participant could withdraw their data up to 7 days following the interview without giving a reason.
- Results of the study may be published in a journal article, and the participant will not be identified in any report or publication, including in the thesis-write-up.
- The participant was then asked again to confirm their informed participation.

Managing withdrawal from the research

Participants had the right to withdraw before, during or after completing their interview without giving a reason. After seven days, it was not possible to as the analysis would have already been started. None of the participants requested to withdraw their data from the project.

Managing participation

All participants were given at least 24 hours between expressing interest and participating in the study so that they had time to reflect and potentially change their mind. If the participant expressed an interest but did not confirm their participation within 7 days, then an email reminder was sent (see Appendix K). If they did not reply to this, then another email was sent 3 weeks later. No more emails were sent after this. This follow-up procedure applied to 2 of my participants who eventually participated in the study.

Participant distress and management of risk

It was recognised that there was a risk of the interview triggering distress for the participants when being asked about their experiences. The PIS highlighted this risk and outlined that, participants could terminate the interview at any time should they wish to. This was also reiterated at the beginning of the interview. Participants were also informed that if they did not feel comfortable in answering a question, they did not have to. It may have been suitable to signpost the participant to services such as their GP or MIND charity should they have wished to seek further support following the interview. If this was required, participants would have been informed that it is their responsibility to co-ordinate this.

If the participant was to disclose information that placed themselves or others at risk of harm, then safeguarding procedures would have been followed. This would have involved a discussion with my supervisors, who are experienced Clinical Psychologists, to guide me to follow the relevant procedures.

The interviews were also conducted with sensitivity and supervision could have been sought if I felt that my own experiences impacted the interview. Whilst several participants became tearful during the interview, their distress was appropriately supported. Following the interviews, the participants were asked how they felt, and all informed me that although the interview discussion brought up some difficult feelings, it was helpful to talk about and became a cathartic experience. As such, procedures to seek further support was not discussed.

Data storage and protection

The PIS informed the participants that their interviews were recorded on an audio recording device and would be kept securely electronically as permitted by the University Information Security Policy. As such, the recordings from the device were transferred immediately onto the secure area and deleted from the audio recorder. All recordings were stored on the University OneDrive and encrypted accordingly, then deleted following analysis. Likewise, the participants demographic information would also be stored in the named secure areas. All data was kept in line with the University Data Protection Policy. Transcribers, approved by the University of Leeds were employed to transcribe seven out of the eight interviews. The transcribers were required to complete the Leeds Institute of Health Sciences transcriber confidentiality form in line with the University Data Protection Policy. Recordings were shared with the transcribers via temporary access to my University OneDrive. In line with the PIS, all participants were reminded that only me and the transcribers had access to their raw interview data.

Quality checks

Qualitative research can be checked for its credibility of findings. Two key frameworks have been developed by Elliott, Fischer and Rennie (1999) and Yardley (2000, 2008) to assess valid and reliable findings and were used to check the quality of this research study's results. Elliott, Fischer and Rennie (1999) identified seven quality criteria: 'owning one's perspective', 'situating the sample', 'grounding in examples', 'providing quality checks', 'coherence', 'accomplishing general vs specific tasks' and 'resonating with the reader'. Additionally, Yardley (2000; 2009) discussed the following as being important in quality checking the data: 'sensitivity to context', 'commitment and rigour', 'transparency and coherence', and 'impact and importance'. The quality checks that I conducted in relation to both frameworks are discussed in Table 2 below:

Table 2. Quality checks conducted in line with the current study.

Quality check	**Evidence**
Sensitivity to context and situating the sample *(Elliott et al., 1999; Yardley, 2000)*	Participants' context was sensitively considered during analysis and documented in my reflective log. A core contextual factor which I reflected on throughout was the impact of the COVID-19 global pandemic on fathers' current experiences. In the write-up, I presented participants' demographic information and provided detailed pen portraits to situate their experiences. Despite this, I felt on-going worry and concern throughout my analysis and write-up about demonstrating fathers' contexts adequately as I wanted each father's unique contributions to be captured. In addition to discussions about different ways to document fathers' backgrounds, supervision also helped me to reflect on the unconscious processes that may have been occurring which contributed to this worry. A reflection on this is captured in the results section.
Transparency and coherence, and grounding in examples *(Elliott et al., 1999; Yardley, 2000)*	I aimed to capture transparency and coherence in my write-up through use of participant quotes and reflective boxes, which also helped to ground participants' examples. The use of figures and tables in the results, and the additional documents in the appendices aimed to support this too. To aid transparency and coherence, I noted reflections throughout the process of my analysis which aided my development of themes. This helped me to consider the hermeneutic stance of the process. These reflections are captured in text boxes throughout the results chapter. I also aimed to clearly document the method, for example, by describing the recruitment methods and how the interview schedule was constructed.
Owning one's perspective	I have aimed to be as transparent and reflective as possible about my own perspectives in the process of conducting this research. I have owned my

(Elliott et al., 1999).	own position and assumptions about fathers and parenting, in addition to my lack of personal experience with ASD. Conversations with supervisors, peers in the IPA supervision group and with the parent consultant helped with my reflexivity, some of which has been captured in the results chapter.
Providing credibility checks and commitment and rigor *(Yardley, 2000 (Elliott et al., 1999)*	My analysis involved several credibility checks which were discussed with my research supervisors, the IPA supervision group, and the parent consultant. Research supervisors: I utlised regular supervision throughout my research. I used this space for reflection throughout the entirety of the process, in the shaping of the research and finally throughout every process in the analysis and write-up. Supervision helped me to consider different perspectives and 'zoom out' from my position. The reflective conversations had in supervision linked with 'owning one's perspective' where I aimed to be reflexive as possible IPA supervision group: The aim of the IPA sessions was to develop an increased knowledge and understanding of IPA, and to use the group to bring IPA related issues or questions that arose within my research. I also used individual supervision alongside this group to discuss IPA methodology as my supervisors are also experienced in supervising IPA doctoral theses. I used my individual supervision to discuss my specific interview data, and the group for more general questions and a review of my interview schedule. These processes helped me to gain different perspectives following my own immersion in the data. I recorded the changes and refinements of the themes which I re-visited during my write-up. An example of the refining stage of the group themes is captured in Appendix G, Parent Consultant: These conversations helped me to consider the power imbalance between myself and participants (demonstrated in feedback given from documents in relation to wording used) and in its relevance to

	parents (demonstrated by sharing thoughts about experience which the researcher had not considered due to limited lived experience of the topic). I also piloted the interview schedule with my Parent Consultant to be mindful of how other parents may receive the questions asked. Additionally, my two supervisors are parents themselves (a mother and a father separately) and so provided further insight into parents' perspectives I also shared my individual and group themes with my parent consultant. Doing this provided a helpful insight as she linked some experiences to that of her husband's experience of parenting their younger daughter. This contributed to the validity and reliability of the findings as the themes seemed to have face value to another father with a similar experience. My reading and re-reading of the data provided quality checks in immersion of the data. This also provided an opportunity to position myself in different perspectives when reading it. It would have strengthened the credibility of the results if they were shared with the fathers who participated. However, due to the time limitations this was not possible. As such, this could be considered for future research.
Resonance with readers, and impact and importance *(Elliott et al., 1999 and Yardley, 2000)*	The current research study is the only one to my knowledge which explores fathers' experiences of parenting adolescent daughters with ASDs. Detailing the findings and discussing the results within the wider context of literature aimed to resonate with readers and demonstrate the importance and impact of the study.
Accomplishing general vs	As will be discussed below in 'limitations', the homogeneity of the sample means that the findings cannot be generalised to all fathers as this sample only captures a socially privileged group. However, the findings indicated

specific research tasks *(Elliott et al., 1999)*	that there were some similarities across the group and thus, have been discussed in relation to other research studies. Therefore, both general and specific tasks have been considered.

Reflexivity

As already mentioned, within IPA the epistemological position and reflexivity of the research is important to capture in order to hold awareness about the double hermeneutic process (Smith et al., 2009). An epistemological position acknowledges that the theoretical underpinnings of IPA and the researcher occupy their own beliefs and assumptions independently (Axup, 2012; MacDonald & Stodel, 2003). As the researcher can never maintain a neutral stance, it is important to share my position in relation to the research topic (Mason, 1996). Thus, I will be sharing my reflections about the findings in the results in chapter three.

Reflexive statement

As mentioned in Chapter one, I was guided towards the topic of parenting because of my interest in it and thus, I will have biases in my approach towards parenting. I am not a parent, but I do have the experience of being parented and have friends and family who are parents.

My mother and father separated at a young age and most of my childhood was spent being parented by my mother. Interestingly, my father holds some stereotypical views about parenting in which mothers, generally, are the primary caregiver. As such, I was initially interested in exploring mothers' experiences of parenting, however, although the literature highlighted a gap for mothers and fathers' experiences of parenting their adolescent daughters with ASDs, an exploration of fathers was prioritised due to an additional under-representation of their general experiences of parenting in the literature. On reflection, my initial response to this was hesitation in changing my research focus to fathers, perhaps due to my assumption that fathers occupy a less active role in parenting, despite being open to and knowing the different roles of fathers within families. I now understand that not only has this assumption developed from my experiences of being parented but also in the social construction of parenting in which fathers have historically occupied a less active role (Lamb, 1997). However, despite societal changes which mean that mothers and fathers are more likely to parent equally (Diamond, 1998), this gender bias was present in my assumptions across several instances in my research. One example was regarding my recruitment, i.e., that it would be more difficult to recruit fathers than mothers, not only due to the historic socially constructed view that males (and fathers) share their emotional experiences less, but also that they would be less willing to do so. These assumptions have been challenged and reflected on throughout this research.

With regards to ASD, I do not have personal experience of living with or parenting a child with ASD, but I have developed a theoretical and clinical understanding of ASD through my role as a trainee clinical psychologist when working directly with families of children with ASDs. However, this experience is limited. Thus, I will continue to notice when both my theoretical assumptions, and the assumptions I developed from my direct clinical work with family’s impact on my analysis. Therefore, I endeavored to capture assumptions which arose in the interview and analysis.

Chapter Three – Results

This chapter presents the findings from the study. Firstly, the participants' demographics will be presented to outline the sample of fathers interviewed, see Table 3. Following this, the pen portraits will provide contextual information about each participant. The group analysis will then be described. Firstly, the findings for the group analysis will be presented in a diagram showing the three superordinate themes with their corresponding sub-ordinate themes. The themes will be presented in a table to capture which participants they apply to. The detailed descriptions will follow, capturing extracts from the participants to illustrate the themes connected to their lived experiences.

Table 3. Demographic information of participants.

Participant number	**Participant pseudonym**	**Age**	**Daughter pseudonym**	**Age of daughter**	**Age of daughter when diagnosed with an ASD**	**Siblings and age (if applicable)**	**Ethnicity**	**Marital status**	**Lives with daughter**	**Length of interview**
1	Paul	48	Charlotte	18	16	One sibling, aged 21	White, British	Married	Yes	1 hour, 47 minutes
2	Robert	41	Olivia	11	7	No siblings	White, British	Married	Yes	1 hour, 48 minutes
3	James	47	Emma	12	9	Two siblings, aged 3 and 4	White, Scottish	Married	Yes	1 hour, 19 minutes
4	Patrick	60	Alex	20	13	Four siblings, aged 35, 34, 24, 22.	White, British	Married	Yes	1 hour, 48 minutes
5	Ryan	48	Maeve	15	13	Two siblings, aged 9 and 17	White, British	Married	Yes	1 hour, 20 minutes
6	John	44	Grace	14	10	One sibling, aged 12.	White, British	Married	No	1 hour, 25 minutes
7	Geoff	60	Hannah	13	12	Two siblings, aged 9 and 12.	White, English	Married	Yes	1 hour, 39 minutes
8	Frederick	55	Leah	15	14	One sibling, aged 18.	White, British	Married	Yes	1 hour, 5 minutes

The sample

Before each participant will be described in more detail in their pen portraits, it is important to consider the nature of the sample of fathers recruited. Table 3 above highlights the participants' demographics, including their age, age at their daughter's diagnosis, living arrangements and marital status.

It is interesting to note that all fathers in the sample are married and living with their spouses. Though the participants sexuality was not recorded, all fathers commented on being heterosexual and were living with their wives. This is consistent with the UK 2021 Census (Office for National Statistics, 2021) data reported in chapter one which highlights that although families are becoming increasingly more diverse, opposite sex married families remain the most common in the UK.

These demographics also highlight that all fathers were White British. This is interesting to highlight as the population of White people living in the UK has been recorded as 86%, with people from Asian ethnic groups at 7.5% and Black ethnic groups at 3.3%. Additionally, mixed/multiple ethnic groups were recorded at 2.2% and other ethnic groups at 1% (Office for National Statistics, 2011).

These demographics are also interesting to consider in relation to the prevalence rates captured in chapter one which states that, the prevalence rates of ASD were highest in Black children across English schools, at 2.11%.

Whilst the sample of fathers recruited have captured White, married fathers, both of which are UK majority groups, families with higher prevalence rates of ASD in the UK have not been captured, notably, Black families (Roman-Urrestarazu et al., 2021). This is an important consideration in the discussion of the results, fathers' experiences, and later implications.

Pen portraits

In this section of the chapter, I will present a pen portrait for each participant. Both fathers and daughters have been allocated a pseudonym to protect their identity. Firstly, I will briefly outline their context, their experiences of their diagnosis journey with their daughter and finally my reflections from the interview. Pen portraits have been included to present each participant's individual stories in addition to the group themes. These are presented in chronological order of participant number.

'Paul'

Setting the context

Paul lives at home with his wife and daughter, Charlotte. Paul also has a 21-year-old son who is living away at university. Paul disclosed at the beginning of the interview that during the process of Charlotte's ASD diagnosis, it became clear that he likely has ASD himself, as does his wife and son. Thus, he shared that the driving force for participating in this study was a combination of sharing his own challenges of getting *"through life"* struggling (line 71) and from the difficulties that his daughter is experiencing from receiving a *"late diagnosis*" (line 27) which he feels has *"had a profound impact on her development"* (line 27).

How was ASD identified?

Charlotte was referred to a Child and Adolescent Mental Health Service (CAMHS) because she was experiencing high levels of anxiety and was self-harming. Here, the process began of assessing Charlotte for an ASD. At the time, Paul simply *"did not see Autism"* (line 245) as Charlotte *"fitted the mould"* (line 234) of the household as they are all shy and introverted people.

Current feelings about diagnosis

On retrospect, Paul *"kicks"* himself (line 438) for not noticing Charlotte's ASD, and now describes understanding Charlotte's traits and 'masking'. Throughout the process of attempting to improve Charlotte's educational experience, Paul identifies as being her 'champion': the strong voice who advocates for change. Paul spoke openly about how Charlotte's diagnosis initiated increased awareness about himself, his family context and about his relationship with Charlotte.

Reflections: my experience of the interview

Paul quickly told me that "communication isn't one of [his] strengths" (line 69) which appeared to act as a disclaimer in his experiences, and highlighted to me that this was an area which he lacked confidence in. However, I did not perceive Paul to be this way.

Additionally, I was struck by the way in which Paul shared his experiences. They appeared to be communicated tentatively but in fact, also appeared to be well thought-through. For example, he often added 'ya know?' at the end of his sentences. This left me feeling confused about his clarity in his explanations and experiences. I suspect that his lack of confidence in his communication contributed to this, but I also wondered whether he was worried about being met with judgement, perhaps reflective of his past experiences. On reflection, I also wonder whether this adjunct invited me in to connect and hear his experiences, as I suspect Paul had had limited opportunity to talk about them in this way. Paul shared with me at the end, that the interview was a cathartic process.

'Robert'

Setting the context

Robert lives at home with his wife and daughter, Olivia. Robert shared that he wanted to participate in the study because, due to his background in community engagement, he thought he *"knew an awful lot about autism before it became a personal thing"* (line 4). However, he has since realised that he *"knew nothing about it!"* (line 5).

Additionally, Robert described Olivia as being passionate about feminism and her gender identity and thus, describes her as being "*gender fluid"* (line 1082).

How was ASD identified?

Robert described that his wife noticed that when Olivia started school *“something was different”* (line 372). However, Olivia did not fit with Robert’s idea about what ASD looked like. He shared initially thinking that *“if she’s got communication skills, then she cannot be autistic?”* (line 389). However, within 2 weeks of a supply teacher coming into Olivia’s class Robert went from, *“ah, do you think, do you think really?”* (line 404) to noticing that Olivia was “*being everything you’d expect”* (405). For example, *“she would sit at home and rock, she would refuse to talk, she’d scream, she’d make very loud noises, she’d run around flapping”* (line 406). Following this, school referred Olivia for an ASD assessment and within a year, she was diagnosed. Since this time, she has also been diagnosed with ADHD, Dyslexia, Irlen’s syndrome and is being investigated for Epilepsy.

Current feelings about ASD

Robert described the initial process of seeking an ASD diagnosis for Olivia as a *“bureaucracy rather than a journey”* (line 442). However, he has also shared the significant emotional demands in parenting Olivia, particularly with regards to supporting her with her mental health alongside her ASD.

Robert additionally shared that since learning about Olivia’s ASD, his childhood has made more sense to him. He described that his *“family situation as a child was very odd”* (line 243) partly because his father, he *“would now say, has autism”* (line 243).

Reflections: my experience of the interview

I experienced Robert as very articulate in communicating his experiences. His satirical sense of humour appeared to help him in managing his difficult feelings when talking about them. Robert described at the end of the interview that despite him finding it a cathartic process, he acknowledged the strong emotion that this triggered in him. Interestingly, although the emotion was understandably strong, I did not feel his emotion in the interview. In fact, I felt that he appeared disconnected from his feelings. Thus, this appears to be Robert’s way of coping.

‘James’

Setting the context

At home, James lives with his wife, daughter Emma, and other two children (aged 3 and 4). As the interview was conducted during the COVID-19 pandemic, he described feeling particularly isolated due to the restrictions, his rural location, being wintertime and having experienced a close bereavement.

How was ASD identified?

Emma was referred to CAMHS because she experienced high levels of anxiety. CAMHS subsequently identified and diagnosed ASD. It is interesting to note that seeking and being diagnosed with ASD did not appear to be a strong narrative in their story as a family. Rather, their focus and challenge appeared to come from Emma’s anxiety, and in the daily challenges in supporting her with this.

Current feelings about ASD

James’ shared some background about his childhood which appears to have shaped his role as a father and triggered some challenge in parenting Emma. For example, James shared that he *“didn’t have the parental role models”* (line, 178) as him and his dad *“never really clicked growing up”* (line 178). Therefore, it was important to him to be connected and supportive of his children. It also appeared to shape his values to be independent, motivated, and ambitious. However, ASD appeared to challenge these hopes for Emma. As such, there were strong themes of frustration throughout his accounts. He shared that Emma *“gets the complete opposite”* that he got from his parents, *“she’s getting that belief and that confidence and that one-to-one support, and our time, and it just doesn’t seem to rub off on her”* (line766). Therefore, it appeared that James struggled with his understanding and acceptance of ASD leading to a lack of resolution in their relationship. This perhaps suggests that James is earlier on in his developmental journey of acceptance, compared to other fathers interviewed.

Reflections: my experience of the interview

I appreciated the openness and honesty that James approached the interview with. James' authenticity left me with feelings of sadness. There was a felt sense that James is trying his absolute best for his daughter but is finding the difficult feelings of perceived frustration and resentment difficult to manage. I wondered whether feelings of frustration were particularly present for James as he appears to value his independence which is challenged as Emma is particularly reliant on him, seeking *"constant reassurance"* (line 521). However, he clearly values his family unit and holds a lot of love for his wife and children which came through strongly in his accounts.

'Patrick'

Setting the context

Patrick's daughter, Alex, was the oldest out of the daughters at age 20. Patrick shared that Alex identifies as non-binary; therefore, Alex will be referred to as 'they' in this write-up.

Alex is the youngest of Patrick's five children and they still live at home with Patrick, his wife and one older sister (aged 22), they also stay with their partner.

Alex was diagnosed with ASD and later, Pervasive Developmental Disorder (PDD) which is a sub-type of ASD. The whole family is diagnosed with ASD, apart from one child who is *"bog standard, neurotypical"* (line, 101). Due to being diagnosed later in life, Patrick described his family as *"late realisers"* (line 135).

Prior to Alex's ASD diagnosis, Patrick and his wife were a part of the Fundamentalist Christian Church which he described as being their *"entire life, all our friends, all our family, everything!"* (line 1058). However, when Alex was diagnosed with ASD, Patrick realised that their *"wonderful fundamentalist church became more and more cult-like"* (line 1050).

How was ASD identified?

Patrick explained that he was friends with a couple who initially identified his wife as having ASD*, "she said to me, you do realise your wife's autistic, don't you?* (line 288). Then when she got to know the family better, this person shared *"watch out for [daughter], watch out"* (line 299). He explained that they then "started to put the pieces together, and then at school, they were beginning to see her getting in trouble for things that were not her fault" such as *"not getting her homework in on time"* and *"spending inordinate amounts of time on some homework"* (line 299). Following this, Patrick was also diagnosed as were his other children. He described that *"before that, unless somebody had actually said "you do realise your daughter's autistic don't you?" We would have thought, hmmm, just a fairly introvert type."* (line 126).

Patrick explained that Alex's high levels of anxiety escalated to a mental health crisis when Alex threatened to attempt suicide. Following this, Alex *"refused to engage with us, with any teacher, with any authority, the police, Barnardo's, local authority, doctors, teachers, there was absolutely no engagement, she completely shut herself off from everything"* (line 456). Therefore, the family experienced a number of years following Alex's diagnosis of struggling to support them, with their mental health.

Current feelings about ASD

Due to learning about Alex and her needs "*over the space of two or three years, just observing [daughter], and putting together with my observation that what is wrong with the church that we were in"* (line 1113), Patrick's world view shifted whereby his values and beliefs changed. He described realising that *"this all falls apart, the church bit falls apart, it doesn't hold water. What [he] thought about relationships doesn't hold water"* (line 1116). Patrick now sees in "*front of [him], this works, and this is brilliant, and this is good"* (line 1118). He reflected that *"it's almost as if both things needed to happen. [He] needed to be out of the church environment, and [he] needed to see what actually life is like out here, and it's okay"* (line 1119).

Reflections: my experience of the interview

I experienced Patrick as finding it difficult to initially access his emotional experiences. Patrick explained that because of his ASD, he often finds it difficult to describe and express his feelings. However, I also wondered whether it felt emotionally difficult to access as well. Once we built a trusting rapport, Patrick shared these difficult feelings and experiences with his daughter. When this occurred, the interview became incredibly emotive. Due to this, I found that during the analysis and write-up of Patrick's experiences, I felt concern about not doing a good enough job of fairly representing or capturing Patrick's experiences.

'Ryan'

Setting the context

Ryan lives at home with his wife, daughter Maeve and two other children (aged 17 and 9). Maeve is their only child diagnosed with ASD. Both Ryan and his wife described valuing their careers as well as family life, and both hold senior positions within their work. Ryan explained that due to Maeve's ASD and mental health difficulties, he decided to step down from his position as director in his company to ensure he was more present for Maeve. He shared that he hopes to take this position back up again at some point in the future.

