"We very much planned our life with an idyllic sense": Being a parent of a young child diagnosed with Autism

Doctorate in Educational Psychology (DEdPsy)

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Signed: *C. Prosser*   (candidate) Date: 26th April 2019

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Quote

The Child Who Never Grew, Pearl Buck (1950) describes her experience as the mother of a child with developmental disabilities:

"Endurance is only the beginning. There must be acceptance and the knowledge that sorrow fully accepted brings its own gifts. For there is an alchemy in sorrow. It can be transmuted into wisdom-" (p.p.25)

Summary

This thesis consists of three parts: a major literature review, an empirical study and a critical appraisal.

In Part One, the literature review begins with exploration of contextual factors, then moves onto exploring research relating to the challenges associated with being the parent of a child diagnosed with autism, before moving onto exploration of literature concerned with the internal experience of being the parent of a child diagnosed with autism.

In Part Two, following a brief overview of the literature, the empirical study provides a detailed account of the research undertaken. This includes an outline of the methodology and method and presents an interpretative phenomenological analysis of semi-structured interviews with four mothers and two fathers of young children with a diagnosis of autism, exploring their early journeys in the broadest sense. This analysis is explored in relation to psychological literature, particularly, before a discussion of the implications for future research and for educational psychology practice. This analysis is explored in relation to psychological literature, particularly systemic thinking, before a discussion of the implications for future research and for educational psychology practice.

Part Three, the critical appraisal, consists of two parts: firstly, a critical account of the research process is given from inception through to completion including ontological, epistemological and ethical considerations as well as difficulties encountered; secondly, a more detailed discussion of the findings is offered in relation to psychological literature and the contribution to knowledge and educational psychology practice.

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"We very much planned our life with an idyllic sense": Being a parent of a young child diagnosed with Autism

PART ONE: MAJOR LITERATURE REVIEW

(Word Count: 8744)

1. Introduction

1.1. Introduction

For most parents, caring for a child is an experience full of triumphs and joy, as well as challenges and stress (Myers et al., 2009). However, being a parent of a child who has an Autism Spectrum Disorder (ASD) comes with challenges which may be very different from the expected challenges of being a parent of a 'neurotypical' child (Peplau and Perlman, 1982, as cited in Deckers et al., 2017; Dunlap, Dyler and Koegel, 1983; Lecavalier, Leone & Witlz, 2006; Woodgate, Ateah and Secco, 2008; Zaidman-Zait et al., 2016; Ludlow, Skelly, & Rohleder, 2012). Challenges for parents may be related to their child's communication differences, managing adverse behavioural responses to stimuli, managing logistical aspects of caring for a child diagnosed with autism (e.g. regular appointments with Health, Education and Social Care), and finding atypical ways to parent (Armstrong et al., 2005, as cited in Siman-Tov & Kaniel, 2011; Ruble, Heflinger, Renfrew & Saunders, 2005). As well as challenges related to autism symptomatology and the practicalities of caring for a child with autism, some of the associated difficulty may be related to the internal experience of the parent, for example, feelings of loss (Boss, 2004, 2006; O'Brien, 2007), innadequacy and ambiguity (Aylaz, Yılmaz & Polat, 2012; O'Brien, 2007) and changes to the self (Brown, 2016), including adaptation to a life that was not expected (Fernańdez-Alcántara et al., 2016).

Research suggests that this group of parents experience high levels of stress, with their self-measured stress being higher than that of parents of 'neurotypical' children (Tomanik, Harris & Hawkins, 2004; Lecavalier et al., 2006; Spratt, Saylor & Macias, 2007; Ludlow, Skelly & Rohleder, 2012; Zaidman-Zait et al., 2018). Parenting stress can be broadly defined as an "aversive psychological reaction to the demands of being a parent" (Deater-Deckard, 1998, p.p.315) and is, thus, distinct from other forms of stress (e.g., work-related stress). Factors such as the cognitive functioning, communication deficits, and atypical behaviour of children diagnosed with autism are highly correlated with both maternal and paternal stress (Davis & Carter, 2008). Literature is vast, and the results are fairly congruent, suggesting that this group of parents experience higher levels of stress and develop 'coping' strategies that align with their new reality (Dabrowska & Pisula, 2010). Thus, the experience is being portrayed as one of 'difficulty'.

Furthermore, the internal experiences associated with being the parent of a child diagnosed with autism, may impact greatly upon how they perceive their parenting role (e.g. "This is not what I expected", "I can't cope", "why us") and may result in feelings of loss, grief, ambiguity and significant changes to the self, including their personal and parental identity (Poslawsky, Naber, Van Daalen & Van Engeland, 2013; Cashin, 2003; Dale, Jahoda & Knott, 2006).