How was ASD identified?

Interestingly, much of the interview was focused on Ryan's experience of how Maeve's ASD diagnosis arose, due to her mental health difficulties. Ryan was very open in his experiences about his daughter's mental health struggles, and with her mental health crisis which led to Maeve spending a period of time in hospital. Ryan described being unaware of Maeve's mental health difficulties until he *"got a call from the school chaplain and it turns out that [daughter] had been to see the school chaplain [clearing throat – emotional] and he was quite concerned about her because she just said "I just don't want to go on anymore with life. It's it's all got too much for me."* (line 181). He described this phone call as being *"a bolt out of the blue*" and something that he *"didn't expect"* because she *"always seemed again, normal, you know, like there's nothing going on in the background whatsoever"* (line, 185). He described that the phone call *"changed the rest of our life in lots of ways"*. (line 185).

As such, Maeve spent some time in hospital and was diagnosed with ASD whilst she was there. Ryan shared that it was a *"massive shock"* as Maeve *"wasn't what [he] thought autism is all about and how it kind of, manifests itself"* (line 303).

Current feelings about ASD

Throughout the rest of the interview, Ryan shared difficult feelings, experiences and reflections in relation to living with ASD and Maeve's co-occurring mental health difficulties. Maeve self-harmed and he described feeling *"naïve"* about this, and like he had previously *"lived in a little bubble"* as he *"didn't even know what self-harm was"* and had *"never really heard of self-harm"* (line 391) before. Ryan shared that *"talking about"* that period of time is still *"really raw and emotional"* (line 118). As such, it appeared that Ryan is still processing much of what has happened regarding his daughter's mental health. Additionally, although Maeve's mental health is now stable and being appropriately managed, *"he can't pretend"* that her ASD is not "*still a bit weird"* for him, because Maeve *"just looks a bit different"* (line 456).

Reflections: my experience of the interview

Ryan's interview was also incredibly emotive. From Ryan's accounts, it appeared that Ryan had not shared his feelings and experiences about his daughter before. He reflected that this was likely because he held a stereotypical view about being a father, i.e., that fathers are needed for strength and support, and do not often show their emotions because of this.

I also held a strong sense that Ryan is still confused about his daughter's ASD and how it presents itself. It is interesting to note that Ryan was keen for me to meet his daughter at the end of the interview. I felt that this was because he was struggling with the invisibility of ASD and was seeking validation for not having identified ASD sooner and thus, preventing her mental health difficulties from occurring. After the interview Ryan described feeling *"emotionally wrung out"* (line 637).

'John'

Setting the context

John lives at home with his wife, son, and dog. His daughter, Grace lives in a residential unit out of county. From the age of approximately 11 years old, Grace has lived in hospitals and in multiple residential units, with no time periods spent at home. Grace visits home for the weekend approximately every 6 weeks, however, due to the restrictions surrounding COVID-19, this aim has been more difficult to meet over the last year.

How was ASD identified?

John shared that Grace's behaviour started to change when she reached puberty at age 10, during her transition to high school. During this time, Grace began self-harming and lived with suicidal thoughts. As such, she spent the following years being supported in hospital.

Interestingly, Grace was not diagnosed with ASD by the statutory services who were supporting her. Rather, John sought a private assessment and Grace was subsequently diagnosed. Grace is also living with a diagnosis of obsessive-compulsive disorder and generalised anxiety disorder.

Current feelings about ASD

John talks angrily about the inadequacy of the systems around Grace, such as the mental health services, school, and the government more generally. John has perceived these systems as dismissing, abandoning, and blaming of him and his daughter. As such, John appears to have accepted Grace's ASD but appears to feel a significant sense of injustice and inequality in the care that she receives. John's anger appears to come from a place of fear about professionals keeping his daughter safe.

Reflections: my experiences of the interview

Throughout John's accounts, he openly shared some background on his childhood experiences, of living with parental mental health difficulties and feelings of abandonment. This was helpful as I wondered whether his daughter's story triggered some childhood memories and related feelings. John appeared to be very angry throughout the interview, and at times, it was difficult to decipher whether he was talking about his experiences with his daughter, or his experiences with his own father regarding perceived feelings of abandonment.

As an interviewer, I did not feel connected to John. I felt this was because John spoke about his experiences from a detached perspective. Interestingly he used phrases such as 'you're' to describe his own experiences. For example, *"you're afraid for the child, you're afraid for the wife"* (line 292). John also appeared to talk in a very professional manner, without stopping to reflect or make sense of his experiences. I suspect that John talked in our interview and shared his story in the same way that he has had to do with other professionals he meets with.

'Geoff'

Setting the context

Geoff lives at home with his wife, daughter, Hannah and two other daughters aged 9 and 12. Geoff described assuming that other fathers would be like his family *"where [his] wife has been the lead"* (line, 159) in seeking an ASD diagnosis for his daughter.

How was ASD identified?

Geoff explained that his wife identified Hannah's ASD from the age of 3. He described that she has worked in childcare for all of her career so is knowledgeable about child development. Geoff shared that his wife had *"8 years of fighting"* (line 879) before Hannah was diagnosed.

Current feelings about ASD

At the beginning of the interview, Geoff emphasised that ASD is a *"hidden disability"* (line 866) which appeared to leave him confused at times. For example, there were moments throughout his interview where he wondered whether he has ASD. He shared that *"the actions that erm, [daughter] was presenting at a young age, [he] didn't see any major thing wrong with it!*" (line 165). He continued to say that this might have been *"because basically [he] was the same when [he] was her age!"* (line 170). Alongside this, he also appeared to search for validation for him being unable to identify ASD in his daughter.

However, throughout the rest of the interview, Geoff appeared to be accepting of ASD and adjusted to his daughter's needs accordingly. He described multiple everyday challenges throughout his interview such as *"uniform, sensory issues"* (line 948) which contributed to Hannah's anxiety. As such, he *"withdrew her from school"* (line 980) because of how these experiences were impacting on her, *"before she gets any kind of self-harming"* (line 975). As such, he *"started to home school her, because [he] was at home"* due to the COVID-19 restrictions and he *"hadn't got any work"* (line 981). Thus, Geoff appeared to identify his daughter's needs and respond the way he considered to be most appropriate.

Reflections: my experience of the interview

I found this interview one of the more difficult interviews to guide and navigate. I felt that a lot was spoken about, but this was at superficial level, and it was difficult to develop a sense of Geoff's emotional experiences. I wondered about two reasons for this: firstly, Geoff made it clear that he was less involved in his daughter's ASD journey compared to his wife so he may therefore feel less emotionally involved. Secondly, I wondered whether this acted as a defense and that in fact, he found it challenging to access his emotions and to share them with me.

'Frederick'

Setting the context

Frederick lives at home with his wife, daughter, Leah, and son (aged 18). Frederick has two businesses, and his wife is a "full-time mum" (line 91). Leah's ASD diagnosis highlighted Frederick to *"suspect that [he] has ADHD"* and his daughter *"does too!"* acknowledging that ADHD is *"co-morbid"* with ASD. (line 350).

Has was ASD identified?

Frederick explained that his wife had been *"doing a lot of reading, and she suspected that [daughter] was on the spectrum and that it presented very differently in girls"* (line 171). As such, his wife *"showed [him] what she'd been reading*" and he *"thought erm actually well, I guess that does make sense that, erm, we need to get her some help if we can."* (line 179). They noticed that Hannah was *"struggling at school...she's always been very full on! ... she's always been very, very demanding, right from when she was a baby, erm, and it just made sense!"* (line 185). Frederick did not describe any difficulties in seeking out the diagnosis.

Current feelings about ASD

Frederick described his relationship with Leah as having lots of significant highs and lows. He shared that *"it's a very close relationship, but erm, ya know, she's very prickly, erm and it, it's erm...I find that hard to deal with, it can be very difficult getting through to her and getting her to do what she needs to do, 'cos she can be very inflexible"* (line 344).

Reflections: my experience of the interview

Interestingly, there were a lot of disruptions during this interview which appeared to reflect Frederick's stress levels and balancing multiple responsibilities. I also felt a sense of Frederick finding it difficult to articulate his experiences as he appeared to be taking time to choose the right words. Perhaps this occurred due to a fear of judgement and needing to 'get it right'.

At the beginning of the interview, I explicitly shared that it was important to have a break in between the interview and their next job or task. Due to Frederick's busy workload, he shared finding this difficult to do, however, at the end, he noticed that he was feeling *"slightly more unsettled than I was when I started [laughs]"* and informed me that he needed to *"push [his] next meeting back by 10 and go for a quick walk"* (line 744). This highlighted to me the challenges that Frederick is constantly managing with regards to feeling unable to attend to his own emotions, as others' needs take priority.

Group analysis

Whilst each participant had unique experiences, there were also similarities across the sample. These similarities were captured and grouped together across three superordinate themes: '**turmoil in understanding relationship with their daughters', 'difficulties in processing own emotional adjustment to ASD'** and **'let down by the system'.** These superordinate themes had sub-ordinate themes within theme to further define fathers' experiences. All themes capture the interrelated experiences that fathers had in parenting their daughters.

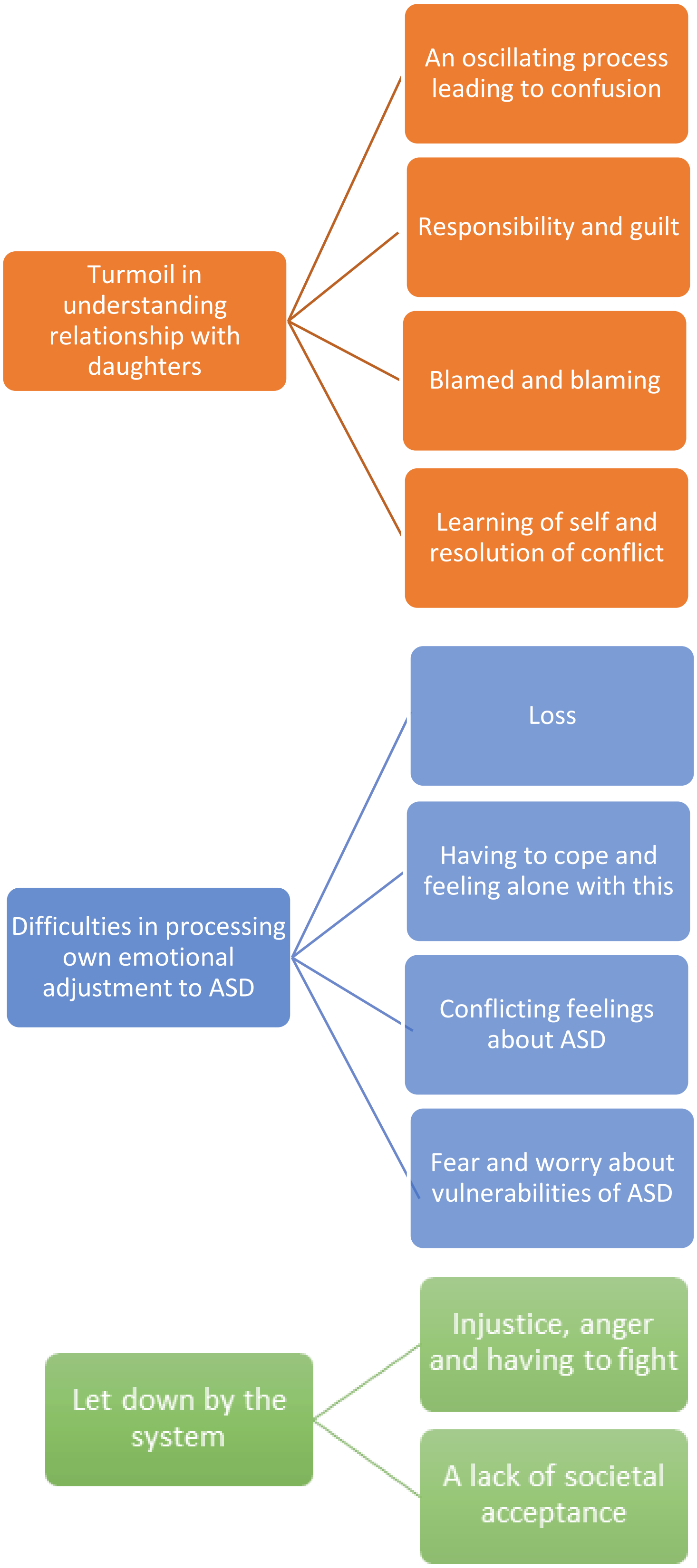


Figure 1. A theme map for the IPA group analysis of superordinate and subordinate theme.

Table 4. An overview of superordinate and subordinate themes across participants.

Superordinate Themes	**Subordinate Themes**	**Paul**	**Robert**	**James**	**Patrick**	**Ryan**	**John**	**Geoff**	**Frederick**
Turmoil in understanding relationship with daughters									
	An oscillating process leading to confusion	√	√	√	√	√	-	√	√
	Responsibility and guilt	√	√	√	√	√	√	√	√
	Blamed and blaming	√	√	√	√	√	√	√	√
	Learning of self and a resolution of conflict	√	√	-	√	√	-	-	√
Difficulties in processing own emotional adjustment to ASD									
	Loss	√	√	√	√	√	√	√	√
	Having to cope and feeling alone with this	√	√	√	√	√	√	√	√
	Conflicting feelings about ASD	√	√	√	-	√	-	√	√
	Fear and worry about vulnerabilities of ASD	√	√	√	√	√	√	-	√
Let down by the system									
	Injustice, anger and having to fight	√	√	-	√	-	√	√	√
	A lack of societal acceptance	√	√	√	√	√	√	√	√

Theme 1: Turmoil in understanding relationship with daughters

This superordinate theme captures the process of fathers' turmoil in understanding their relationship with their daughters. Participants described a variety of feelings and experiences in this process which came from a position of trying to understand what had been happening prior to their daughters ASD diagnoses, and what is happening now. These processes were captured by four subordinate themes: ***'an oscillating process leading to confusion'***, ***'responsibility and guilt'***, ***'blamed and blaming'*** and finally, ***'learning of self and a resolution of conflict'.*** Throughout this chapter, all themes presented are inter-related, so multiple overlaps between themes will occur. However, the presentation of this section will focus on the differences between the themes that arose from participants accounts of their experiences.

'An oscillating process leading to confusion'

This theme emerged from seven out of the eight interviews and related to participants having mixed feelings and experiences in their relationships with their daughters. This theme focusses on the oscillating processes that occurred in fathers turmoil of trying to understand their relationship with their daughters, rather than on the specific feelings themselves. This experience left fathers feeling confused about their position in their relationships.

Fathers faced some challenging situations with their daughters, which left them with difficult feelings, such as rejection, frustration, and sadness. Alongside this, perhaps to manage their emotions, fathers searched for reasons or a rational understanding of their emotions. Despite this attempt to make sense of their experiences, fathers still felt confused about their relationships with their daughters. See Figure 2 for a conceptual map of the oscillating process which occurred throughout fathers' accounts.

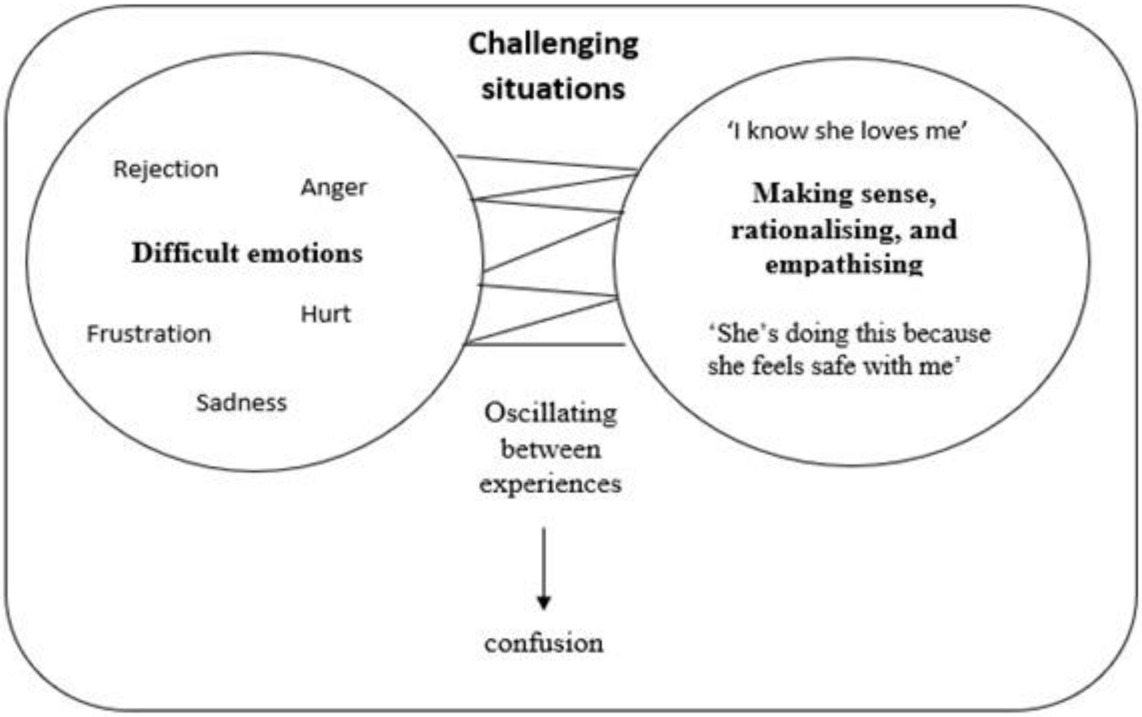


Figure 2. A conceptual map for the sub-ordinate theme of 'an oscillating process leading to confusion' in fathers' attempts to understand their relationships with their daughters.

Robert shared an example of a challenging situation which occurred with his daughter where he had to remind himself that his daughter *"doesn't actually hate [him] despite what she's just screamed in [his] face, and that actually the very opposite's true"* (Robert, line 816). Here and throughout his accounts in his interview, Robert oscillated between feeling hurt about his daughter's behaviour, whilst also offering an empathic, rational perspective in an attempt to understand her behaviour.

Later in the interview, Robert reflected on his process of oscillating between his emotional experiences and a rational perspective. He explained that he tries to detach from the emotion with the aim of staying in the 'making sense, rationalising and empathising' part of the process (see Figure 2) to feel more able to cope. He described this as *"snapping out of it"* (Robert, line 948). This way of coping appeared to help Robert feel less confused and more contained in his relationship with his daughter. However, this only provided temporary relief as another difficult experience would occur which would trigger the same oscillating process.

Patrick experienced similar feelings of rejection during his daughter's mental health crisis when he felt *"a sense of hatred, bitter hatred from* her (Patrick, line 1181). However, he was told that his daughter expressed those feelings towards him because he *"was the one she felt most secure with"* (Patrick, line 1203). Despite both Robert and Patrick rationalising their experiences, they found this emotionally difficult to deal with, leading to confusion about their relationships with their daughters.

As highlighted in Figure 2 frustration was also a difficult emotion that fathers grappled and oscillated with. Geoff spoke about attending a day out with his wider family which triggered some feelings of protection over his daughter as his family did not understand her needs. He shared that they *"did know that [daughter] had got issues before we came"* and told them that it would not *"bother [him] if [they] went their separate ways"* (Geoff, line 2349). However, he also shared his own frustrations with his daughter. This suggested that he knew what his daughter needed but felt frustrated with her for it: *"I can preach this way then half an hour later I might be screaming and shouting at her! (laughs)"* (Geoff, line 2350). Again, leading to a sense of confusion about their relationship.

This subordinate theme also occurred more subtly throughout participants accounts. For example, James described that he bought his daughter a *pair of Vans…they'd been designed with autism in mind, so there were no seams… there was me thinking I was being dad number one and buying her this, but she won't wear them"* (James, line 572). Here, James not only appeared to feel rejected by his daughter, but it seemed to lead him to confusion about what his daughter needs from him and questioning whether he is a good enough father. James not only wondered about how these feelings impacted on his relationship with his daughter, but also with his wife and other children. James appeared to reassure himself that despite these difficulties, there is "*a lot of love in [their] house"* (James, line 938). Thus, oscillating between feelings of disconnection and reassurance.

However, one participant, John, did not appear to feel the confusion that other participants felt. Throughout the interview, John held some clear understandings and beliefs about his experience of his daughter's ASD and related mental health difficulties. As such, he did not consider his relationship with his daughter to be a concern. Instead, his distress was regarding the professional support systems around his daughter, which will be described in the superordinate theme 'let down by the system'. Interestingly, John was the only father who did not live with his daughter as, at the time of the interview, she had been living in hospitals and residential homes for the previous four years. This appeared to hold significance in John's view of his relationship with his daughter, perhaps seeing it as more positive compared to other fathers.

Reflective box 1: Reflections on the subordinate theme, 'a process of oscillation leading to confusion'.

This theme captured a variety of feelings but all with the same process of oscillation between their experiences, leading to a sense of confusion. I found this theme the most difficult to pinpoint throughout the analysis as it appeared to occur throughout fathers' accounts in different ways. I wanted to pay attention to the process but wondered whether I was naming it correctly. This was also made harder because it linked with other themes closely. However, supervision helped me to identify that the process was linked specifically with fathers' relationship with their daughters, rather than with their relationship with ASD. I wonder whether there was a parallel process occurring as the difficulty I felt was also confusion about what was happening in their relationships. For example, I noticed there were ambivalent feelings about their relationship at times, but that this was not consistent. Sometimes I noticed that they felt close with their daughters, and other times they felt distanced, and so, this left me feeling confused. As such, the process of drawing the conceptual map in Figure 2 helped me to understand.

'Responsibility and guilt'

This theme emerged for all participants. The feeling of responsibility and guilt was significant throughout fathers' accounts as they appeared to hold a view that their role of being a father is to protect, be connected to and be supportive of their children. However, fathers found it difficult to understand their daughters and had times of distance or conflict in their relationship which challenged their values and roles. Thus, leaving them to feel that they have not been a good enough father and a sense of guilt about this. Most fathers reflected on things that they could have done differently, whilst also noticing how hard it was because of the feelings that were triggered in challenging situations with their daughters.

Paul shared feelings of responsibility and guilt strongly:

"I kick myself, I still kinda kick myself, I still look back and think, if only I'd have been different ya know, if only I could have…I'd approached things the way that you kinda see on television, and, really strong sort ,of, families, ya know, like, Dad and daughter kinds of relationships…if we had had that kind of relationship would she be going through this cycle of self-harm, would she have this high anxiety?" (Paul, line 433 – 443).

This example highlights the responsibility and guilt Paul felt in his daughter's suffering, and in how he approached and related to his daughter. This quote also highlights feelings of loss and self-blame, both of which are addressed in following sub-ordinate themes.

Frederick describes a similar experience:

"I think about it now and it's like … you just regret it!...You just can't help but be triggered and you know, get upset. And, and, and get cross. And erm...you know and they're such, such important times and it's the same now! You know they're such important times and erm … you don't want to spend them arguing! (Frederick, line 333).

Like Paul, Frederick describes feelings of responsibility and guilt regarding his response and approach to his daughter, leaving him feeling that he has not got it right.

Patrick however, appeared to feel guilt and responsibility about some Christian beliefs he previously held:

"There's something very powerful there, and it's something that I can see in [daughter] as well, that quality of fantastic love and care she has for other people. Being a person who is quite outspokenly atheistic and gay and a-gender, I've got to start reassessing what I think, and what I think is complete rubbish. [silence - tearfulness] It's still a process I'm going through." (Patrick, line 1158).

Responsibility and guilt appeared to be a significant emotional experience for Patrick, as highlighted by his tearfulness. Like Paul, Patrick also appeared to feel loss and self-blame.

Alternatively, John appeared to experience responsibility and guilt in a different way to the other fathers, likely because his daughter was primarily being cared for by professionals. Due to this, John described that the responsibility of parenting had been taken away from him and instead, not having it left him feeling guilty in relation to his role as her father. He described that *"the most painful thing for me is…dropping her off and leaving…another heart string goes every time I leave her! 'Cos you're handing your kid over to a system! You are trusting these strangers to look after her." (John, line 1306).* Within John's accounts, there are subtleties about his expectation of his fathering role not being met, thus, feeling guilt at not being the dad he hoped to be for his daughter.

'Blamed and blaming'

This theme occurred in all fathers' accounts. 'Blamed and blaming' refers to the relational reciprocity of perceived blame which appeared to occur in fathers' attempt to make sense of their relationships with their daughters. Perceived blame appeared to occur as a defense for fathers feeling judged or criticised by others, or alternatively by their internal judgements or self-criticism about not doing a good enough job in their roles as fathers. Blame was perceived to be occurring within a triad of relationships: professionals, fathers, and their daughters.

It was clear that through their daughters' ASD journeys, fathers perceived blame from professionals about their daughters suffering, which they internalised and blamed themselves for. I also perceived blame to be unconsciously directed towards daughters in fathers' attempts to understand their relationship. See Figure 3 which outlines this process.

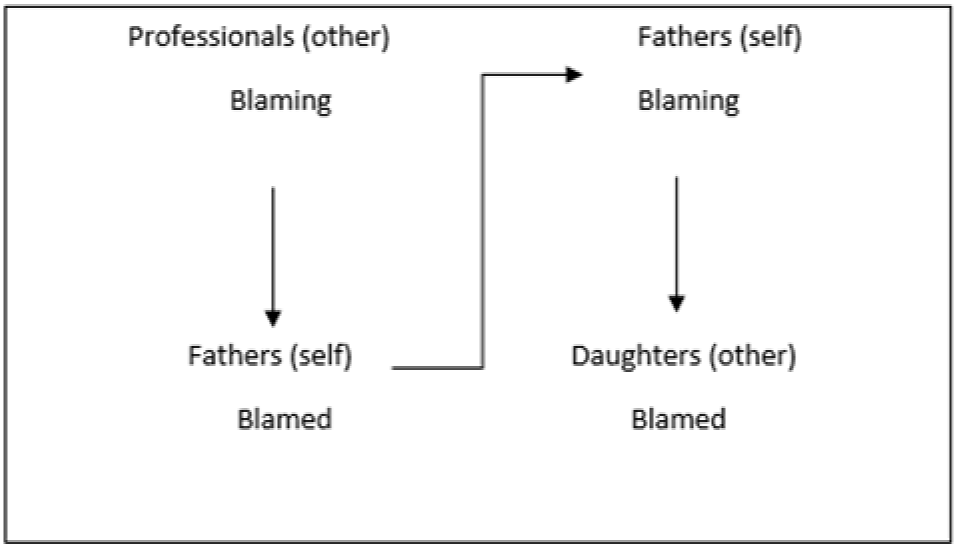


Figure 3. A conceptual map of the perceptions of blame amongst fathers' relationships.

As the conceptual map outlines in Figure 3, fathers perceived blame to come from professionals for their daughter's distress. For example, Patrick described being *"accused of bad parenting"* (line 403) because his daughter was not attending school. He was *"saying to school 'back off', if she can't come into school, leave it alone"* (line 404). However, he then found that *"the local authority*" was *"on [his] case, fining [him] for [his] child who isn't attending school"* (line 406). Patrick's descriptions highlight a perception of blame from multiple professional groups, which occurred without a resolution.

Similarly, John described that before his daughter was diagnosed with ASD, blame was perceived from CAMHS:

"They tried to blame it on me! ... they said, oh I think you've got anger issues! And I said, 'I have now! 'Cos we've got no diagnosis, no support, and no help at home, and you've just thrown that in my face!" (John, line 437).

John's descriptions outline the unhelpfulness of blame and how it can contribute to anger.

Blame also appeared to become internalised for fathers. Ryan described significant feelings of self-blame about his daughter's difficulties:

"I feel, I feel ashamed about myself as a parent, really. That that I've allowed her to to do that, even though I haven't. And I, I mean I'm, I'd do anything to be able to reverse that somehow, but I know I can't but... for me, to think that she was feeling that level of pain and she couldn't come and talk to me or a parent or anybody and and rather kind of inflict those injuries on herself, is is really tough." (Ryan, line 400).

Alongside this, there was a perception of blame towards their daughters. As described above, this appeared to develop from a position of trying to understand their relationships. More specifically, Ryan tried to understand why his daughter had approached her school about her self-harm and suicidal thoughts instead of him. It was clear that Ryan tried hard to understand his daughter's position but had difficulty with it.

"I felt a little bit let down that she couldn't have come to talk to us about it, but it was obviously so difficult that she couldn't understand how she was feeling. And again, I think, I think as a kid like that, as a kid like that, probably you don't self-diagnose, do you? You don't think 'I've got autism', because kids at that age don't even understand what autism is really." (Ryan, line 321).

Additionally, there also appeared to be a perception of blame towards daughters as a defence for being blamed themselves by others. For example, in response to reports of shouting and screaming from his neighbours, John described:

"From their point of view, we were abusing her! In actual fact she was tossing plates at my wife's head! She was screaming at my wife! She was punching and kicking my wife, and while I was at work! My wife didn't tell me half of what was going on." (John, line 437*)*.

This extract by John highlights the impact that blame has, which has led John to not feel listened to or their experiences validated.

Reflective Box 2. Reflection on the sub-ordinate theme of 'blamed and blaming'.

Drawing out Figure 3 helped me to understand the process of blame which appeared to be occurring within different relationships around fathers and their daughters. Highlighting fathers' perception of blame towards their daughters generated some uncomfortable feelings in me and urged me to consider how I would document this without fathers perceiving that they are being blamed, accused, or criticised again. Whilst this was a 'valid' interpretation that I made from the data, it led me to hypothesise its function. As such, it felt important to emphasis the function of blame as a defence against conflict.

'Learning of self and a resolution of conflict'

This theme captured the experience of fathers having had some conflictual experiences in their relationship with their daughters. However, fathers appeared to learn about their daughters' ASD over time, which allowed them to reflect on their experiences. This reflection appeared to lead to learning about themselves and in turn, some resolution of conflict.

Interestingly, this theme occurred in the accounts of five fathers. Four out of the five fathers described their learning specifically being related to ASD and realising that either themselves or other family members have ASD or another neurodevelopmental disorder. Paul and Patrick learned following their daughters ASD diagnosis that they also had ASD and so did their wives and children. Robert learned that his father likely has ASD, and Frederick learned that he likely has attention deficit hyperactivity disorder (ADHD) which his daughter was also diagnosed with. Fathers described the impact of their own ASD on their relationships with their daughters. Paul explicitly talked about how his ways of relating, likely due to his ASD, created some distance in his relationship with his daughter. He also commented on how his difficulty in regulating his emotions creates distance in their relationship together and is something that he has recognised and continues to work on. However, Patrick described his ASD as being beneficial in his ways of relating to his daughter because he understands what she needs better, due to his personal experience. Patrick appeared to see his ASD as less of a problem in his relationship with his daughter, compared to Paul. These experiences were less relevant for Robert and Frederick, however, as they did not have ASD themselves. This learning about appeared to resolve and make sense of some conflict about their lifelong experiences.

Frederick shared a conversation which he had with his daughter about their shared "neurodiversity" (Frederick, line 583). As such, this learning has created some connection in their relationship together. It also appears that noticing his daughter's strengths helped him move towards a resolution of conflict.

> "*This ADHD … if that is indeed what we both have?...There is a lot…to bring to the party, you know if you, if you think in a certain way. And I just say to her "look, it's not … you know you will change the world if you can, you know, this is not … you, you're not going to have a boring life."* (Frederick, line 581).

Additionally, fathers described the learning that took place for them as individuals regarding an increased self-awareness. Paul specifically, reflects on how the learning about himself would not have occurred unless he had been through painful experiences.

> *"If she'd had had the diagnosis before she was 10, and the system just worked for her, I don't think that the reflection, I don't think I would have learned as much about myself. Because actually, the support mechanisms' taking the onus off me, I don't get sucked into it as much, which seems like a really strange thing to say but I think that's the case, because I have to fight so, ya know, I feel as if I have to fight so…be a champion for her, then I go away and I reflect, and the reflection is so much stronger than the, the learning experiences are so much more, the, the experience has been so strong. I've never really thought of it that way, this is all like, wow, yeah, this kind of makes sense, this makes sense!* (Paul, line 639).

Ryan however, learned about himself differently; he learned about his emotional self. Interestingly, Ryan appeared to hold some stereotypical views about how he should manage emotion as a male and as a dad, which his experiences have challenged for him. At the start of the interview, he shared:

"If I do shed a tear at any point then just ignore it and just carry on 'cause I don't cry. That's not what I do. (Ryan, line 20).

Then Ryan reflected on how his experiences have changed him:

"You know I used to just go through life, just kind of batting things off and dealing with it. Now I'm probably a lot more sensitive. My wife will probably laugh at that, but I do think I'm, you know, I've experienced things that I'd not experienced, and it's definitely changed me as a dad. And as a person, really, the whole experience. But it has been tough. Really, really, really tough" (Ryan, line 504)

These extracts highlight the power of fathers' learning experiences which appeared to have occurred due to the emotional pain they felt. The remaining fathers, James, John, and Geoff appeared to be earlier in their emotional journeys, and thus, in their learning experiences. It is hypothesised that this occurred as James and Geoff were less emotionally invested in their daughters' ASD than the other fathers interviewed. For example, James shared that they did not seek a diagnosis for ASD, rather, she was diagnosed following CAMHS involvement for her anxiety. As such, it appears that James continues to see his daughters' difficulties through the lens of her mental health rather than ASD, and the challenges are regarding living with these. Similarly, Geoff stated early in his interview that his wife is his daughter's primary caregiver and so, has taken the lead in her care. Whereas John's learning experience appeared to be different. It is hypothesised that John was highly emotionally invested but instead, he appeared to be living in 'survival mode'. As such, it is known that for reflection and learning to take place, a person needs to feel safe – emotionally and physically. Thus, as John appeared to be living in his threat system regularly, his emotional learning and reflection will be limited (Gilbert, 2009).

Theme 2: Difficulties in processing own emotional adjustment to ASD

This superordinate theme focused on ASD specifically and the emotional experiences that occurred for fathers leading to a difficulty in processing their own emotional adjustment to ASD. These experiences are captured by four sub-ordinate themes: ***'loss'***, ***'having to cope and feeling alone with this'***, ***'conflicting feelings about ASD'*** and finally, ***'fear and worries about vulnerabilities of ASD'.*** Again, the themes are interrelated and at times run parallel to each other.

'Loss'

Loss occurred for all fathers and was significant in their experiences, leading to difficulties in processing their own emotional adjustment to ASD. Loss showed in various ways throughout fathers' accounts. Robert, James, Ryan, Geoff and Frederick described grieving for their hopes and expectations for a 'normal' family life.

Geoff reflected that:

> *"Oh, when I said there's no expectations, but in a way there's a slight expectation that you expect your child to leave school at 16. Go to an apprenticeship or go to college or … stay on at school and then leave and then get a job. Erm but that isn't … what's going to happen with [daughter]"* (Geoff, line 1019).

James appeared to feel loss when he observed differences in his other children.

> *"This is going to sound awful, you forget, is this how it should be? Is this what it is? Cos this is three kids that don't look as though they've got any additional support needs, you know, they are picking up and running with things and kind of being really switched on, you know. They're not scared, and they're not shy, and they're not... they've just got that oomph about them."* (James, line 803*).*

This extract highlights that ASD has challenged James' own hopes and values i.e., to be ambitious, work hard and have good friends. However, James' daughter, likely due to having ASD, does not align with his hopes and values, thus leaving him feeling loss.

There was also loss in relation to a felt closeness with daughters. Paul, specifically, described loss regarding how he relates to his daughter, likely because of his ASD.

> *"It's as if I'm almost pushing her away with one hand because I'm like, I need to focus on this now [daughter], thank you for sharing that, we need to fix this, and then I go off on a mission to try and fix it. In reality, I needed to go towards [daughter] to focus on it, and that's been the kind of like, the story, that's the difficulty of a dad with a daughter, and probably a dad with his own communication problems."* (Paul, line 421).

Paul reflects on his way of relating being due to being a male, and a male with 'communication problems'. This suggests that Paul holds some beliefs about males' ways of relating being different to females' ways of relating. On top of this, he has the added complexity of having 'communication problems', creating even more challenge for him.

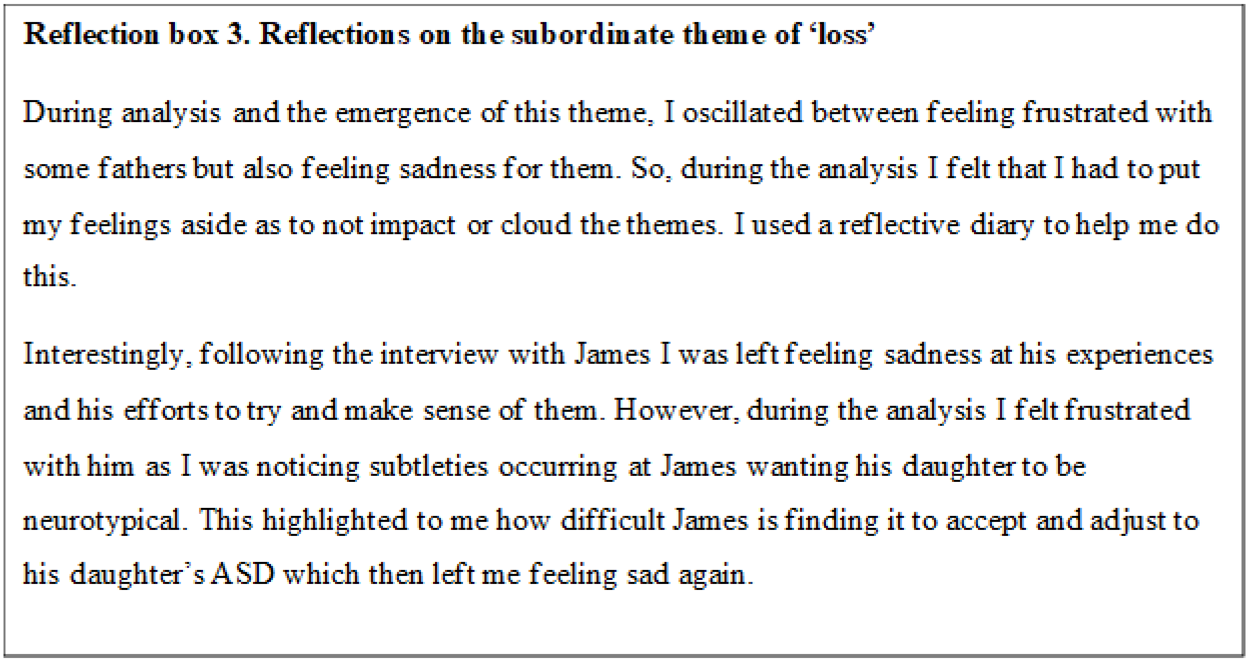
Patrick however, appeared to feel loss in relation to his daughter's struggles and challenges that they managed as a family. Although their relationship has now improved, he feels loss in his relationship with her during those difficult periods of time.

> *"We just left food outside the door, two or three weeks. And eventually she began to come down and have a meal in the same part of the house downstairs, but not at the table. And we now, after five years have a fantastically good relationship, but it's taken that long. [sigh and tearfulness]." (Patrick, line 469).*

John described loss in relation to not being able to live with his daughter and be the father he hoped to be for.

> *"Well I mean it starts from the minute she goes to hospital. It's like your child's died. You're walking past an empty bedroom every day! (line 744)...So when you're waving goodbye to your own child going off in the car with someone, drives off and goes an hour and a half*

> *away, that's hard! And that never gets any easier! That, that's a punch in the stomach every time! (John, line 788).*



Reflection box 3. Reflections on the subordinate theme of 'loss'

During analysis and the emergence of this theme, I oscillated between feeling frustrated with some fathers but also feeling sadness for them. So, during the analysis I felt that I had to put my feelings aside as to not impact or cloud the themes. I used a reflective diary to help me do this.

Interestingly, following the interview with James I was left feeling sadness at his experiences and his efforts to try and make sense of them. However, during the analysis I felt frustrated with him as I was noticing subtleties occurring at James wanting his daughter to be neurotypical. This highlighted to me how difficult James is finding it to accept and adjust to his daughter's ASD which then left me feeling sad again.

'Having to cope and feeling alone with this'

All fathers experienced this theme. It became clear throughout their accounts that to cope with their feelings, they did not attend to them. Instead, they appeared to compartmentalise their emotional experiences in order to survive and carry on. Fathers described needing to do this as their family depended on them to cope. Thus, this experience of having to carry on and cope left fathers feeling alone as they held their feelings to themselves.

Additionally, some fathers reflected on their ways of coping as a 'father' as opposed to a 'mother'. For example, John talked about having to support his wife through her feelings, and then breaking down when he was "*on [his] own with the dog.* He described being *"in pieces!... But then you have to carry on because you've still got your son. You've still got your job. You've still got your responsibilities!"* (John, line 686). John's anger alongside this theme appears to come from a position of feeling that he does not have choice but to cope and carry on.

Similarly, Ryan shared that:

"I think as a dad you try and suppress a lot of your feelings and I do find it difficult to get emotional really. I don't like to cry, and I've never cried. I don't think my kids have ever seen me cry. Um, and I think, I don't know, I probably have that stereotype dad role really, where my job is to you know, be strong and... But I do have a soft underbelly really and, but I don't like to show it. And my way of dealing with it all the way through has been to just be pragmatic to try and deal with the practical things. I have struggled with with the emotional side of things, it's not something that comes easy to me, and even talking about this kind of stuff today really feels outside of my comfort zone." (Ryan, line 475)

Paul described that because of his ASD and his extreme emotional responses, he has to put up *"harder walls, and special tidal flow type things just to try and keep everything as calm as possible… it's almost as if [he] consciously tries to keep [himself] at a distance because the emotion is so strong."* (Paul, line 622). Again, this suggests that he has to hold onto his emotion to be supportive of his daughter.

Interestingly, Robert linked his experience of coping in this way specifically to being a parent of a child with an ASD. He suggests that this way of coping is crucial for survival for all parents who have children with ASDs.

"That is a fundamental part of being a parent of a child with autism and not breaking. That when it's done, you have to snap out of it and you have to get on with it. Because if you stopped and reflected on all of those times and all of those battles and took it all personally, which some people do, it will break, it would kill you. I don't understand how it couldn't [laughs]"
(Robert, line 793).

Robert appears to suggest that this coping strategy is helpful for the short-term, however, he also reflects on the likely long-term impact.

"At some point, something has to give and that's what breaking would be. It could be anything. It could be, it could be as simple as, um, it could be as simple as saying actually, this was my one night of the year when I was going to go out and I'm not gonna. I just, I can't face other people and completely missing that opportunity. It could be as serious as saying, I've had

enough of this, I'm leaving, and I am not coming back. It could be anything in that spectrum." (Robert, line 974).

Ryan shared the difficulty he felt in having to cope alone as separate from his wife for the first time. He reflected that although they have experienced some other significant life stressors together, nothing compares to the experience of parenting their daughter with ASD who also has had severe mental health difficulties.

"Cos you do you feel like that, you know, you feel like completely alone, and and and even you know my, my wife, you know probably my best friend, but it's probably the one thing we've argued against, about more than any other single thing you know and and so I found that quite difficult as well..." (Ryan, line 295).

Fathers also described attempts to reach out to family or friends but then felt even more alone with their experiences when they found that others did not understand. John shared that since going through the challenges with his daughter, he can no longer relate to people who *"moan about a cancelled holiday".* This leads him to find that *"your circle of friends shrinks and shrinks"* (John, line 906).

Moreover, Frederick reflected how his coping style is different to his wife's and is a strategy which he actively uses:

"I think I … I tend to shut myself off and kind of deal with what's in front of me now! Erm … and I, if I thought about that all the time, you know, we'd be penniless because I think you know, well … my business would go down the pan and, and you know but it, it's, I kind of almost seal that one off! Whereas I know with [wife] she does lie awake at night thinking about it (line 430).

'Conflicting feelings about ASD'

This theme occurred in six out of the eight participants and captures their experiences of feeling both positively and negatively about ASD.

Frederick described both positive and negative feelings simultaneously, in which he noticed the talent and uniqueness that ASD offers, but also the challenges of this.

> *"She'll pick me up if she thinks my argument is weak! Erm … erm, and erm I just really appreciate that! I mean it's irritating of course! [laughter] … Erm … but I just, you know, I, I just think she's a very special erm, a really special person. And erm … you know I … I was, I wouldn't have it any other way. Obviously, I would, I'd rather it wasn't as stressful when it is!"* (Frederick, line 533).

Similarly, Ryan appears to be accepting of ASD in one moment, and then struggling with acceptance of ASD in the next.

"To be honest with you compared to where I was three years ago, I actually don't care anymore really what she looks like if she's safe and she's happy and she's healthy. They're the only things that really make a difference. But but I can't pretend that it's still a bit weird for me... [Daughter] looks just a bit different, you know. But that's that's mainly for me to come to terms with, I think. You know that difference, really. I wouldn't want to change her." *(*Ryan, line 453 – 458).

Geoff shared a conversation he had with his wife about him also having ASD. This is interesting as this appeared to trigger a defense. Thus, suggesting that although he has spoken positively and acceptingly of his daughter's ASD, it is perceived differently, and more negatively if he were to have it.

[Wife] said well maybe you're autistic? [Laughs] I said well maybe I am? You know it wasn't, it wasn't around in 1965/66! Well it was around but it wasn't identified, so I might have been classified as a bit of a handful. A naughty kid. But maybe I wasn't? I don't know! Maybe I did have it. But it's nothing to do with intellect (Geoff, line 789).

Finally, conflicting feelings about ASD also arose in fathers' approach and attitude to their daughters. In some moments, James spoke positively and thoughtfully about his daughter's ASD but in another he spoke appearing more frustrated, suggesting some conflicting feelings.

"I've told her that when she's doing brilliant, I'll tell her when she's doing brilliant. But she needs to pull her socks up, I'll also equally tell her that, so she knows I'm being consistent." (James, line 741).

This theme did not occur for Patrick or John. This appeared to be because they are generally more accepting of ASD and showed consistent, more positive feelings about it compared to the other fathers. Both Patrick and John appeared to believe that the difficulties which arose with their daughters occurred due to their environments, rather than due to the ASD. Thus, the environment is the negative component, not the ASD.