Most of the research exploring experiences of being a parent of a child with autism focuses on parents of children who are beyond the age of six years, leaving a gap in the data (Woodgate, Ateah & Secco, 2008; Neely-Barnes, Hall, Roberts, & Graff, 2011). Although, research addressing the underrepresentation of parents of young children diagnosed with autism within phenomenological research is scarce, it is suggested that this may be due to fewer children receiving a diagnosis within their early years' (Buescher, Cidav, Knapp & Mandell, 2014; Brett, Warnell, McConachie & Parr, 2016), resulting in a smaller cohort of participants. For those parents whose child has received a diagnosis of autism within their early years, capacity to engage in research may be limited, as they get used to and adapt to their new reality.

However, there may be something distinct within the experiences of parents of young children diagnosed with autism that requires further exploration. During this period, parents maybe experiencing increased feelings of inadequacy relating to their parenting capabilities and are possibly yet to access internal and external resources, resulting in a lack of capacity to adapt to the new experience of being a parent of a child with autism. Ludlow, Skelly & Rohleder (2012) alludes to this, suggesting that autism-related challenges become easier to deal with over time, as parents learn how to respond to challenging behaviours or due to the severity of challenging behaviours diminishing as the child ages. Furthermore, many parents of autistic children report improved psychological well-being over time, which

may be in-line with theorists who suggest that this group of parents navigate a process of adaptation, over time (McCubbin & Patterson, 1983; Lazarus & Folkman, 1984; Wallander, Varni, Babani, Tweddle Banis & Wilcox, 1989; Hobfoll, 1989; Pearlin, Mullan, Semple & Skaff, 1990; King, King, Rosenbaum, & Goffin, 1999; and Knafl & Deatrick, 2003).

This thesis will explore the experience of being the parent of a young child diagnosed with autism in greater detail.

1.2. Note of terminology

Autism has many names both "official" and cultural, with different people favouring different terms (see, for example, Kenny et al., 2016). As the current research focuses on the experiences of parents whose children have been given a diagnosis, the current diagnostic terminology of DSM-5 (APA, 2013) will usually be used, namely autistic spectrum disorder (ASD) or Autism. However, within the literature review, the vocabulary may also reflect usage in the articles under discussion. Where children and young people are referred to as "with ASD" and "autistic", this is to be understood as having a diagnosis of Autism.

"Neurotypical" is used throughout this paper and refers to those who do not identify as having autism and view themselves as having 'typical'

neurological development. Oxford Dictionaries (2019) define 'neurotypical' as 'not displaying or characterized by autistic or other neurologically atypical patterns of thought or behaviour'.

This thesis is concerned primarily with children who might be considered to fit a 'Childhood Autism' profile, that is those with a clinically significant delay in language or cognitive development; the presentation of their autism symptoms will have been evident in early development and are pervasive. This was set as inclusion criteria and was highlighted to parents prior to the commencement of their involvement within the research.

1.3. Description of key search terms and literature

Initially, the following electronic databases were searched for literature relevant to this thesis: PsycINFO, Orca and Google Scholar. Combinations of the following sets of search terms were used: Autism, Asperger's, ASD; parent, family, parenting, mother, father; coping, managing, difficulty, challenge, challenge faced; adapting, adaptation; mental health, well-being; and qualitative, quantitative, phenomenological, experience, experience of, perception, perception of, lived experience. Chosen literature was restricted to that published in English, in peer-reviewed journals, since 2008. Details of searches are given in Appendix 1.

Exclusion criteria included: articles which focused on autistic adolescents and adults and articles related to being a parent of a child with an autism diagnosis in non-Western cultures. Literature related to other conditions related to autism was excluded due to the ambiguity of associated difficulties. For example, Amr, Raddad, El-Mehesh, Mahmoud, & El-Gilany (2011) suggest that the core symptomatology of autism can differ between cultures due to differences in child-rearing practices and therefore the literature review was restricted to research conducted within western cultures. A small set of international papers were found but not included for reasons of cultural specificity.

The process of iteration allowed for exploration of research included within reference lists of identified articles, as suggested by Greenhalgh & Peacock (2005). In total, 104 references are included in the literature review.

1.4. Introduction to Literature Review

The literature review will consider both breadth and depth of research relating to being the parent of a child diagnosed with autism and will hold the view that experiences are complex, multifaceted and personal to the individual. It will therefore be important to consider the context within which the stories are being told. Exploration of contextual factors which shape experiences, including historical views of autism will also be important to

understand the experience of the parent in a holistic manner. It will also explore the perceptions of autism-related challenges and the impact that these have on the parent, including the internal experience of being the parent of young child diagnosed with autism.