'Fear and worry about vulnerabilities of ASD'

All fathers except for Geoff described some fear and worry about the vulnerabilities that ASD presents for their daughters, and what this might mean for their futures. There was a spectrum of worries ranging from fears about their daughter not becoming independent and needing more support from them, to managing worries about their safety due to their mental health difficulties.

For example, Frederick described having a *"feeling of ... it ... of it not getting better. Of ... not becoming independent* (Frederick, line 376). Furthermore, James shared that his daughter *"sees the good in every single person, even to the point that I think it will make her a victim later on in life…she doesn't think that anybody can be bad or mean to her"* (James, line 341).

Both Robert and Paul described concerns at their daughter's ongoing safety. Paul shared:

"It's a terrible terrible thing to have on your shoulders, to think, when I come home from work today, will my daughter still be alive? That is a terrible terrible thing to have. So, I mean, that's the crux of it, that's where I am." (Paul, line 671)

Additionally, Robert shared some worrying feelings about his daughter's expression of emotion:

"Emotions as [daughter] demonstrates when she has her meltdowns is, emotions can end up in a physical place. So, you know, [daughter] is never going to intend to kill herself. But she, she puts a plastic bag over her head in a temper to make a point, essentially, to try and express something that she can't express any other way. But ultimately, if she has a plastic bag over her head for long enough, she is going to die." (Robert, line 989).

Moreover, John highlighted an on-going difficulty about his daughter's visits home:

"With the autism it might manifest 2 days later in a meltdown… which is why the contact has to be very carefully managed. I think we've pushed it out now to every 6 weeks? Because if it's too frequent, she misses home so much … that she spends 3 days being upset and self-harming and violent." (John, line 794).

Whereas Geoff's accounts did not appear to show any fears or worries about his daughter's ASD vulnerabilities. However, Geoff talked very little about both his daughter's future and any vulnerabilities that she may have. This suggests that he has either not allowed himself to think about them or he does not believe his daughter is vulnerable. Both instances may suggest a coping strategy of avoidance or denial.

Theme 3: Let down by the system

This superordinate theme applied to all fathers and captured their experiences of feeling let down by the support systems around their daughters. The 'system' includes school, mental health professionals, the government and society more generally. Participants described a range of feelings in their response to the system's lack of awareness and understanding about ASD and thus, their lack of adaption. These feelings ranged from feeling disappointed to feelings of anger and abandonment.

As such, this theme captures fathers' experiences of ***'injustice, anger and having to fight'*** and realising there is ***'a lack of societal acceptance'*** for ASD.

‘Injustice, anger and having to fight’

John appeared to feel intense anger in his experience of feeling abandoned by the systems around his daughter. In John’s case specifically, anger appeared to be driven by terror at the impact the system was having on his daughter’s mental health and consequently, her safety. He described that:

“People need to know there is a war. Raging on. Their kids have been failed on a daily basis and some kids manage to kill themselves! There’s a lack of accountability. There’s a lack of legal action being taken against these hospitals.” (John, line 850).

John’s extract also highlights his experiences of injustice, and how the mental health system is failing children in being unable to keep them safe.

Similarly, Robert shared his anger and views of having to fight due to the injustice that his family are experiencing:

“This is not just a battle, it's a game and it's a political battle, it's a bureaucratic battle. It is a sociological battle, a philosophical battle. It's just a constant fight. And luckily, for, that's kind of what gets me up in the morning. So, I won't pretend that it's got me up every morning, and I won’t pretend that there haven't been days when you say, “well can’t we just have five fucking weeks where we can just have normal time?” (Robert, line 493).

Furthermore, Geoff explained that this family experienced years of seeking a diagnosis for his daughter:

“Eight years of fighting and going through CAMHS and MIND and NSPCC. At one time they tried to blame it on [wife’s] parenting... So she pushed and then there’s CAMHS... we had everybody involved! And she’s fought and fought and fought and fought!” (Geoff, line 879).

Patrick not only described feeling unsupported, but perceived the system to be actively working against him:

"CAMHS itself was useless, utterly useless. In fact, it almost gave us the impression that CAMHS and the school were conspiring with each other. They held meetings to which we were not invited, and where's, hang on a minute, the parents are centre in all this!" (Patrick, line 415).

John considered his perceived injustice from a political perspective. He added that injustice and inequality occur more frequently for working class families, with regards to their access to appropriate health care.

"My, my life is about survival and making sure my kids get the best possible outcome available. You know I'm, the last 10 years have been austerity cutbacks. Unemployment going through the roof. Homelessness going through the roof. Mental services being decimated. Social services being decimated. I'm not stupid. I know what's going on! And I don't care what side's in power! It doesn't get any better for the people at the bottom!" (John, line 924).

This is interesting to highlight as other fathers also tried to make sense of 'being let down by the system' by noticing differences in social class. Patrick shared perceiving that seeking private professional support is most beneficial compared to statutory services:

"We had a glimmer of light in going private, and getting letters written by a senior consultant psychologist…which we paid for" (Patrick, line 407).

John reinstated his message by sharing that if parents are seeking an ASD diagnosis for their child, *"if you've got the money, go private!"* (John, line 479)

Whilst Robert reflected that:

"Other parents you speak to won't be as privileged as we have been. Or had the time to be as insightful or the skills or the knowledge themselves. So, there will be other people you speak to whose kids are suffering, not because their parents are failures or because their parents

are struggling, but simply because there isn't a system in place to cope with this" (Robert, line 1147).

Interestingly, James and Ryan did not experience the need to fight for understanding and support, nor did they feel anger or injustice. In both fathers' accounts, they did not appear to see their daughters' difficulties through an ASD lens. Instead, they appeared to see their daughters' struggles through a mental health lens. Thus, mental health services were perceived to be appropriately supporting their daughters because the focus of the difficulty was on their mental health, as opposed to their ASD.

Reflective Box 4. Reflection on the sub-ordinate theme "anger, injustice and having to fight".

In my analysis of this theme, I noticed myself feeling anger alongside fathers' when they reflected on their injustices about ASD. I noticed this sense of anger significantly increasing when reflecting on how working-class families' injustices are likely to be even more challenging, as Robert highlighted. Again, for the purposes of the analysis, I had to put my own feelings aside to not cloud fathers' experiences as my own. As such, I recorded my feelings about this topic in my reflective log which I referred to when re-visiting this theme in my analysis and write-up.

This theme also left me thinking about assumptions I had made about participants' social privileges. I did not ask fathers about their socio-economic statuses, but I assumed that all fathers were largely from middle class backgrounds. They also described their ethnicity as being 'White-British'. Therefore, I assumed that fathers had sufficient resource in being able to 'fight' against the system for their daughters. For example, they appeared to experience limited social prejudice and appeared to have sufficient financial stability; all of which offered a privileged platform to fight for support. These assumptions were taken from implicit observations and descriptions which fathers offered. Thus, they informed and shaped fathers' experiences and eventual group themes.

‘A lack of societal acceptance’

This theme captured fathers overall experience of realising a prevalent lack of acceptance of ASD within society. Some fathers talked more worryingly about the lack of acceptance for their daughters, and others talked more angrily about it. This lack of societal acceptance captured two responses in fathers; some fathers viewed their daughters as not fitting into society, and others viewed society as the problem, including its inflexibility to meeting their daughters' needs.

For example, Paul shared realising the extent of the lack of acceptance within his daughter's school:

“In reality, I think we thought that things were going to be so much easier, because we had the diagnosis, because those kinds of reasonable adjustments would be put in place for her, that she'd get an opportunity, that she'd get a seat at the table. But, in reality, it's just been…such a struggle.” (Paul, line 369).

Although James' account did not apply to the previous sub-theme, he did acknowledge that society is not set up to consider people with ASD:

“We should probably not be worrying too far in advance. We should probably be right in front of us, but you can't help but think, what's the world going to be like for her?” (James, line 682).

Robert described concerning feelings about the lack of acceptance that his daughter may likely receive from society. In fact, although Robert acknowledged this as unacceptable, his view appeared to suggest that his daughter needs to accept this injustice in order to survive in society.

> *“It does concern me that she needs to find her way, and that. And it does concern me that she needs to understand that if she wants to openly be gender fluid, people will make judgements on that. She needs to understand. I don't care what those judgments are. And I in fact would denounce somebody who makes those judgments, but nevertheless they are going to make them. And it's what I keep saying to her about autism as well, you know*” (Robert, line 1082 – 1084).

This chapter detailed the results of the study which were captured and synthesised from fathers’ accounts of their experiences. The following chapter will embed these findings within the current literature and discuss its implications.

Chapter Four – Discussion

The current study explored fathers' experiences of parenting their adolescent daughters with ASDs. As such, the research question was:

What are fathers' experiences of parenting their adolescent daughters with ASDs?

This chapter will provide an overview of the main findings and their relation to the context of the wider research literature. Following this, the study will be evaluated by discussing its strengths and limitations. Then, implications will be presented including those for future research. Finally, the conclusions and final reflections will be outlined.

Summary of results

The findings offer an account of eight fathers' experiences of being parents to adolescent daughters with ASDs, an insight which is not currently captured in the psychological research literature. Although each participant had unique experiences, for the purpose of the IPA analysis, their experiences were synthesised into three distinct super-ordinate themes and ten sub-themes. A summary of the findings will be presented, then each theme will be detailed within the wider context of the literature.

Theme 1: Turmoil in understanding relationship with daughters

Summary of findings

The first superordinate theme captured fathers' experiences of turmoil in understanding their relationship with their daughters**.** Fathers described experiencing significant and distressing challenges linked with their daughters' ASD which led to perceived distance in their relationships.

Fathers attempted to understand their relationship with their daughters which appeared to involve ***‘an oscillating process leading to confusion’.*** This sub-ordinate theme captured fathers’ internal processes in response to challenging situations with their daughters. Fathers held two distinct internal experiences: they felt the ‘difficult emotions’ such as frustration and rejection in response to their daughters, and then attempted to ‘make sense, rationalise and empathise’ with the situation. The ‘oscillation’ part of the process is where fathers moved between both experiences which left them feeling confused about their relationships.

Fathers felt ***‘responsibility and guilt’*** which occurred in relation to their perception of not having fulfilled their role as a father to protect, be close to and support their daughters. ASD appeared to challenge this as fathers found it difficult to understand and connect with their daughters leading to distance and conflict in their relationship. In response to this fathers’ felt responsibility and guilt as they reflected on what they could have done differently whilst they also acknowledged the challenge of the situation.

There were perceptions of being ***‘blamed and blaming’*** which were perceived to be occurring within a triad of relationships: professionals, fathers, and their daughters. It appeared that throughout their daughter’s ASD journey, fathers perceived blame from professionals about their daughter’s suffering, which they appeared to internalise and blame themselves. Blame was also perceived to be unconsciously directed towards daughters. All of which appeared to be a process of fathers and professionals attempting to make sense of daughters’ experiences.

Some fathers experienced a ***‘learning of self and a resolution of conflict’***. This theme captured the experience of fathers having had some conflictual experiences in their relationship with their daughters. However, these experiences encouraged reflection and thus, learning, and some resolution of conflict. Some experiences of learning about themselves occurred in relation to realising that either themselves or other family members had ASD or a neurodevelopmental disorder. This led fathers to learn more about themselves and appeared to resolve and make sense of some conflict in their lifelong experiences. Fathers’ learning also allowed them to reflect on their approaches with their daughters’ and thus, changed it accordingly. As such, this strengthened their relationship, helping them to move towards a resolution of conflict.

Findings within the wider literature

This superordinate theme highlighted fathers' disconnection and resulting confusion about their relationship with their daughters. Fathers appeared to search for meaning about the difficulties that they felt in their relationships with their daughters. It appeared that their distress likely occurred because they did not feel connected to their daughters and thus, wanted to feel closer to them (Xiong & Detzner, 2005).

Understanding fathers' emotional processes - 'the process of oscillation leading to confusion'

The theme, *'the process of oscillation leading to confusion'* occurred after the diagnosis and is an experience which can be understood from a theoretical framework for understanding grief. The Dual Process Model of Coping with Bereavement (DPM) (Stroebe & Schut, 1999, 2010) proposed ways in which individuals come to terms with grief. It suggested that people move (oscillate) between loss-oriented and restoration-oriented coping through everyday life experiences after a bereavement. The loss-oriented coping part of the model referred to the experience of focusing on and processing the loss itself and the difficult feelings which arose with this, and the latter focused on the consequences of the bereavement such as attending to practical life changes without their loved one (Stroebe & Schut, 1999, 2010). Whilst fathers did not appear to experience these specific types of coping in relation to grief, the dynamic process of oscillating between two coping experiences is similar. Strobe & Schut (1999, 2010) emphasised the oscillation process in their model as it was a fundamental parameter of coping and reflected the "complex regulatory process of confrontation and avoidance" (Stroebe & Schut, 2010, p.278). Thus, at times fathers, like the bereaved, confronted aspects of their emotion (e.g., rejection or frustration with daughters), and at other times, avoided them. The model also suggested a 'time out' when the person is not living within these orientations. The authors highlighted that an important feature of the model is that oscillation between the two types of stressors is necessary for adaptive coping. Moreover, developments of the DPM over the last decade suggested that it can be applied to other forms of loss such as 'complicated grief'

(Stroebe & Schut, 2008). Thus, although the theme of ‘the process of oscillation leading to confusion’ does not focus on grief, feelings of loss were present in experiences of processing and adjusting to their daughters ASDs.

Still focusing on the DPM, it is interesting to mention one father, Robert, and his process of oscillation. Robert did not appear to oscillate between these emotional experiences but instead, aimed to align with the ‘restoration-orientated’ comparison of the DPM model, thus he avoided oscillating between the two orientations. This is interesting as Stroebe and Schut’s (2008) model of ‘complicated grief’ suggested that those who suffer from a traumatic bereavement may have trouble alternating smoothly between loss and restoration orientation, which leads to more extreme experiences of intrusion and avoidance. Although Robert did not state that he experienced symptoms of trauma, his experiences aligned with the complicated grief model. This may suggest that Robert is attempting to manage some traumatic experiences, thus, his ‘maladaptive coping’ as described by Stroebe and Schut (2008) occurred from a position of survival.

As such, this model emphasised the significant, and perhaps, traumatic distress that fathers are currently living with in parenting their adolescent daughters with ASDs and associated mental health difficulties. This finding is also consistent with identified gender differences in coping. Generally, men have been found to be more restoration-oriented whereby they actively engage in rational thinking and practical issues, whereby women appear to be more loss-oriented (Wijngaards et al., 2008). More literature will be discussed on gender and coping in the following theme.

The DPM of coping with bereavement (Stroebe and Schut, 1999) offers an integrated understanding of fathers’ emotional experiences, focusing on the dynamic process of the emotional experience. Although this model has not been researched and applied to parents of children with ASD, it offers a useful framework for understanding the findings of the current study.

However, there are several limitations of the DPM which should be considered in the context of fathers’ experiences in the current study. Firstly, the DPM only explained processes which occurred after the bereavement, and it did not consider whether these processes began prior to it (Carr, 2010). For example, an individual may begin grieving for their loved one before they die, such as experiences of ‘ambiguous loss’ (O’Brien, 2007). As described in chapter one, ambiguous loss is the emotional experience which occurs when the outcome of a stressor is uncertain or unpredictable, such as when caring for a family member with Alzheimer's. O'Brien (2007) also described ambiguous loss occurring in parents of children with ASDs, whereby fathers felt loss in relation to the uncertainty about their daughters' future. This leaves a question about fathers' emotional processes prior to their daughters' diagnosis. This appeared to be particularly important for fathers' emotional process with ASD as many fathers, although not all, suspected ASD for years prior to being diagnosed.

Difficult internal experiences - 'responsibility and guilt', and 'blamed and blaming'

As described in the summary above, fathers appeared to be living with significantly difficult internal experiences in response to their daughters' ASD diagnosis. This seemed to be in relation to not having met their daughters' needs by identifying ASD earlier and preventing their distress ('*responsibility and guilt'*). This also occurred in relation to their perceived experiences of blame in attempts to understand their daughters' diagnoses (*'blamed and blaming'*). These feelings appeared to occur as fathers perceived themselves to have been inadequate in broadly fulfilling their fathering roles for their daughters.

Lindsay and DePape (2014) conducted a systematic review which examined parents' experiences of ASD. The authors found that parents often felt guilt and blame as part of their reaction to their child's ASD. Parents blamed themselves for their child's difficulties and felt blamed by health professionals for their child's behaviour (Alqahtani, 2012, Gray, 2002; Midence & O'Neil, 2012, Hutton & Caron, 2005). As stated, these findings also occurred in the current study. However, although Lindsay and DePape's (2014) review aimed to capture mothers and fathers' experiences equally, they found that many studies had limited father input. Additionally, most mothers were caring for a son with ASD. As described in the introduction, this gender imbalance in Lindsay and DePape's (2014) study sample reflects the gender disparity in the literature. Despite this, results from the current study align with their findings which suggest that not only mothers experience feelings of guilt and blame, but so do fathers.

Moreover, this finding challenged previous literature about fathers only occupying practical and financial roles in parenting as it highlights their emotional involvement and response to their daughters (Lamb, 1997). Although some studies have acknowledged that this stereotypical traditional view is less present today, evidence still suggests that fathers' approach to parenting is different to mothers (Cheuk & Lashewicz, 2016).

The specific responses of fathers in this study, regarding their feelings of responsibility about their daughter's distress, can be considered from a perspective about their fathering roles. Connell and Messerschmidt (2005) described a concept called 'hegemonic masculinity' which proposed that masculinity is a pattern within society, idealising stereotypical male characteristics. The authors suggested that this concept also permeates with beliefs about fathering, including fathering children with disabilities (Connell & Messerschmidt, 2005). As such, Lien, Lashewics, Mitchell and Boettcher (2021) used this concept as a framework to consider fathering roles with children with ASDs. Interestingly, they found that fathers of children with ASD neither copied nor challenged hegemonic masculinity, but rather fathered their children by blending traditional and nurturing roles. Moreover, they brought together "both provider and caregiving responsibilities" (Lien et al., 2021, p.277). As such, fathers were described as "being intent on earning and exercising financial power" but were also "willing to expose themselves" in relation to "speaking tenderly about their child's care needs and the intricacies of meeting them" (Lien et al., 2021, p.277). Specifically, fathers' descriptions of feeling protective of their children in relation to their child's struggles demonstrated traits of traditional masculinity blended with compassion and nurture. Thus, feelings of responsibility, guilt and blame in relation to daughters' distress in the current study can also be considered from a perspective of blending traditional and nurturing fathering.

Fathers' developmental journey to acceptance - 'learning of self and a resolution of conflict'

All the themes within fathers' experiences of turmoil in understanding their relationships with their daughters appear to contribute to the process of fathers' learning about themselves and resolving conflict, i.e., leading to acceptance.

Kübler-Ross (1969) ‘change curve’

The Kübler-Ross (1969) ‘change curve’ taken from Kübler-Ross' five stage grief model has also been applied in studies to the emotional journey that individuals go through when managing a significant change or transition in their life. Thus, this change curve can also be applied to fathers’ experience of moving towards acceptance of their relationship with their daughters. Moreover, it is suggested that if fathers learn to understand how they react to their change, it will help them to better manage it.

The five stages of the model referred to are: denial, anger, bargaining, depression, and acceptance (Kübler Ross, 1969). The authors suggested that in order to move towards a position of acceptance of the change, individuals must go through these stages. Although each of these stages were not explicitly outlined in the themes, elements occurred throughout. Table 5 below, presents a synopsis of Kübler Ross (1969) stages and how they linked with fathers’ experiences in the current study.

Table 5. Fathers’ experiences linked to Kübler-Ross’ five stages of change (1969).

Stage	**Description for fathers**
Denial	This stage tentatively applied to some elements of defense where fathers prevented themselves from thinking about the uncertainty of their daughters’ future. For example, one father Geoff, did not describe any fears or worries about his daughters’ vulnerabilities, but this was suggested to be because he was in denial about them.
Anger	Anger appeared in fathers’ perceptions of feeling blamed and perceived blame towards their daughters.
Bargaining	Again, bargaining is a subtle, tentative stage but appeared to occur when fathers were trying to negotiate the boundaries of parenting and ASD. For example, Robert de*scribed “I absolutely won’t have her play the autism card, but I absolutely I won’t have people not adapting to her needs either”* (line 850).

Depression	Fathers appeared to be managing feelings of sadness in relation to the responsibility and guilt they held about their daughter’s ASD and subsequent distress.
Acceptance	Acceptance appeared to occur for the fathers who engaged in reflection and learning about themselves and in their relationship with their daughters.

As such, Table 5 captures fathers’ developmental journeys of acceptance about their relationship with their daughters, using Kübler-Ross’ (1969) stages of change. Each father appeared to experience more than one stage, but not all had yet reached a level of acceptance. Whilst this is a useful model to capture fathers’ developmental experience of moving towards acceptance of their relationship with their daughters’, there are some clear limits to the model. Firstly, the model does not suggest the length of time an individual is likely to occupy each stage, nor does it consider what factors influence an individual to progress onto the next stage. In assessing all fathers’ accounts, the length of time that daughters had been diagnosed with ASD did not appear indicative of fathers’ progression in their emotional development. This suggests that other factors and contexts likely influence fathers emotional experience in moving towards acceptance.

This critique can be considered in the context of Bronfenbrenner’s Ecological Systems Theory (EST) (1979) which suggested that a child develops in the context of multiple systems including their immediate environment, family, school and the broader socio-cultural context. Thus, fathers’ emotional development can also be considered this way, whereby multiple contextual and systemic factors influence their internal experiences.

Finally, Kübler-Ross’ (1969) stages of change suggests that change occurs linearly. However, the human experience is complex which suggests that individuals may move backwards and forwards between stages as the DPM suggests (Strobe & Schut, 2010).

Post-traumatic growth

Research suggests that fathers’ ability to resolve and accept their daughters’ diagnoses is considered important as it has been associated with positive outcomes for parents, including less emotional distress and more positive outcomes as a family unit (Oppenheim, Koren-Karie, Dolev & Yirmiya., 2012; Hastings et al., 2005; Ekas et al., 2015; Ickovics, Meade, Kershaw, Milan, Lewis & Ethier, 2006).

This personal growth after a child's ASD diagnosis has been referred to as 'post-traumatic growth' (Tedeschi & Calhoun, 2004). Post-traumatic growth refers to the strengths that parents develop following traumatic experiences related to their child's ASD. Tedeschi and Calhoun (2004) identified five domains of post-traumatic growth: 'new possibilities', 'appreciation of life', 'personal strength', 'relating to others', and 'spiritual/religious change'. Interestingly, all fathers in the current study appeared to experience some form of post-traumatic growth. For example, Patrick described a changed world view related to a 'religious change' that he experienced. Previously he was a part of the Fundamentalist Christian Church until he learned about and thus, understood his daughter's mental health difficulties, gender identity, sexuality and atheism in the context of her ASD which changed his values and beliefs. Similarly, Paul described his growth in the context of 'new possibilities' and 'relating to others' in his descriptions of taking on a new role as advocating for his daughter and learning about his relating to others. This learning led Paul to change his approach with his daughter and an improved relationship with her. Lastly, Ryan appeared to encompass post-traumatic growth through 'personal strength' in his reflections about his emotional development as a father and how his experiences have led him to become more sensitive and attuned to his emotional self.

Furthermore, evidence suggests that post-traumatic growth has occurred in mothers specifically of children with ASDs across different countries (Zhang, Yan, Barriball, While & Liu, 2015; Kayfitz et al., 2010, Phelps, Hodgson, McCammon & Lamson, 2009). However, there is no identified study conducted in the UK, and there is also no study having explored fathers of children with ASDs in relation to experiencing post-traumatic growth. Though, it must be noted that post-traumatic growth was only examined in mothers who had not accessed mental health services (Zhang et al., 2015), therefore, although this concept has not been researched and applied to all groups of mothers, it provides a useful framework for understanding the findings of the current study in relation to fathers' learning experiences. Interestingly though, it is hypothesised that fathers in the current study would not likely identify as having a mental health difficulty, thus, this would have to be carefully considered in its application to fathers.

Theme 2: 'Difficulties in processing own emotional adjustment to ASD'

Summary of findings

Fathers described experiences related to feelings about ASD specifically, which appeared to lead them to difficulties in processing and adjusting to living with their daughters' ASD.

All fathers described ***'loss'*** as a significant emotional experience in response to processing and adjusting to their daughter's ASD. Loss was perceived in fathers' hopes and expectations for a 'normal' family life. Fathers also appeared to feel loss in their relationships with their daughters, particularly when their daughter was also living with mental health difficulties as co-occurring with their ASDs.

Fathers appeared to feel a lack of choice about their circumstances leading to feelings of ***'having to cope and feeling alone with this'.*** Fathers described the experience of having to cope as their family depended on them both emotionally and practically. Having to hold onto their feelings and cope in this way left fathers feeling alone and isolated with their experiences.

Fathers also found it difficult to process and adjust to ASD as they had ***'conflicting feelings about ASD'.*** This is where fathers held onto both positive and negative feelings simultaneously, whereby they noticed the strengths and unique qualities that their daughter had, but also found the challenges particularly difficult to content with.

Lastly, fathers appeared to find difficulty in managing their ***'fear and worry about the vulnerabilities of ASD'*** and what this might mean for their futures. Fathers held a spectrum of worries, ranging from fears about their daughter not becoming independent, as TD young people often do, to feeling worried about how their vulnerabilities often impacts on their safety linked with their mental health difficulties.

Findings within the wider literature

‘Loss’

As stated, fathers described loss in relation to their hopes and expectations for a ‘normal’ family life. This appears to be an experience which is well researched in the literature in parents of children with ASDs; where adapting to the diagnosis is like grieving a TD child as their expectations have been disrupted (Mansell & Morris, 2004; Heiman, 2002). As mentioned previously, O’Brien (2007) captured and named this experience as ‘ambiguous loss’ and is deemed related to several factors. These include, the uncertainty of the diagnosis and prognosis, their child having variable daily functioning, their child having seemingly normal development, and their child’s difficulty in regulating their emotions (O’Brien, 2007). Interestingly, researchers found that parents’ experiences of ambiguous loss were not identified at just one time point, rather, they felt this grief backwards and forwards continuously, particularly when their children did not reach expected developmental milestones (Rarity, 2007). These findings also support and link with the function of oscillation as captured by the DPM (Strobe & Schut, 1999).

Bravo-Benitez, Perez-Marfil, Roman-Alegre and Cruz-Quintana (2019) conducted a study which explored the experience of grief and loss in primary caregivers of children diagnosed with ASD. Their results indicated that the loss experienced by families was specifically regarding the loss of their child who was ‘normal’ during their early development, not the loss of their ideals, hopes and expectations for their child which was found in other studies (Casey et al., 2012; Heinman, 2002; Fernandez-Alcantara, Garcia-Caro, Perez-Marfil, Hueso-Montoro, Laynez-Rubio & Cruz-Quintana, 2016). This is an interesting finding and important to decipher for families in order to understand their relationship with their child more fully. This type of grief was particularly present in the current study for one father, Ryan. Ryan described having a ‘normal’ child, and then at the age of 13, his daughter’s mental health quickly deteriorated, and she was diagnosed with ASD during her mental health crisis in hospital. Ryan’s perceived loss of his daughter was with regards to both her ASD and co-occurring mental health difficulties. This combination of difficulties likely adds complexity to fathers’ grief.

Furthermore, Bravo-Benitez et al., (2019) also found that the experience of grief at the time of the diagnosis was reported to be more intensive than other studies describe. For example, primary caregivers explained it to be like "grieving the death of a family member, or even more painful" (Bravo-Benitez, 2019, p. 13). Participants in Bravo-Benitez (2019) study described this grief in relation to uncertainty and unpredictability about their child's future, as at the time, they did not know enough about ASD. When comparing these findings to the current study, this experience of grief appeared to be strikingly present for John whose daughter no longer lives with him, and instead lives out of county in a residential home due to her ASD and mental health difficulties. John explicitly shared feeling "*it's like your child has died*" (line 778). This not only highlights the painful feelings of loss which are different to losses related to hope and expectations, but also highlights the impact of mental health difficulties in adolescent young females with ASDs.

A third type of grief was described by Bravo-Benitez et al., (2019). The third type of loss was in relation to parents having to change their lifestyle in order to meet the needs to their child, such as changes in hobbies or in their occupation. This experience of grief was also present in the current study's findings and applied to multiple fathers. Ryan described stepping down from his position as director at his company in order to better meet the needs of his daughter. He described valuing his career and having worked hard for his position so appeared to feel the loss outlined by Bravo-Benitez et al., (2019). Overall, the authors' explanation of different variations of loss reflects the findings in the current study.

However, although Bravo-Benitez et al., (2019) acknowledged some diversity and inclusivity in parenting whereby biological parents were not always the child's primary caregivers, males were still significantly underrepresented in the sample. Additionally, this study focused on children aged 6 to 12 years old, and their genders were not specified. Thus, the current study extends the findings by Bravo-Benitez et al., (2019) by examining fathers' experiences of loss in parenting their adolescent daughters with ASDs.

Fathers coping experience: 'having to cope and feeling alone with this'

Although the notion that fathers cope differently to mothers has been alluded to in an above theme, this section will focus specifically on the gender differences in coping which appeared to be prominent throughout fathers' accounts in relation to traditional stereotypes of masculinity. However, before doing so, it is helpful to understand why 'having to cope' may arise for fathers.

Lazarus (1966) suggested that stress arises when the demand of a situation exceeds the individual's resources, impacting on their emotional wellbeing. Lazarus & Folkman (1984) proposed that the way individuals interpret (appraises) their situation determines whether this experience becomes challenging and stressful for them. When the situation is appraised as challenging, coping strategies are initiated to manage these difficult emotions. As such, fathers' experiences of 'having to cope and feeling alone with this' likely occurred due to a perceived lack of resource.

Interestingly, in Gray's (2003) paper examining the role of gender and coping among parents of children with ASD, he presented some background literature on gender differences of coping. This included studies which described women reporting a lesser sense of control over their stressful circumstances compared to men (Sigmon, Stanton & Snyder, 1995). A study also reported that men use a "stoical and inexpressive style of coping" (Thoits, 1995 in Gray, 2003, p. 632), whereas women are reported to use a more emotional and expressive style of coping. (Thoits, 1995). This author also identified that women are more likely to seek social support from family members and friends. These opposing ways of coping can be compared to Lazarus' (1993) cognitive model of coping. Here, two types of coping were deciphered, 'problem-focused coping', attempting to change the nature of the problem and 'emotion-focused coping', activities which are aimed to distract attention away from the problem or an expression of feelings. Gray (2003) outlines in his paper that although there may be exceptions, the evidence base generally suggests that men cope with stress in a problem-focused way, and women engage in emotion-focused coping. However, other researchers have suggested that coping is more complex than Lazarus' (1993) explanation. For example, coping with a child with a disability may hold different significance for men and women. As such, women are suggested as being more likely to blame themselves for their child's disability (Anderson & Elfert, 1989). This was supported by a study which found that even when men and women experience the same conflicts regarding work and family roles, their interpretation of the conflicts are different (Simon, 1995).

Furthermore, Gray (2003) found that when examining gender differences in coping styles of parents of children with ASDs, mothers and fathers both reported anticipating difficulties as a specific coping strategy. However, both parents also acknowledged being aware that they cannot predict every problem that arises. Moreover, fathers often coped by suppressing feelings of anger and frustration. However, these fathers also acknowledged that this worked temporarily and showed itself through other ways such as unreasonably angry responses with their families. Additionally, fathers reported feeling as if they need to be the source of support for their families, specifically, their wives and children, whereas mothers reported expressing their feelings and seeking social support from other family or friends.

Additionally, Grebe, Mire, Kim and Margulis (2021) conducted a study comparing fathers' and mothers' perspectives on their child's ASD which includes an examination of their coping and social support from a large sample of 361 biological parents. Out of these, 294 participants were mothers and 67 were fathers. The authors found that mothers consistently reported better and more frequently drawing on their coping skills compared with fathers. As such, it was suggested that fathers likely have fewer adaptive coping skills with regards to their child's ASD diagnosis compared to mothers which includes asking and communicating their questions about their child's ASD. In this study, fathers also appeared to use their work to cope and sought less social support. The authors also examined experiences of stress and coping across different age ranges of children and found that when looking at parents of adolescents with ASDs, that mothers were more likely to report their stress, and report it as a function of their relationship of their adolescents. Grebe et al (2021) explained that this is likely to be because mothers still take on the primary caregiving role, thus, spending more time with their adolescent likely leads to more focused attention on difficulties with their child's mood and behaviour which is not only associated with ASD, but also adolescence. Though despite the authors aiming to address mothers and fathers separately, fathers were significantly under-represented. Thus, the current study extends these findings suggesting that fathers' needs are less captured, recognised and understood in the literature and in health services.

Interestingly, the findings from the current study support's Gray's (2003) and Grebe et al's., (2021) evidence. As such, fathers appeared to hold their emotional experiences to themselves as they needed to *"carry on"* (John, line 686) as their partners and children relied on them for their own emotional and practical support. Therefore, in line with Gray's (2003) findings, fathers appeared to suppress their feelings in order to cope. This finding is interesting as, like Gray (2003) suggests, subtleties of anger and frustration appeared in some fathers' interviews where they perhaps felt unable to express this more directly.

Moreover, all fathers in the current study appeared to limit their access to social support, perhaps due to their coping strategies of holding onto their emotional experiences. For example, Frederick described tending to *"shut [himself off]"* to *"deal what is in front"* of him (line 430). John described finding that since his daughter's ASD, his *"circle of friends shrinks and shrinks"* (line 906) as he found it difficult to relate to others who had not had similar experiences to him. This in turn, appeared to lead to feelings of isolation as they felt unable to share their feelings with others. One father, Ryan even talked about feeling isolated from his wife they did not appear to understand each other's experiences. McGrath and Chesler (2004) captures that *"the mother cries to someone, the father cries alone"* (p.47), emphasising that fathers likely have the same emotional experiences, but manages them differently to mothers. This also highlights others perception of fathers to be managing effectively.

It is interesting to consider why these differences occur between men and women's emotional management. In the current study, Ryan alluded to this reason being due to the gender stereotypes for men where his *"job"* is to be *"strong"* (line 475). It is suggested that men's experiences and expressions of their emotions and thus, mental health are strongly influenced by dominant social narratives and ideals of masculinity (Oliffe & Phillips, 2008). These ideals are also intersected by social differences such as age, ethnicity, religion and social class. Whilst masculine norms may vary, and men's alignment with them, masculinity appears to be an on-going factor influencing fathers' coping, and in turn, influencing their access to both social and professional support (Oliffe & Phillips, 2008).

As such, these findings not only highlight fathers' types of coping and their emotional needs but also the barriers they face in accessing support.

ASD specific related feelings: 'Conflicting feelings about ASD' and 'fear and worry about vulnerabilities of ASD'

These themes highlight fathers' ambivalent feelings about their daughters' ASD, and also in relation to their fears and worries about their daughters' vulnerabilities linked to their

ASDs. These feelings appear to be a common experience amongst parents of children with ASDs (Axup 2012, Cheuk & Lashewicz, 2016). When exploring fathers of children with ASDs perceptions of how they are managing, fathers often compared their parenting experiences to those of fathers who had TD children, which highlighted some feelings of jealously when comparing their lifestyles (Cheuk & Lashewicz, 2016). As such, these comparisons could be considered in terms of typical parent development and fathers' ideas about what parenting

traditionally appears to be.

Friedman's (1957) model of parent development as outlined in chapter one proposed that both mothers and fathers of TD children progress through developmental stages when parenting. This model suggests that when their child is an adolescent, going through their own developmental stage of 'identity vs role confusion' (Erikson, 1968), parents progress through a stage of 'learning to build a new life' simultaneously. Friedman proposed that as their adolescent's independence grows, parents learn to build a new life, but still supports their child "quietly in the background" (Friedman, 1957, p.28).

This model is similar to that of the Family Life Cycle (FLC) which proposes a set of Family Life Cycle stages which families progress through (Carter & McGoldrick, 1989). These stages include 'leaving home as young adults', 'the joining of families through marriage', being a 'family with young children', being a 'family with adolescents', 'launching children and moving on' and finally, being a 'family later in life'. As such, fathers in the current study likely compare themselves to TD families who are 'families with adolescents' and 'launching children and moving on'. The former refers to families requiring increasing flexibility of family boundaries to include the adolescent's independence. Developmentally as a family system this means that parent-child relationships require shifting to allow the adolescent to develop their independence and move in and out of the family system. The latter, requires families to renegotiate their home life as a dyad between husband and wife as children leave the family home. Moreover, the parent-child relationship develops into adult-to-adult relationships. This model additionally suggests that families may experience distress when developmentally transitioning to the next stage of the cycle. (Carter & McGoldrick, 1989).

Therefore, in addition to the identified stressors and challenges of fathering adolescent daughters with ASDs, fathers in the current study may also be experiencing distress about their parent and family development to that of typical, socially constructed family ideals. However, both Friedman's (1957), Erikson's (1986) and Carter and McGoldrick's (1989) models focus on stereotypical families who are heterosexual, cis-gendered, married and live together, who are socially privileged and do not have children with additional needs.

Therefore, in order to develop a better understanding about fathers' experiences of parenting, it is useful to consider more adapted models of family experiences. Lindsay and DePape (2014) conducted a systematic review of literature on family's experiences of parenting children with ASDs. They synthesised articles from peer reviewed journals between 1980 and 2013. The articles which were included in the review were articles where: the child had a primary diagnosis of ASD, the diagnosis did not include co-morbid symptoms, the children were 18 years old or younger, the children were living in the parental home, the authors focused on parents' experiences in the form of benefits and/ or challenges of parenting their child and finally, where the researchers employed a primary qualitative design for data collection and analysis. Unpublished work and case studies were excluded. From this, they developed a model using the FLC as a framework to understand how families develop in response to the challenges that ASD presents with.

Lindsay and DePape's (2014) model identified six themes of experiences: 1) pre-diagnosis, 2) diagnosis, 3) family life adjustment, 4) navigating the system, 5) parental empowerment, 6) moving forward. For the purpose of relating the findings to the current study, only the relevant themes will be discussed. In this section and in relation to fathers' experiences of having mixed feelings about the ASD, and in their fears and worries about their daughters' vulnerabilities, the stages of Lindsay and DePape's (2014) model which most applies is 'moving forward'. One of the sub-categories within the stage of 'moving forward' were parents' concerns for their children's future. For example, it appeared that many of the parents in the literature wanted their child to live independently in adulthood (Ludlow, Skelly & Rohleder, 2011; Midence & O'Neill, 1999). Midence & O'Neil (1999) described that their child's independence was considered important in terms of their personal development but also regarding concerns about what would happen to their son or daughter after they passed away (Gray, 2003, Ludlow et al., 2011). This evidence supports that of the current study where fathers' fears about their daughter not living independently were linked to concerns about how their daughters would cope after they were no longer around. This finding was particularly prominent for Frederick who described being an older father and this worry being more present for him compared to other fathers. Similarly, fathers also shared concerns at their daughters not being able to manage the work environment and thus, wondering what their adult lives would look like (Midence & O'Neill 1999; Shu, Hsieh, Hsieh & Li., 2001). Patrick described that *"the whole autistic side of things, means that unless something unusual happens in the future, she won't be in the workplace, because it's too demanding."* (line 330). however, fathers also balanced this with wanting their daughter to be happy (Lutz et al., 2012). It appeared that the uncertainty about their daughters' futures was the underlying worry present throughout their accounts, as supported by the literature collated in Lindsay and DePape's (2014) systematic review. Again however, although these findings provide evidence to suggest that families of children with ASD's have similar mixed feelings and worries about their children's future, the studies in the review were largely based on mothers' reports on their school aged sons. Thus, findings from the current study provides evidence that fathers' felt similarly about their adolescent daughters with ASDs.

Theme 3: 'Let down by the system'

Summary of findings

Fathers appeared to feel let down by the support system around their daughters, such as schools, mental health services, social services, and the government regarding its political context of austerity. Fathers' feelings about the system ranged from disappointment to abandonment and often presented as anger and frustration towards them.

Fathers perceived the system as not understanding ASD, particularly adolescent females' needs with ASD which, as outlined in chapter one, is different to males due to females' 'masking' tendencies. As fathers perceived the system to not understand ASD, adaptions were not made which left feelings of ***'injustice and anger and having to fight'.*** Fathers felt the system was failing to keep their children safe, thus, some fathers were fearful for their child, which often presented as anger. One father, Patrick, not only described injustice but he perceived the system to be actively working against him. Fathers also reflected on their social privileges and how their experience of the system would likely be even more challenging if they were from a lower socio-economic status.

Lastly, all fathers acknowledged' ***a lack of societal acceptance'*** of ASD. Some fathers talked worryingly about it, holding in mind their daughter's future, and others talked more angrily about it. All emotional responses appeared to come from a position of concern about the impact that society has on their daughters' mental health, and the impact of this on their futures.

Findings within the wider literature

The findings related to perceived inadequate support from parents of children with ASDs appears to be common across the literature. In Lindsay and DePape (2014) systematic review, one stage in their model was regarding 'navigating the system' which suggests this experience is prominent across a spectrum of age ranges of children and not just adolescent females. This experience was on-going throughout their parenting lives and often did not appear to reach an end goal of the system reaching an understanding. Lindsay and DePape (2014) highlight a range of experiences with the system with regards to the school and health system specifically. These experiences were captured as feeling "dissatisfied" (p. 8) with the school and parents finding themselves working to support teachers with their understanding of ASD (Shu et al., 2001). They outlined that some teachers did not understand ASD and thus, how to support their children to manage their behaviour in the school environment (Woodgate, Ateah & Secco., 2008), Divan, Vajaratkar, Desai, Strik-Lievers & Patel., 2012, Aylaz, Yilmaz & Polat., 2012). Parents reported that this lack of understanding led to some teachers making inappropriate comments about their children. This finding is consistent with the current study where fathers described feeling let down by some teachers' comments. John specifically, reported that one teacher told his daughter *"I don't care if you're autistic, you're using it as an excuse to misbehave! If you don't like the noise from assembly, just stop moaning and put ear plugs in!"* (line 381). This highlights John's anger in response to the lack of understanding and in turn, lack of adaptation for his daughter.

The systematic review also highlights some challenges that parents faced in accessing appropriate health care services for their children. Parents in Hutton and Caron's (2005) study only had positive experiences, whereas others had challenges, for example, in relation to ineffective communication leading parents to wonder whether professionals had the required expertise to support their child's needs (Fong, Wilgosh & Sobsey, 1993). Interestingly the study conducted by Hutton and Caron was in a rural region of the United States and thus, their health system likely looks different to England's health system.

Again, the outlined studies are mostly from mothers' accounts of their experiences with their school aged sons. Additionally, the majority of the studies were from the United States (US), with only 2 out of 31 studies conducted in England. This is important to capture because the system's understanding of ASD in the US may be different to England's. Therefore, although the synthesis of studies captured by Lindsay and DePape (2014) capture some specific parental experiences of children with ASD, there also appear to be some vast differences regarding the impact of the system on families. In the current study, fathers appeared to be angry at not only the system's lack of understanding, but also their perceived lack of effort to understand, leaving fathers feeling alone in supporting their daughters.

The experiences regarding the perceived failures of the systems in supporting families is a worrying finding. The European Commission (2018) which helps shapes the European Union's strategies, outlines that the inclusion of people with disabilities is one of the principles constituting the European Pillar of Social Rights, where people with disabilities should have inclusive access to services. Moreover, the Equality Act (2010) states that there is a legal obligation to make reasonable adjustments for individuals with ASD, as they have unique support needs which require specific understandings and approaches for their needs to be met (Posada, Garcia, Primo, Ferrari & Martin-Arribas, 2007). Thus, if not adequately supported, their opportunities for optimal development will likely be hindered, placing them at risk of social exclusion. Thus, this places fathers' angry responses and fears about ASD not being accepted in society as more than just an individual concern for their daughter. Rather, this appears to be a chronic, societal issue which families are living with and thus, appear to be excluded by.

Again, the importance of these issues can be considered from a systemic perspective using Bronfenbrenner's Ecological Systems theory (EST) (1979) as described earlier in the chapter. To reiterate, EST is a well-known psychological theory of human development which suggested that individuals live and are embedded in multiple systems. As such, a person's development is a result of the complex interactions between themselves and the systems in which they live in. Focusing on the systemic influences which EST presents for fathers of daughters' with ASD, its approach is more aligned with the sociological perspective of disability and less on the psychological position of it (Barton, 1988). Thus, EST is considered a useful framework for the discussion of inclusion and Special Educational Needs (SEN) for young people in schools because it considers various factors, internal and external to the young person which may interact and influence their inclusion. Alternatively, several studies have critiqued social inclusion research which has either over-individualised or over-socialised disability and SEN, thus, suggesting that the EST can provide a better balance between social and individual needs (Kamenopoulou, 2016).

However, focusing on a social approach to understanding disability, the Social Model of Disability (SMD) (Oliver, 1996) suggests that individuals are disabled by the barriers in society, not by their difference or impairment. This links to the current study's findings as fathers perceived the systems around their daughters to be barriered and unaccepting of their daughters' ASDs.

Interestingly, Graby (2016) suggested that the SMD has been more successfully employed for people living with physical disabilities in the US but is less embedded in the UK and its Equality Act (2010). Moreover, the SMD is even less considered for those with neurodiverse labels such as ASD (Milton, Martin & Melham, 2016).

Furthermore, Woods (2017) outlined that inclusion is not successfully integrated into the UK's education system. For example, there are high numbers of children and young people with ASD diagnoses with Educational Health and Care Plans (EHCPs) which is indicative of a "bolt-on support" (p. 1091) for anyone who is considered different from the "norm" (Woods, 2017, p. 1091) (Milton, Martin & Melham, 2016). This notion of disability and inclusivity is described as perpetuating ableism (Campbell, 2008). Woods (2017) thus emphasises that this poor implementation of inclusion policies contributes to the distress that parents face in seeking adequate support for their children. This argument aligns with the findings from the current study as fathers' experiences of distress as a result of the system.

To address this argument, Woods (2017) suggests some ways in which to implement the model for individuals with ASD. Scholars have suggested that one primary social barrier is regarding the use of negative language and discourse surrounding the label (Levitt, 2017; Woods, 2017) such as, referring to it as a deficit and disorder. Therefore, a "blanket Autism Spectrum label" (p.1093) could help ensure prevention of negative stereotypes and support a more positive discourse of ASD (Woods, 2017). Additionally, Woods (2017) suggested that the model should be disseminated to all individuals with ASD to support the recognition that they are the experts, allowing for increased self-advocacy and self-regulation. Furthermore, supporting those with ASD, in this case, young people and their families to be understood, listened to, and responded to, will likely reduce the impact on their mental health.

However, Woods (2017) suggested that the SMD should be complemented with other relational models in order to offer a more holistic approach to inclusivity. This is because the SMD does not explain how disability is experienced, for instance, how people with ASD experience the world compared to neurotypical people (Mallett and Runswick-Cole, 2014). Alternatively, however, the primary goal of the social model is not on the individual's perspective but rather, its aim is to shift the focus onto societal structures which are causing barriers for individuals (Woods, 2017). This model is considered useful to capture fathers and their families in the current study as they described societal barriers and a general lack of acceptance of their daughters' ASDs.

Added to the social barriers which families face with ASD, fathers in the current study also shared concerns about their daughters' navigating their gender identity alongside their ASDs. Coleman-Smith, Smith and Milne (2021) explored the experiences of GD for adults with ASD using IPA and emphasised that the social environment is restrictive, hindering understanding, exploration, and expression of gender identity. In turn, this was found to amplify and maintain the lack of acceptance that individuals with ASD felt regarding both the dominance of cis normativity in Western society and the lack of acceptance for neurodiversity. However, the study found that accessing supportive relationships was fundamental in enabling understanding and an exploration of their gender identity on an individual level. Therefore, fathers can play a pivotal role in contributing to a safe expression of their daughters' gender identity. However, the findings from the current study suggests that fathers also need the required support to do so.

Concluding contextual thoughts

Overall, the findings from the current study aligns with the gaps in the current evidence base which suggests that fathers' experiences of parenting their children with ASDs, specifically adolescent daughters, has not previously been attended to. The discussion suggested that this is likely due to traditional masculine roles about males, but specifically, fathers in parenting. The discussion also highlights differences and masculine ideas compared to mothers regarding their expression of emotion and coping, i.e., that fathers were more likely to hold onto their feelings and not reach out for social support. As such, the findings support Cheuk and Lashewicz (2016) argument where there is a need to break "habitual practices" (p.9) of attending less to fathers' experiences. The findings challenge past literature, such as Cassano, Adrain, Veits and Zeman (2006), and highlights fathers' keenness to share their experiences. Interestingly, as summarised by Cheuk & Lashewicz (2016), Braunstein, Peniston, Perelman, Cassono (2013) reviewed the nature of parent involvement in studies of children with ASD and emphasises the conflation of mothers and fathers' perspectives which are then discussed as 'parent' views, suggesting that they are the same. As such, the authors outline the need to target and examine fathers' perspectives in order to offer a more balanced and understanding view of fathers' experiences (Braunstein et al., 2013; Cheuk & Lashewicz, 2016).

Furthermore, a concluding critique from the current evidence base of fathers' experiences of parenting their children with ASDs only appears to capture father heterosexual, cis-gendered fathers from white, middle-class backgrounds. As such, fathers from different minority groups would offer a more in-depth and diverse understanding of fathers' needs in relation to their experiences of parenting their adolescent daughters with ASDs in today's current society.

Implications

In the following section, key clinical implications of the current findings will be discussed. The most immediate implications will be for future research studies which will be discussed in the section 'Future Research' below. However, although the findings cannot be generalised to all fathers' experiences, the results appear to indicate some implications for fathers of daughters with ASDs. Overall, the current study underlines the importance of fathers in raising their adolescent daughters with ASDs. These findings highlight two distinct avenues of implication to practice. The first is regarding the individual support needs of fathers and the second is regarding implications for schools and health care providers, and hearing fathers' voices within these systems.

Fathers’ individual support needs

The findings from this study highlighted fathers’ distressing experiences of supporting their daughters through challenges presented by their ASD and co-occurring mental health difficulties. As such, the findings suggest that fathers not only had limited social support, but also that they likely struggled to express their emotional experiences due to the socially constructed, stereotypical ideas they held about being a father. Moreover, not only is it important to meet the needs of fathers at an individual level but also at a systemic level when considering the Ecological Systems Theory (Bronfenbrenner, 1979) as discussed in the earlier section. This model suggests that if fathers are not supported in their emotional wellbeing at a universal level, then they may require mental health support from secondary mental health services. However, due to the current context of political austerity, the National Health Service (NHS) is stretched leading to limited capacity and long waiting lists. Currently within CAMHS, families are limited to one parent support group following diagnosis which does not appear to be meeting the needs of fathers. In turn, this influences the macrosystem which fathers live within causing more challenge and financial strains. Thus, if fathers’ emotional needs can be recognised and met sooner, fathers and the systems surrounding them will benefit. Additionally, if fathers learn to understand their own emotions and how they respond to change, it will help them to better manage it.

With consideration of the challenges discussed regarding the emotional experience of fathers ‘having to cope’ and the current limited capacity of NHS, two long-term approaches can be considered. The first is highlighting the importance of continued research to better understand the needs of fathers. This research can be used to evidence gaps in current NHS service provision and policy, with the aim of increasing adequate statutory support for fathers following diagnosis.

Second, is the consideration of increasing fathers’ support networks so that they feel better able to manage the demands of fathering their adolescent with an ASD. Tentative suggestions in how to increase their current support networks involve NHS services having an increased awareness of fathers’ needs following their daughters’ diagnosis and informing fathers of appropriate avenues of support, including recognising the importance of supportive relationships and local non-statutory service information, such as access to Dad's groups.

Hearing fathers' voices within the system

Another main finding was regarding fathers' negative and often, detrimental experiences of the support systems around their daughters where they appeared to experience injustice and were not heard by professionals. As above, Woods (2017) suggested that knowledge on the Social Model of Disability (Oliver, 1996) should be disseminated to individuals with ASDs to support their recognition of being their own experts. However, with regards to the current study, this recommendation should also be employed with fathers to support advocation for their daughters. In light of this implication, the current study calls for practitioners, policy makers and educators to consider and incorporate parents' voices within their services, but specifically, fathers', in their adolescent's health and social care, and education.

The above finding also highlights the importance of schools and healthcare providers' understanding of female adolescent ASD, and the impact that their response has on the young person's mental health, in turn, influencing fathers' experiences. Whilst direct support for fathers has been discussed, it is also important to consider ways of increasing educators and health and social care providers understanding alongside this (Locke et al., 2019). As such, training in ASD in young people with a consideration of its presentation across genders and ages is a useful intervention to increase the quality of an adolescent's experience, and also their fathers'. The training should include how best to incorporate mothers' and fathers' perspective in meeting their adolescents' education and health care needs. In considering the context of limited resource within the NHS, training for education and, health and social care providers is useful as it is not limited to statutory NHS services. As such, a universal training offer is considered an effective systemic intervention which may have a positive impact on adolescents' and reduce seeking of secondary mental health services. As described above, this not only supports adolescents and their fathers, but it also prevents further strain on secondary mental health service provision. Moreover, during a time of limited resource, the quality of the service being offered is central to effective service delivery, thus, the training offer should also be regularly evaluated (Ham, Berwich & Dixon, 2016).

An evaluation of the study: strengths and limitations

This section will begin by outlining the strengths of the study, which will include an exploration of the quality checks made. The final part will discuss its limitations and considerations for future research.

Strengths

A strength lies in the study's interpretation of the homogenous group of fathers' experiences who have traditionally been under-represented in the literature. Moreover, it follows fathers' emotional journey with their daughters and how they make sense of their experiences which offers a nuanced insight into their lives which has not previously been captured in the literature. Moreover, the study has also provided fathers an opportunity to share their experiences when typically, their voices have been under-represented. As mentioned in chapter three, many fathers reported the interview experience as being a cathartic experience.

In addition, this study captured experiences from a homogeneous sample which is an important requirement for IPA (Smith et al., 2009). In addition, the study recruited eight participants which is also within the sample size aim for an IPA doctoral thesis (Smith et al., 2009). Both of these factors contributed to the reliability and validity of an IPA research study.

Another strength is with regards to the findings as they appear to indicate that there are commonalities across experiences of this group of fathers, in addition to some similarities in the literature based on 'parents' generally.

As outlined in chapter two, this study also had the involvement of a parent consultant to ensure the study was appropriate for its participants. The involvement of a parent with lived experience of having a child with ASD improved the quality checks of the study and in turn, improved the reliability and validity of the research.

Quality Checks

Another strength of the study is with regards to the quality checks, previously discussed in chapter two. These quality checks were implemented in line with Elliott et al (1999) and Yardley's (2000) frameworks and used throughout the study to ensure reliability and validity of the findings.

However, quality checks could have been improved. Elliott and colleagues' (1999) 'providing credibility checks' could have been strengthened by seeking an additional perspective from a peer who is also conducting IPA research as part of their doctoral thesis. Thus, an opportunity for improved quality checks was missed. However, this was not facilitated due to time constraints and so, discussions about the analysis and eventual themes with supervisors and the parent consultant was considered sufficient.

Limitations

One key limitation is regarding a consideration of the global climate in which the research was being conducted. Fathers participated in this study during the COVID-19 global pandemic, thus, this likely impacted on fathers' experiences and should be considered in its application to fathers of a similar group. More specifically, the findings of 'loss' and 'having to cope and feeling alone with this' may be experienced more strongly due to the social restrictions of having to isolate from their support networks during the national lockdowns. However, the findings should also not be underestimated due to this.

Although the involvement of a parent consultant was key throughout the research and provided invaluable input and insight into the lived experience of being a parent of a child with ASD, the reliability and validity would have been strengthened if it had been a father of an adolescent daughter with ASD. However, this was not deemed appropriate as the parent consultant was already recruited and involved when the research stance changed from exploring mothers to fathers. As discussed, this was managed by the parent consultant drawing on her husband's spoken experiences alongside her own.

As already discussed in chapter two, the generalising of findings from qualitative research may be recognised as conceptually different to the statistical-scientific generalising of findings in quantitative research. However, the current study and its methodology did not seek to generalise its findings. Rather, the aim was of an explorative nature due to the lack of understanding and research in this area of inquiry.

Furthermore, a key limitation regarding the methodological design is that IPA has been critiqued for its lack of acknowledgement about discourse in the theory (Willig, 2013). As such, critiques have suggested that language is socially constructed and so, participants will describe their experiences in relation to their social experiences and the discourses about them. Moreover, IPA researchers rely on participants to adequately communicate and articulate their experiences using language. Thus, they suggest that IPA analyses the way in which participants talk about their experiences, instead of the actual experience (Willig, 2013). However, this critique does not acknowledge hermeneutics and the importance that IPA places on the interpretation of language and the spoken experience (Smith et al., 2009).

Additionally, although the homogeneity of the study was considered a strength, heterogeneity was increased by the age of fathers' daughters which ranged from 11 to 20 years old. Although the range of daughters' ages was 9 years, this is significant in terms of adolescent development (Erikson, 1968). However, this age range also provided an insight into fathers' emotional developmental journey as discussed earlier in the chapter. Moreover, these ages were within the recruitment inclusion criteria as guided by the World Health Organisations' (WHO) definition of adolescence as it is deemed to align more closely with adolescent growth and development in today's society (Sawyer et al., 2018).

Lastly, the findings are focused on highly involved fathers from predominantly intact and middle-class socio-economic backgrounds (Cheuk & Lashewicz, 2016). As such, other factors such as intersectionality likely played a role in their experiences such as social class and socio-economic factors. A consideration of these factors are discussed in the 'future research' section below.

Future Research

As already stated, the current study recommends researchers to continue to capture the experiences of fathers in parenting, as they remain to be an under-represented group in the parenting literature. More specifically however, continued research is needed to explore fathers' experiences of parenting their adolescents' daughters with ASDs to better understand their needs, and to contribute as evidence to gaps in current service provision.

Moreover, as the current study recruited fathers who were white, married, cis-gendered and heterosexual, fathers’ experiences from minoritised and marginalised backgrounds have not yet been captured and thus, their needs are not yet understood. Therefore, an exploration of diverse groups of fathers are considered important for future research as they likely have different needs to the current sample of privileged fathers. To successfully recruit fathers from minority groups, future research requires elaborate recruitment methods to consider how best to reach and incorporate fathers of adolescent daughters with ASDs who are more socio-economically and structurally diverse (Cheuk & Lashewicz, 2016).

As such, continued research is required to support fathers to have their voices heard and their support needs met for the purposes of developing research, practice, and policy arenas (Cheuk & Lashewicz, 2016).

In addition to undertaking further research with fathers, findings from this study also highlighted the need to further understand the barriers in the professional system which fathers described as often detrimental to their daughters. Whilst the current study has discussed possible reasons for the barriers, further research would better understand them in order to improve fathers’ experiences of the system.

Moreover, as further emotional, and social support for fathers is considered beneficial to their mental health, further evaluation of current interventions would be considered integral to the current, limited support offers. This is especially important as the quality of the service being offered is central to effective service delivery during a time of limited resource (Ham, Berwich & Dixon, 2016).

Conclusion

In conclusion, this study explored fathers’ experiences of parenting their adolescent daughters with ASDs. Though there were unique similarities and differences in their accounts, the similarities were captured by three superordinate themes.

Fathers appeared to find their experiences of parenting their daughters confusing as they did not know where they stood in their relationship and why their relationship was challenging at times. However, they attempted to make sense of their relationship and over time, this seemed to lead to learning and some resolution of conflict. More specifically to ASD, fathers appeared to find it difficult to process and adjust to their daughters ASD which triggered some feelings of loss and further conflict, and fear and worry about their futures. This highlighted some fathers' coping strategies of feeling that they had to hold onto their emotional experiences. The discussion embedded this further in the literature linking these experiences to fathering roles specifically, and hegemonic masculinity within todays' society.

Finally, fathers appeared to feel injustice from the support systems in place for their daughters as there was an on-going experience of professionals not understanding daughters ASD. This lack of understanding significantly impacted on some of their daughters' mental health which led fathers to feel angry and that they had to fight for their daughters' rights. This experience also highlighted a lack of societal acceptance for ASD.

Although there is no other identified study exploring fathers and adolescent daughters with ASD, there appeared to be some similarities with mothers regarding their emotional experience and reaction to their child's diagnosis. However, there were also some stark differences which appeared to be specific to fathers with adolescent daughters regarding their ways of coping and their fathering roles. Additionally, there appeared to be a striking experience specific to having an adolescent daughter with regards to the response from the support systems and society where fathers felt 'let down by the system'. Overall, this appears to fit with the literature describing female adolescents 'masking' their difficulties which leads others to believe that they are coping and managing well. Thus, contributing to fathers' experiences of not feeling heard or listened to.

Final reflections

I am left feeling very proud of this research project. Whilst conducting the interviews and analysis, I was in awe of fathers sharing their honest, raw and open reflections of their highly emotive experiences with me. I feel incredibly privileged to not only hear their stories but also to be able to capture them in a write-up and to disseminate it for others to read.

Highlighting fathers' voices as a researcher has also made me feel passionate about continuing to do this in my clinical work as a qualified Clinical Psychologist with families. I feel that the insight I have gained from fathers is invaluable and I am hopeful that the study's focus on trying to meet fathers' needs, will develop services appropriately. There is an opportunity for further exciting and extremely meaningful research which will likely have a significantly improved impact on fathers' experiences of parenting their adolescent daughters with ASDs.

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Appendices

Appendix A: Interview schedule

Interview schedule

<u>Exploring fathers' experiences of parenting their adolescent daughter with ASDs</u>

Thank you for agreeing to take part in this interview today. As we have already discussed I am conducting research as part of my Doctorate in Clinical Psychology at the University of Leeds. As you know, the purpose of the study is to explore fathers' experiences of parenting their adolescent daughters. This involves an interview which takes approximately one hour.

I will start by summarising the main points covered in the participant information sheet. I will then go through the consent form and ask for your verbal consent in participating in this study.

A summary of the participant information sheet is as follows:

- *Both your personal information and your interview will be kept strictly confidential. However, it is our duty of care to inform appropriate services if you disclose that you or others are at risk of harm.*
- *Your interview will be audio recorded and will be deleted following transcription of the data.*
- *Any personal or identifiable information will be changed.*
- *You can withdraw your data up to seven days after the interview.*
- *Results of the study may be published in a journal article, but you will not be identified in any report or publication.*

Do you have any questions?

In order to gain your verbal consent to participate in the project, it is also necessary to audio record our discussion of this. This is where I will talk through the consent form and ask you if you agree.

Are you happy for me to start the audio recorder? (set up audio recorder)

Audio recorder is on now.

Do you confirm that you have read and understood the information sheet explaining this project, and that you have had the opportunity to ask questions about the project?

Do you agree that the data collected from yourself will be stored and used in relevant future research in an anonymised form?

Do you understand that relevant sections of the data collected during the study may be looked at by auditors from the University of Leeds or from regulatory authorities where it is relevant to your taking part in this evaluation project? Do you give permission for these individuals to have access to your data?

Do you give your consent for audio recordings of the interview to be made? Do you understand that this is for the purposes of analysing the information you provide in the interview to allow for the anonymous reporting of the feedback? Do you understand the people hearing the interview (the researcher and transcriber only) will keep the information confidential, and that recordings will be stored under secure conditions?

Given the importance of the research data, the findings and/or anonymised transcripts from the project may be used for additional research. Do you give permission for direct quotes to be used anonymously, so that you are not identifiable?

Do you understand that you can withdraw my data before, during or up to 7 days following the interview without giving a reason? Do you also understand that if this occurs, any data that has already been provided will be deleted.

Finally, do you agree to take part in this research project?

Will you also inform me if your contact details change during the project, and if necessary, afterwards?

Thank you very much.

If there are any questions in the interview that you would rather not answer, then please let me know.

(Give them a copy of the interview schedule to have a read over which they can keep during the interview as a guide. To return following the interview.)

I will start the interview now.

1) **I'm interested to hear about what why you chose to take part in this research study?**

2) **Tell me about your family**
   Prompts: Who lives at home? Children? How old? Do the adults in the family work? What do they do? How would you describe your family? How would you describe different members of your family?

3) **I'm going to ask you to cast your mind back to when you found out you were going to be a father to X – what was this time like?**
   Prompts: What were your thoughts? What were your expectations of being a dad? Hopes? Worries?

4) **What's it like being a Dad to X?**
   Prompts: Do you have interests/days out/hobbies together? What do you like about these? Examples of moments of closeness? Examples of more difficult moments? How was your own expectation of being a father changed given your daughter's disability?

5) **When did you first have concerns about your daughters' development?**
   Prompts: Were you concerned or was somebody else? Why were you/was someone else concerned? When did she get diagnosed? What was this like for your daughter, X? Challenges?

Positives? What was this like for you as her father? Were you offered any information, support, or signposting to support at the point of diagnosis?

6) I'm interested to hear about what it is like fathering X as an adolescent/young adult?
Prompts: use examples when explaining these
- *Future anticipations/predictions? (What did you think it might be like vs what it's really like? What do you anticipate for the future?)*
- *Positives?*
- *Challenges?*
- *Role of ASD in adolescence?*
- *How do these experiences make you feel?*
- *Why do you think you feel this way?*
- *Do you share your views feelings with others?*
- *Are there any support networks/forums for you to share your views and feelings with others?*
- *What do they think? Why do they think this?*

7) Is there anything else you would like to tell me that we haven't already covered?

Demographic information:

- *Age of father*
- *Ethnicity*
- *Live with their daughter? (Full-time, part-time or not at all)*
- *Co-parent (with who?) or single parent?*
- *Current age of daughter*
- *Daughter's age when you first had concerns about your daughter's development*
- *Daughter's age when you first contacted the health system about your child in relation to their eventual ASD diagnosis?*
- *Daughter's age when given diagnosis*

(Interviewers copy only)
Notes about initial response to interview:
- *My reactions, feelings in response to the participant and their experiences*
- *Observations from the interview (e.g., participants non-verbal response to questions)*
- *Questions that I may have missed which could have been helpful*
- *Questions that may have been unhelpful*

Appendix B: Recruitment flyer

School of Medicine

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Fathers' experiences of parenting their adolescent daughters with Autism Spectrum Disorders (ASDs)

Are you a father to a daughter with an ASD, aged 10 – 24 years old?

Can you take part in the study?

You are eligible to take part if:

You are a **father** to an **adolescent female** with an **ASD who does not also have an intellectual disability.** Your daughter must be aged between **10 -24 years old**.

AND

You have been **present** during the **identified concerns and diagnosis**. You do not need to be living with your daughter but should **be actively involved** in parenting her.

AND

English is your first or second language.

What is involved?

One interview lasting approximately one hour by telephone or video call, in your home or at The University of Leeds. During the interview, we will discuss your experiences of parenting your daughter who has an ASD.

If you would like to find out more, please contact:

Lucy Kerrigan (Psychologist in Clinical Training)

by email on: umlck@leeds.ac.uk

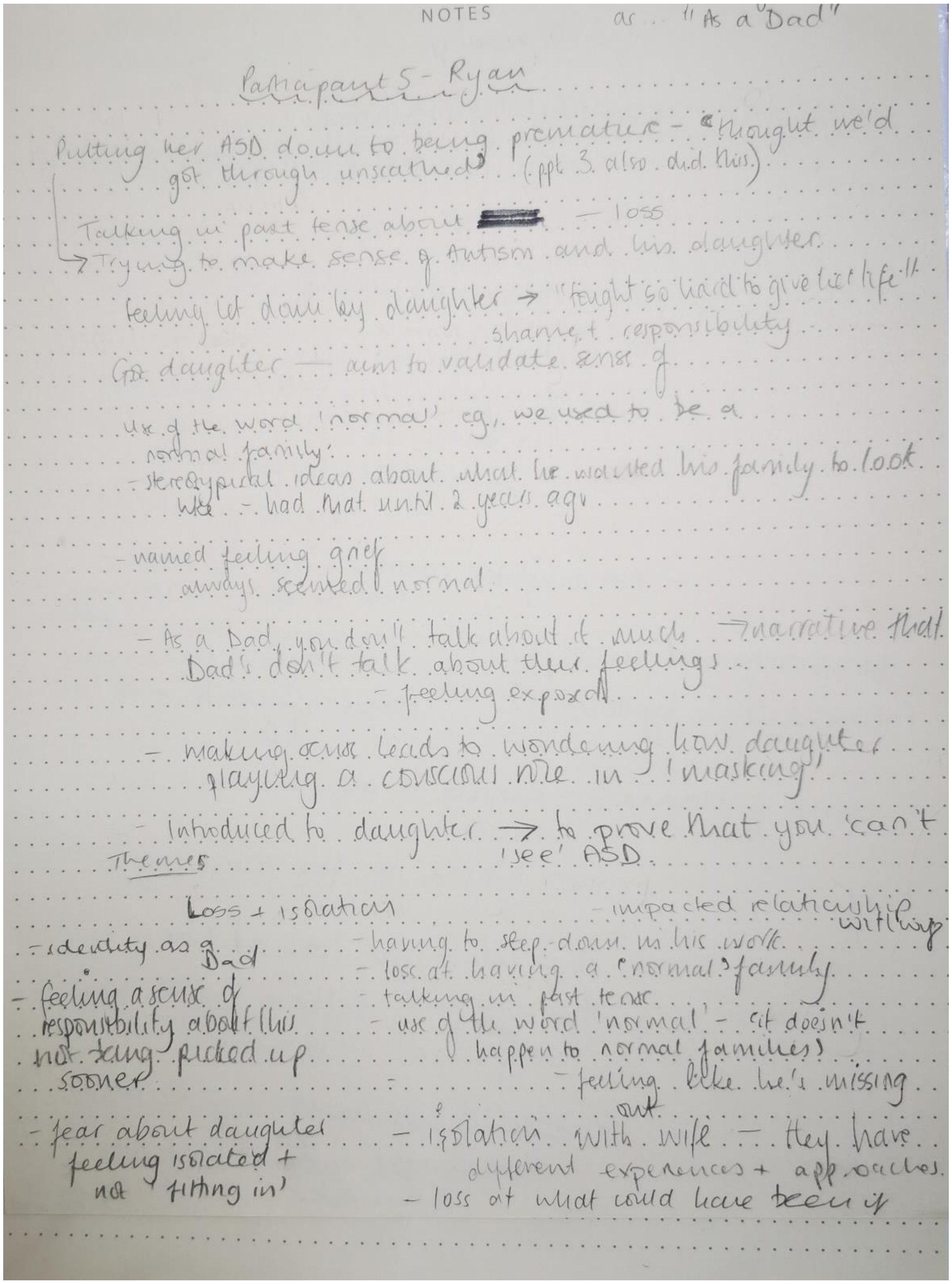
This study is supervised by Dr Tracey Smith (Clinical Tutor) and Dr Tom Cliffe (Lecturer in Clinical Psychology) and has been approved by the University of Leeds School of Medicine (SoMREC Ethics Committee (MREC19-084; date approved: on 14/08/20).

Title project	*Document type*	*Version #*	*Date*
Thesis research project	Recruitment flyer	3	13/07/20

Appendix C: Analysis - initial noting

Mirroring of social experiences in father and daughter Lifelong experience of injustice and misunderstanding led to negative comparison of self to others. Daughter's diagnosis of ASD initiated a better and helpful understanding about himself.	communication isn't one of my strengths, um, but, ya know, I'm what? 48 now and I, I kind of, got through life, and struggled, but now at least I understand so, ya know, maybe the last, two or three years when my daughter was getting her diagnosis we were, sort of, discussing the traits and things and that's when it became quite clear to me, and quite evident, and that in itself helped me, and that actually, has taken some weight off my shoulders because instead of me thinking… I was slightly unusual and…didn't quite always fit well in social situations and was uncomfortable, um, when everybody else just seemed to sail through life, um, they, ya know, just that whole diagnosis and and understanding has just really, sort of, helped me, and so, I didn't have any, any concerns, any reservation in doing this. R: Ah brilliant. P: And yeah, I'm looking for positive	'No doubt' – absolute clarity. Makes complete sense to him now. Showing a lack of confidence in his communication. Declaration of age have a factor? An assumption that at 48 he shouldn't be struggling, or he should have a better understanding of himself? Or that ASD traits should have been identified at a younger age, so he didn't have to struggle the way he did? Sounds like he puts his communication difficulties down to having ASD. Use of 'at least' - what else is he hoping for? Change? Support? Use of 'ya know' a lot – taking the weight of what's saying off of him? Wanting to tentatively share it. Is he worried about my response? Improved understanding about himself because of his daughter's diagnosis. 'Taken weight off my shoulders' - Relief and clarity in improved understanding. He was holding the weight of being different and not understanding his anxiety, for all his life. Understanding himself as having ASD has allowed him to be more compassionate to himself? Comparison of self to others as not coping well. Negative comparison of self. 'everybody else just seemed to sail through life' – feeling injustice, misunderstood? Use of 'ya know' - tentatively relating, wanting to be

Appendix D: Handwritten notes on the development of emergent themes



NOTES

as .. "As a Dad"

Participant 5 - Ryan

Putting her ASD down to being premature - "thought we'd got through unscathed" (ppt 3 also did this)

Talking in past tense about [redacted] - loss

→ Trying to make sense of Autism and his daughter

feeling let down by daughter → "fought so hard to give her life"
shame + responsibility

Got daughter — aim to validate sense of

Use of the word 'normal' eg, we used to be a normal family'
- stereotypical ideas about what he wanted his family to look like - had that until 2 years ago

- named feeling grief
always seemed normal

- As a Dad, you don't talk about it much → narrative that Dad's don't talk about their feelings
- feeling exposed

- making sense leads to wondering how daughter playing a conscious role in 'masking'

- Introduced to daughter → to prove that you 'can't 'see' ASD

Themes

Loss + isolation

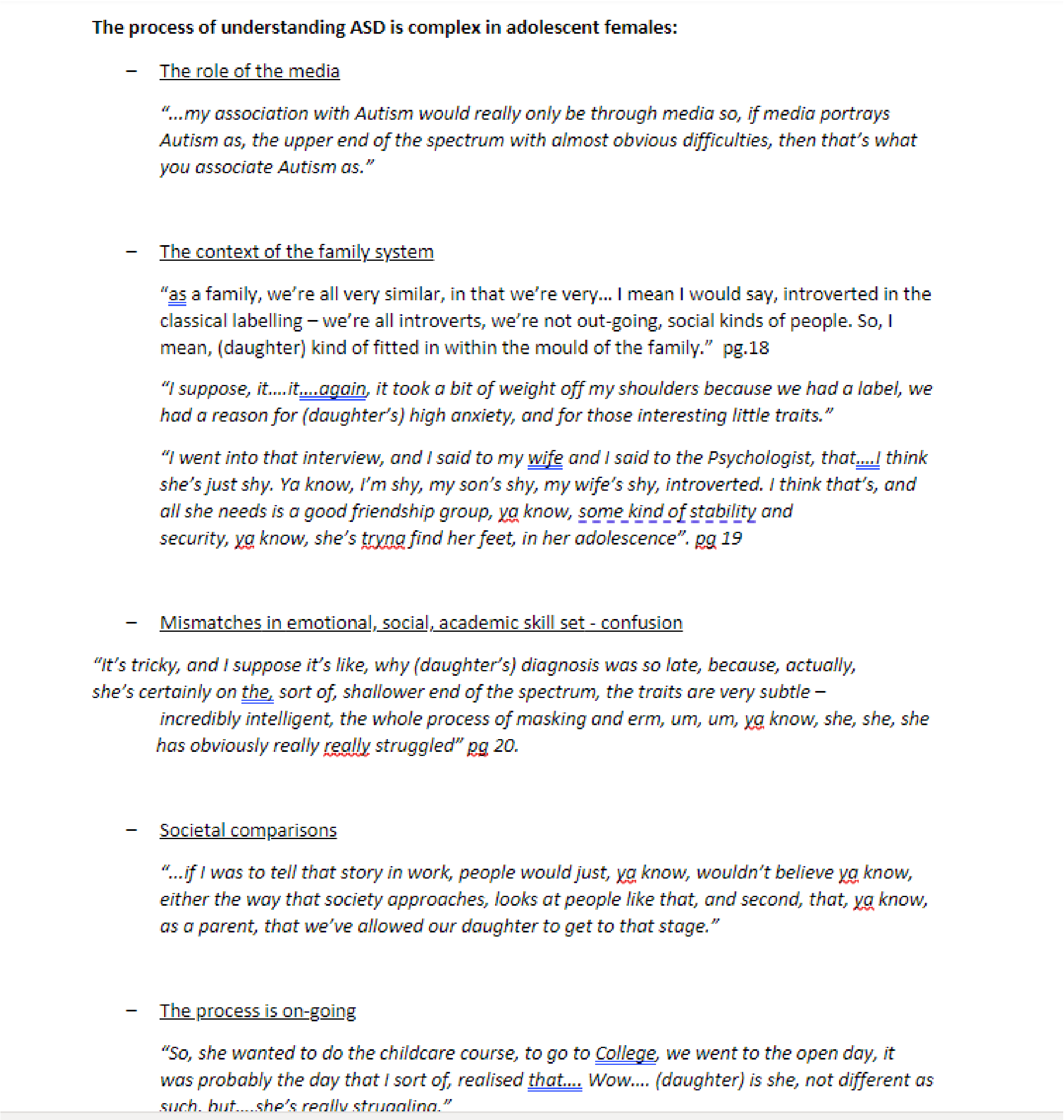
- identity as a Dad

- feeling a sense of responsibility about this not being picked up sooner

- fear about daughter feeling isolated + not fitting in'

- impacted relationship with wife
- having to step down in his work
- loss at having a 'normal' family
- talking in past tense
- use of the word 'normal' - 'it doesn't happen to normal families'
- feeling like he's missing out
- isolation with wife - they have different experiences + approaches
- loss at what could have been if

Appendix E: Emergent themes with quotes



The process of understanding ASD is complex in adolescent females:

– The role of the media

"...my association with Autism would really only be through media so, if media portrays Autism as, the upper end of the spectrum with almost obvious difficulties, then that's what you associate Autism as."

– The context of the family system

"as a family, we're all very similar, in that we're very... I mean I would say, introverted in the classical labelling – we're all introverts, we're not out-going, social kinds of people. So, I mean, (daughter) kind of fitted in within the mould of the family." pg.18

"I suppose, it....it....again, it took a bit of weight off my shoulders because we had a label, we had a reason for (daughter's) high anxiety, and for those interesting little traits."

"I went into that interview, and I said to my wife and I said to the Psychologist, that....I think she's just shy. Ya know, I'm shy, my son's shy, my wife's shy, introverted. I think that's, and all she needs is a good friendship group, ya know, some kind of stability and security, ya know, she's tryna find her feet, in her adolescence". pg 19

– Mismatches in emotional, social, academic skill set - confusion

"It's tricky, and I suppose it's like, why (daughter's) diagnosis was so late, because, actually, she's certainly on the, sort of, shallower end of the spectrum, the traits are very subtle – incredibly intelligent, the whole process of masking and erm, um, um, ya know, she, she, she has obviously really really struggled" pg 20.

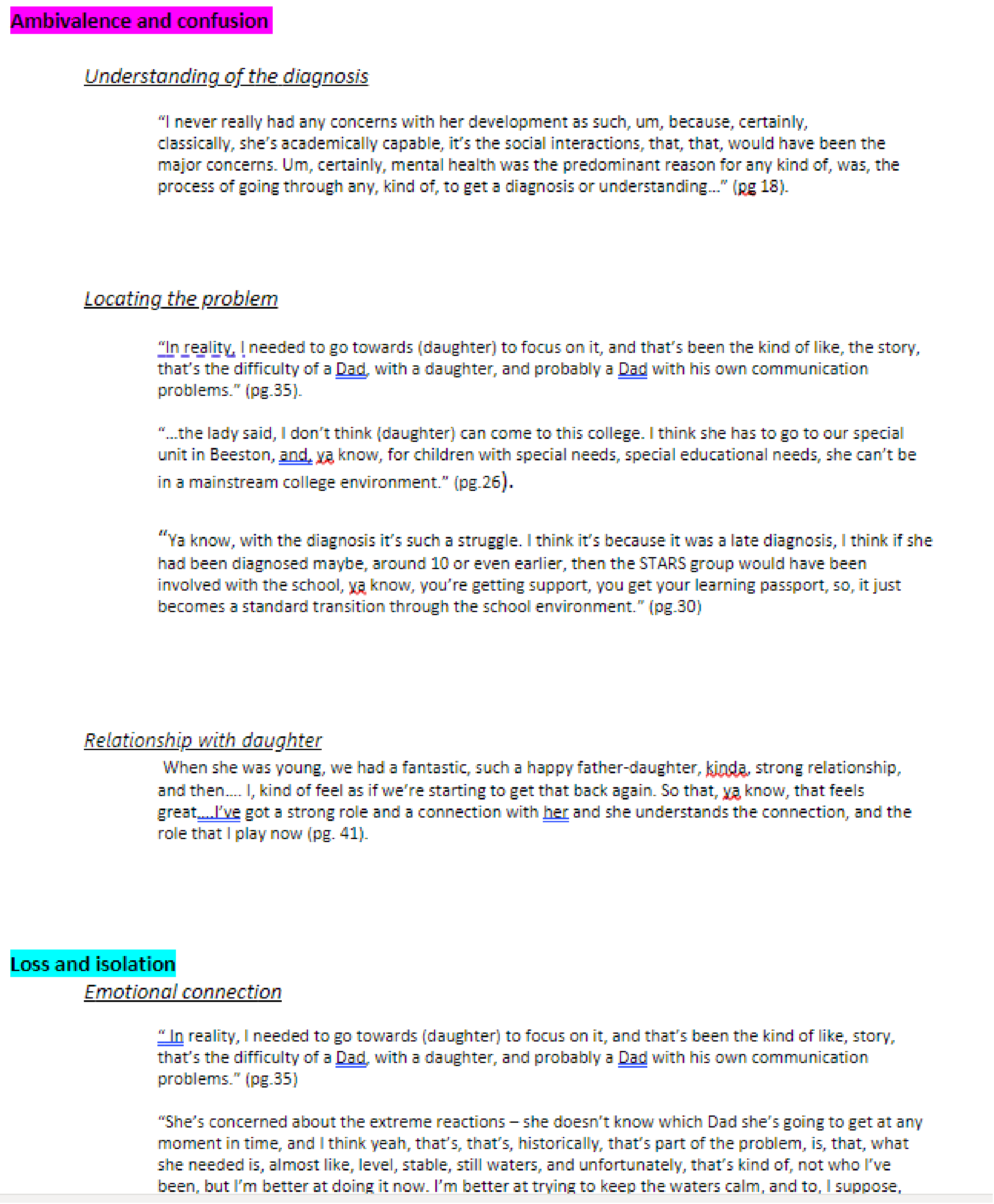
– Societal comparisons

"...if I was to tell that story in work, people would just, ya know, wouldn't believe ya know, either the way that society approaches, looks at people like that, and second, that, ya know, as a parent, that we've allowed our daughter to get to that stage."

– The process is on-going

"So, she wanted to do the childcare course, to go to College, we went to the open day, it was probably the day that I sort of, realised that.... Wow.... (daughter) is she, not different as such, but....she's really struggling."

Appendix F: Individual participant theme



Ambivalence and confusion

Understanding of the diagnosis

"I never really had any concerns with her development as such, um, because, certainly, classically, she's academically capable, it's the social interactions, that, that, would have been the major concerns. Um, certainly, mental health was the predominant reason for any kind of, was, the process of going through any, kind of, to get a diagnosis or understanding…" (pg 18).

Locating the problem

"In reality, I needed to go towards (daughter) to focus on it, and that's been the kind of like, the story, that's the difficulty of a Dad, with a daughter, and probably a Dad with his own communication problems." (pg.35).

"…the lady said, I don't think (daughter) can come to this college. I think she has to go to our special unit in Beeston, and, ya know, for children with special needs, special educational needs, she can't be in a mainstream college environment." (pg.26).

"Ya know, with the diagnosis it's such a struggle. I think it's because it was a late diagnosis, I think if she had been diagnosed maybe, around 10 or even earlier, then the STARS group would have been involved with the school, ya know, you're getting support, you get your learning passport, so, it just becomes a standard transition through the school environment." (pg.30)

Relationship with daughter

When she was young, we had a fantastic, such a happy father-daughter, kinda, strong relationship, and then…. I, kind of feel as if we're starting to get that back again. So that, ya know, that feels great….I've got a strong role and a connection with her and she understands the connection, and the role that I play now (pg. 41).

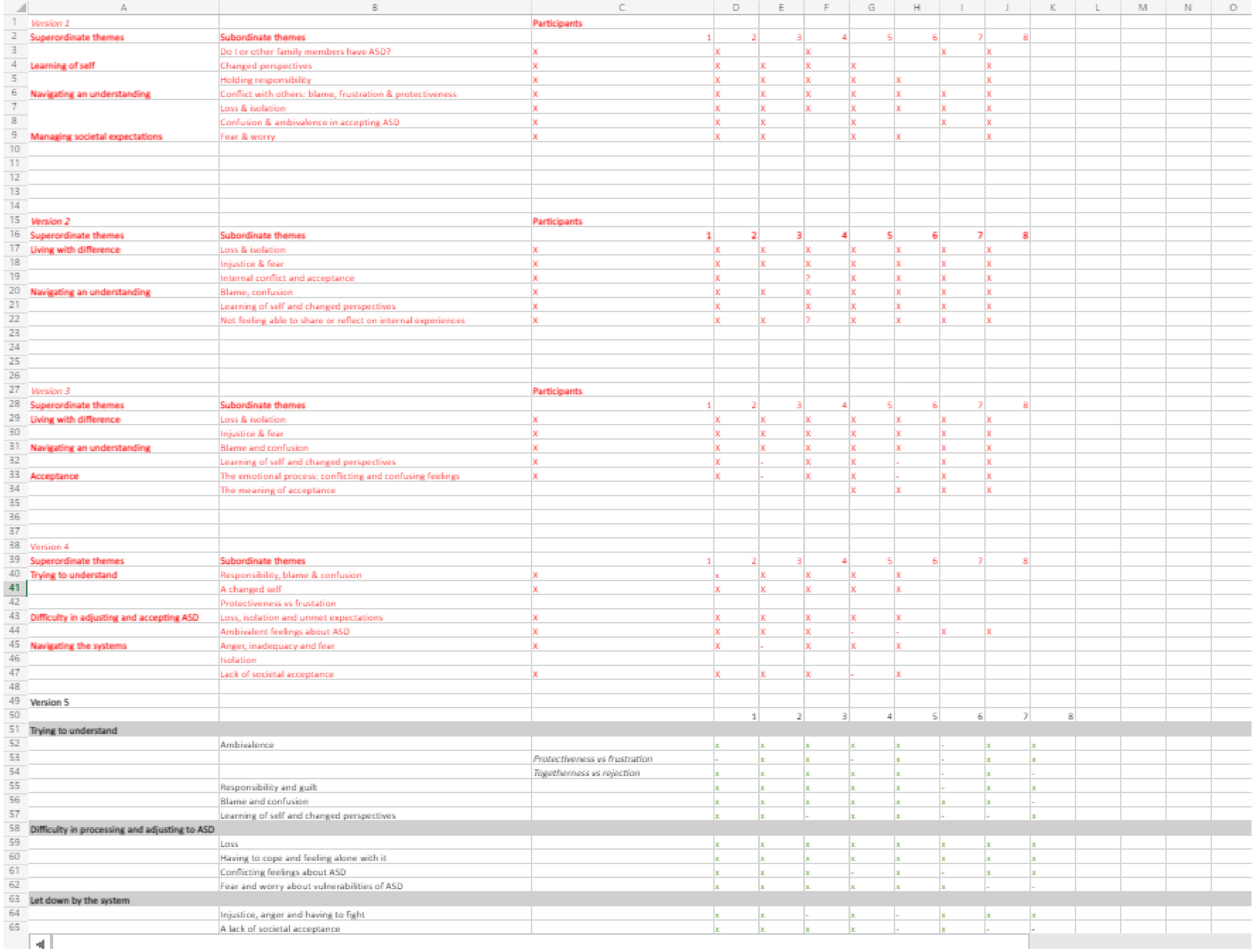
Loss and isolation

Emotional connection

" In reality, I needed to go towards (daughter) to focus on it, and that's been the kind of like, story, that's the difficulty of a Dad, with a daughter, and probably a Dad with his own communication problems." (pg.35)

"She's concerned about the extreme reactions – she doesn't know which Dad she's going to get at any moment in time, and I think yeah, that's, that's, historically, that's part of the problem, is, that, what she needed is, almost like, level, stable, still waters, and unfortunately, that's kind of, not who I've been, but I'm better at doing it now. I'm better at trying to keep the waters calm, and to, I suppose,

Appendix G: The re-visiting of the group analysis and superordinate themes



	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O
1	*Version 1*		**Participants**												
2	**Superordinate themes**	**Subordinate themes**	1	2	3	4	5	6	7	8					
3		Do I or other family members have ASD?	x	x		x			x	x					
4	**Learning of self**	Changed perspectives	x	x	x	x	x			x					
5		Holding responsibility	x	x	x	x	x	x		x					
6	**Navigating an understanding**	Conflict with others: blame, frustration & protectiveness	x	x	x	x	x	x	x	x					
7		Loss & isolation	x	x	x	x	x	x	x	x					
8		Confusion & ambivalence in accepting ASD	x	x	x		x		x	x					
9	**Managing societal expectations**	Fear & worry	x	x	x		x	x		x					
10															
11															
12															
13															
14															
15	***Version 2***		**Participants**												
16	**Superordinate themes**	**Subordinate themes**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**					
17	**Living with difference**	Loss & isolation	x	x	x	x	x	x	x	x					
18		Injustice & fear	x	x	x	x	x	x	x	x					
19		Internal conflict and acceptance	x	x		?	x	x	x	x					
20	**Navigating an understanding**	Blame, confusion	x	x	x	x	x	x	x	x					
21		Learning of self and changed perspectives	x	x		x	x	x	x	x					
22		Not feeling able to share or reflect on internal experiences	x	x	x	?	x	x	x	x					
23															
24															
25															
26															
27	*Version 3*		**Participants**												
28	**Superordinate themes**	**Subordinate themes**	1	2	3	4	5	6	7	8					
29	**Living with difference**	Loss & isolation	x	x	x	x	x	x	x	x					
30		Injustice & fear	x	x	x	x	x	x	x	x					
31	**Navigating an understanding**	Blame and confusion	x	x	x	x	x	x	x	x					
32		Learning of self and changed perspectives	x	x	-	x	x	-	x	x					
33	**Acceptance**	The emotional process: conflicting and confusing feelings	x	x	-	x	x	-	x	x					
34		The meaning of acceptance					x	x	x	x					
35															
36															
37															
38	Version 4														
39	**Superordinate themes**	**Subordinate themes**	1	2	3	4	5	6	7	8					
40	**Trying to understand**	Responsibility, blame & confusion	x	x	x	x	x	x							
41		A changed self	x	x	x	x	x	x							
42		Protectiveness vs frustation													
43	**Difficulty in adjusting and accepting ASD**	Loss, isolation and unmet expectations	x	x	x	x	x	x							
44		Ambivalent feelings about ASD	x	x	x	x	-	-	x	x					
45	**Navigating the systems**	Anger, inadequacy and fear	x	x	-	x	x	x							
46		Isolation													
47		Lack of societal acceptance	x	x	x	x	-	x							
48															
49	Version 5														
50				1	2	3	4	5	6	7	8				
51	**Trying to understand**														
52		Ambivalence		x	x	x	x	x	-	x	x				
53			*Protectiveness vs frustration*	-	x	x	-	x	-	x	x				
54			*Togetherness vs rejection*	x	x	x	x	x	-	x	-				
55		Responsibility and guilt		x	x	x	x	x	-	x	x				
56		Blame and confusion		x	x	x	x	x	x	x	-				
57		Learning of self and changed perspectives		x	x	-	x	x	-	-	x				
58	**Difficulty in processing and adjusting to ASD**														
59		Loss		x	x	x	x	x	x	x	x				
60		Having to cope and feeling alone with it		x	x	x	x	x	x	x	x				
61		Conflicting feelings about ASD		x	x	x	-	x	-	x	x				
62		Fear and worry about vulnerabilities of ASD		x	x	x	x	x	x	-	-				
63	**Let down by the system**														
64		Injustice, anger and having to fight		x	x	-	x	-	x	x	x				
65		A lack of societal acceptance		x	x	x	x	-	x	-	-				

Appendix H: Ethical Approval

Rachel De Souza [Medicine]
Fri 14/08/2020 12:23

To: Lucy Kerrigan
Cc: Medicine and Health Univ Ethics Review; Tom Cliffe; Tracey Smith

Dear Lucy

MREC 19-084- Fathers' experiences of parenting their adolescent daughters with Autism Spectrum Disorders?

NB: All approvals/comments are subject to compliance with current University of Leeds and UK Government advice regarding the Covid-19 pandemic.

I am pleased to inform you that the above research ethics application has been reviewed by the School of Medicine Research Ethics Committee (SoMREC) and on behalf of the Chair, I can confirm a conditional favourable ethical opinion based on the documentation received at date of this email and *subject to the following condition/s which must be fulfilled prior to the study commencing:*

- **C7. Please add that the definition of a mild intellectual disability will include young people who have an IQ of 70 or below**
- **Both versions of the PIS have two dates at the bottom, one from 2019 and another from 2020, which should be resolved**

The study documentation must be amended where required to meet the above conditions and submitted for file and possible future audit.

Once you have addressed the conditions and submitted for file/future audit, you may commence the study and further confirmation of approval is not provided.

Please note, failure to comply with the above conditions will be considered a breach of ethics approval and may result in disciplinary action.

Please retain this email as evidence of conditional approval in your study file.

Please notify the committee if you intend to make any amendments to the original research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please see https://leeds365.sharepoint.com/sites/ResearchandInnovationService/SitePages/Amendments.aspx or contact the Research Ethics & Governance Administrator for further information on FMHUniEthicsc@leeds.ac.uk if required.

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, risk assessments and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

I hope the study goes well.

Best regards
Rachel
On behalf of Dr Naomi Quinton and Dr Anthony Howard, co-Chairs, SoMREC

~~~~~~

Rachel de Souza, Lead Research Ethics & Governance Administrator, The Secretariat, Room 9.29, Level 9, Worsley Building, Clarendon Way, University of Leeds, LS2 9NL, Tel: 0113 3431642, r.e.desouza@leeds.ac.uk

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Lucy Kerrigan
Fri 14/08/2020 14:0

To: Rachel De Souza [Medicine]
Cc: Medicine and Health Univ Ethics Review; Tom Cliffe; Tracey Smith

Thesis PI sheet v0.4.doc
83 KB

Thesis ethics application form v.04.doc
915 KB

Thesis PI sheet PLANB v0.3.doc
83 KB

3 attachments (1 MB)Download allSave all to OneDrive - University of Leeds

Hi Rachel,

Following your email this morning, I'm replying and attaching the documents that required changes (listed in the email below) for filing/auditing submission purposes before the study may commence. The changes required on the ethics form are highlighted in turquoise.

Thanks very much, Lucy

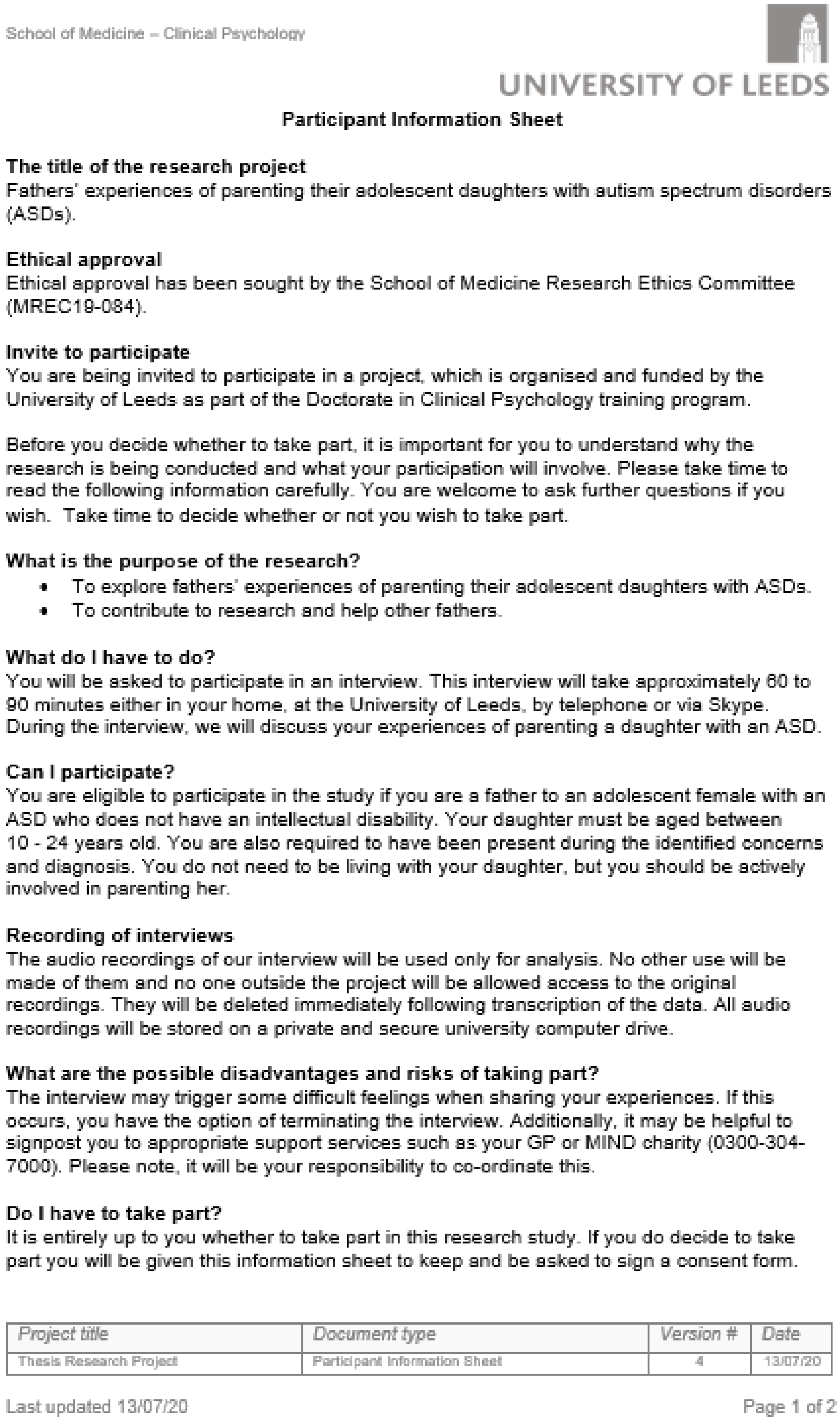
Rachel De Souza [Medicine]
on behalf of
Medicine and Health Univ Ethics Review
Mon 17/08/2020 11:20

To: Lucy Kerrigan
Cc: Medicine and Health Univ Ethics Review; Tom Cliffe; Tracey Smith

Great, thanks, Lucy. Hope all goes well.

Best wishes
Rachel

Appendix I: Participant Information Sheet (PIS)



School of Medicine – Clinical Psychology

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Participant Information Sheet

The title of the research project
Fathers' experiences of parenting their adolescent daughters with autism spectrum disorders (ASDs).

Ethical approval
Ethical approval has been sought by the School of Medicine Research Ethics Committee (MREC19-084).

Invite to participate
You are being invited to participate in a project, which is organised and funded by the University of Leeds as part of the Doctorate in Clinical Psychology training program.

Before you decide whether to take part, it is important for you to understand why the research is being conducted and what your participation will involve. Please take time to read the following information carefully. You are welcome to ask further questions if you wish. Take time to decide whether or not you wish to take part.

What is the purpose of the research?

- To explore fathers' experiences of parenting their adolescent daughters with ASDs.
- To contribute to research and help other fathers.

What do I have to do?
You will be asked to participate in an interview. This interview will take approximately 60 to 90 minutes either in your home, at the University of Leeds, by telephone or via Skype. During the interview, we will discuss your experiences of parenting a daughter with an ASD.

Can I participate?
You are eligible to participate in the study if you are a father to an adolescent female with an ASD who does not have an intellectual disability. Your daughter must be aged between 10 - 24 years old. You are also required to have been present during the identified concerns and diagnosis. You do not need to be living with your daughter, but you should be actively involved in parenting her.

Recording of interviews
The audio recordings of our interview will be used only for analysis. No other use will be made of them and no one outside the project will be allowed access to the original recordings. They will be deleted immediately following transcription of the data. All audio recordings will be stored on a private and secure university computer drive.

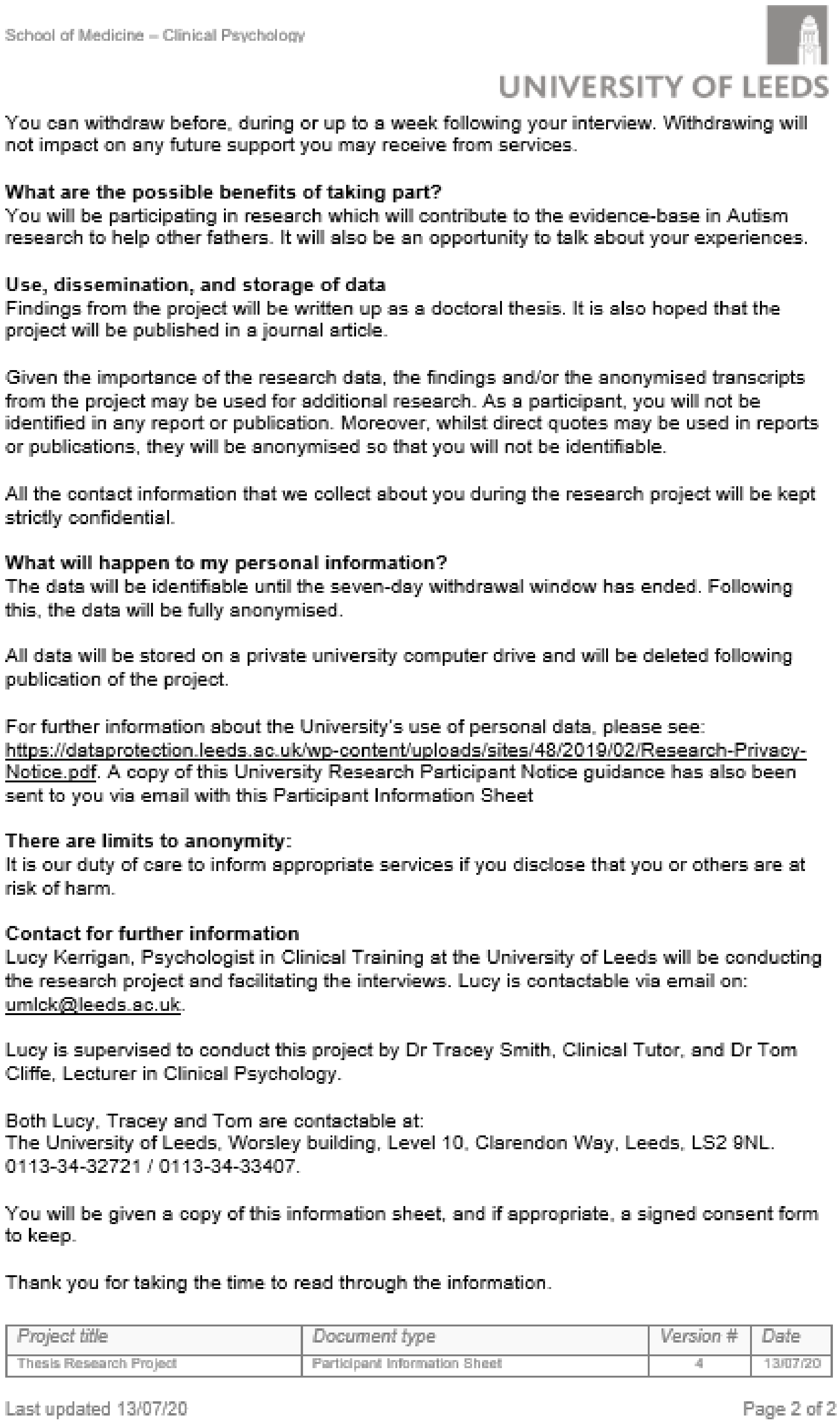
What are the possible disadvantages and risks of taking part?
The interview may trigger some difficult feelings when sharing your experiences. If this occurs, you have the option of terminating the interview. Additionally, it may be helpful to signpost you to appropriate support services such as your GP or MIND charity (0300-304-7000). Please note, it will be your responsibility to co-ordinate this.

Do I have to take part?
It is entirely up to you whether to take part in this research study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

Project title	*Document type*	*Version #*	*Date*
Thesis Research Project	Participant Information Sheet	4	13/07/20

Last updated 13/07/20

Page 1 of 2



You can withdraw before, during or up to a week following your interview. Withdrawing will not impact on any future support you may receive from services.

What are the possible benefits of taking part?
You will be participating in research which will contribute to the evidence-base in Autism research to help other fathers. It will also be an opportunity to talk about your experiences.

Use, dissemination, and storage of data
Findings from the project will be written up as a doctoral thesis. It is also hoped that the project will be published in a journal article.

Given the importance of the research data, the findings and/or the anonymised transcripts from the project may be used for additional research. As a participant, you will not be identified in any report or publication. Moreover, whilst direct quotes may be used in reports or publications, they will be anonymised so that you will not be identifiable.

All the contact information that we collect about you during the research project will be kept strictly confidential.

What will happen to my personal information?
The data will be identifiable until the seven-day withdrawal window has ended. Following this, the data will be fully anonymised.

All data will be stored on a private university computer drive and will be deleted following publication of the project.

For further information about the University's use of personal data, please see: https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf. A copy of this University Research Participant Notice guidance has also been sent to you via email with this Participant Information Sheet

There are limits to anonymity:
It is our duty of care to inform appropriate services if you disclose that you or others are at risk of harm.

Contact for further information
Lucy Kerrigan, Psychologist in Clinical Training at the University of Leeds will be conducting the research project and facilitating the interviews. Lucy is contactable via email on: umlck@leeds.ac.uk.

Lucy is supervised to conduct this project by Dr Tracey Smith, Clinical Tutor, and Dr Tom Cliffe, Lecturer in Clinical Psychology.

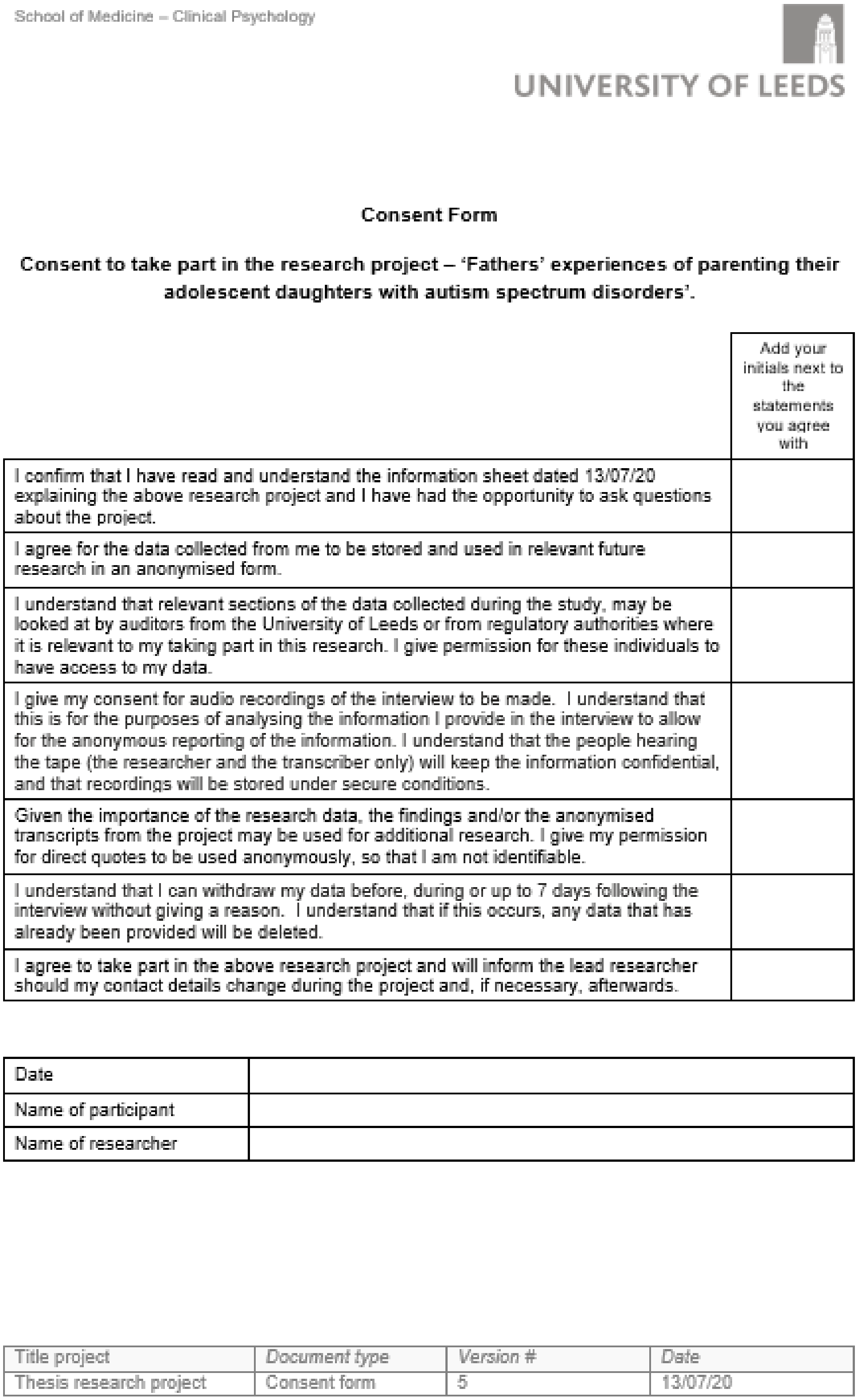
Both Lucy, Tracey and Tom are contactable at:
The University of Leeds, Worsley building, Level 10, Clarendon Way, Leeds, LS2 9NL.
0113-34-32721 / 0113-34-33407.

You will be given a copy of this information sheet, and if appropriate, a signed consent form to keep.

Thank you for taking the time to read through the information.

Project title	*Document type*	*Version #*	*Date*
Thesis Research Project	Participant Information Sheet	4	13/07/20

Appendix J: Consent form (used as a guide for seeking verbal consent).



School of Medicine – Clinical Psychology

UNIVERSITY OF LEEDS

Consent Form

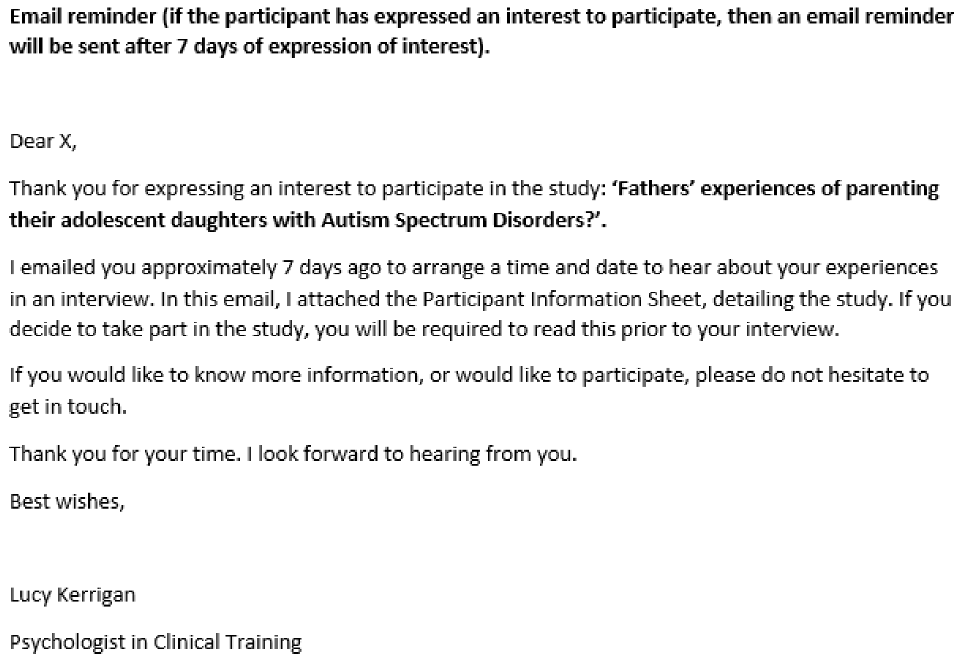
Consent to take part in the research project – 'Fathers' experiences of parenting their adolescent daughters with autism spectrum disorders'.

	Add your initials next to the statements you agree with
I confirm that I have read and understand the information sheet dated 13/07/20 explaining the above research project and I have had the opportunity to ask questions about the project.	
I agree for the data collected from me to be stored and used in relevant future research in an anonymised form.	
I understand that relevant sections of the data collected during the study, may be looked at by auditors from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.	
I give my consent for audio recordings of the interview to be made. I understand that this is for the purposes of analysing the information I provide in the interview to allow for the anonymous reporting of the information. I understand that the people hearing the tape (the researcher and the transcriber only) will keep the information confidential, and that recordings will be stored under secure conditions.	
Given the importance of the research data, the findings and/or the anonymised transcripts from the project may be used for additional research. I give my permission for direct quotes to be used anonymously, so that I am not identifiable.	
I understand that I can withdraw my data before, during or up to 7 days following the interview without giving a reason. I understand that if this occurs, any data that has already been provided will be deleted.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change during the project and, if necessary, afterwards.	

Date	
Name of participant	
Name of researcher	

Title project	*Document type*	*Version #*	*Date*
Thesis research project	Consent form	5	13/07/20

Appendix K: Email reminder to participants



Email reminder (if the participant has expressed an interest to participate, then an email reminder will be sent after 7 days of expression of interest).

Dear X,

Thank you for expressing an interest to participate in the study: **'Fathers' experiences of parenting their adolescent daughters with Autism Spectrum Disorders?'.**

I emailed you approximately 7 days ago to arrange a time and date to hear about your experiences in an interview. In this email, I attached the Participant Information Sheet, detailing the study. If you decide to take part in the study, you will be required to read this prior to your interview.

If you would like to know more information, or would like to participate, please do not hesitate to get in touch.

Thank you for your time. I look forward to hearing from you.

Best wishes,

Lucy Kerrigan

Psychologist in Clinical Training