2. What is Autism?

2.1. Introduction

According to The Diagnostic and Statistical Manual – Fifth Edition (DSM-5; APA, 2013), Autism or Autism Spectrum Disorder (ASD) is defined as 'Persistent deficits in social communication and social interaction across multiple contexts', 'Restricted, repetitive patterns of behaviour, interests, or activities'. The symptoms must be present in the early developmental period, cause clinically significant impairment in social, occupational, or other important areas of current functioning, and disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

2.2. Autism: Historical and Cultural Perspectives

The relationship between our perceptions, the perceptions of others and the social and cultural context is one of reciprocity (Hogg, 2006). The views held within any given community and the context which frames it influence personal views. Therefore, it is important to consider the historical and contextual factors relating to autism to ensure that parental experiences are framed appropriately.

Early theories about autism's aetiology blamed parents, particularly mothers, for the condition, resulting in parents being stigmatised and led to feelings of isolation (Bettleheim, 1967, as cited in Kim, 2012; Langan, 2011). In 1949, Leo Kanner, described the parenting of children with autism as follows:

> 'Most of [my] patients were exposed from the beginning to parental coldness, obsessiveness, and a mechanical type of attention to material needs only. They were the objects of observation and experiment conducted with an eye on fractional performance rather than with genuine warmth and enjoyment. They were kept neatly in refrigerators which did not defrost. Their withdrawal seems to be an act of turning away from such a situation to seek comfort in solitude.' (p.p. 425)

Influential theorists have shaped the culture of diagnosis and the views held by others in relation to parents and particularly mothers of children diagnosed with autism. The impact of such views has rippled

through the decades influencing common beliefs about autism. Parents continue to notice the impact of this view and parental perceptions are compounded by the ongoing negative stigma associated with autism (Altiere & von Kluge, 2009a; Lutz et al., 2012). Parents describe their child's public displays of externalising behaviours (e.g. meltdowns, aggression, crying, etc.) as being associated with onlookers viewing the situation critically and making comments related to bad parenting (Neely-Barnes et al., 2011).

Autism was first recognised in Western Culture in the early twentieth century, with the German psychiatrist Eugen Bleuler (1911, as cited in Evans, 2013) describing autistic thinking as characterised by "…infantile wishes to avoid unsatisfying realities and replace them with fantasies and hallucinations" (p.p.4). According to theorists, 'Autism' defined the young person's symbolic 'inner life' and was not readily accessible to observers (As cited in Bleuler, 1950). Later, Psychiatrists such as Leo Kanner (1943) and Hans Asperger (1944, as cited in Evans, 2013) made use of the term used by Bleuler, which shaped the child development profile used by medical professionals. In the 1960s, British child psychologists began to reshape the landscape of autism, providing evidence which suggested that children who experienced autism symptomatology were not devoid of reality, but quite the opposite. For example, Michael Rutter, a leading child-psychiatric researcher who conducted the first-ever genetic study of autism, claimed in 1972 that 'the autistic child has a deficiency of fantasy rather than an excess' (Rutter, 1972, p.p.327) - The meaning of the word 'autism' was then radically altered from

a description of someone who fantasised excessively to one who did not fantasise at all.

In the early- to mid-twentieth century, psychiatrists and child psychologists believed that 'autism' was because of 'Refrigerator Mothers' – i.e., a mother who displayed a lack of parental warmth and attachment to their autistic child. Kanner (1949, as cited in Kroncke, Willard & Huckabee, 2016) attributed autism to a "genuine lack of maternal warmth" (p.p.6), with others coining the phrase 'Refrigerator Mother' (Bettelheim, 1976, as cited in Douglas, 2014) because of this research. Bernard Rimland (1964), a psychologist with an autistic son, produced the book 'Infantile Autism: The Syndrome and its Implications for a Neural Theory of Behavior', which began to change the 'Refrigerator Mother' hypothesis. However, this phrase continued to impact upon the opinions of professionals about parents (especially for mothers) of children diagnosed with autism for some time, with reports of parents experiencing professionals who continued to use this terminology as late as the 1980s (Golding & Stacey, 2018).

Sousa (2011) suggests that 'blame' has reformulated in to a "warrior-hero" archetype, resulting from a drive to solidify the social construction of a good mother. This places a cultural expectation on mothers to 'do battle' to attain resources and find possible cures for their children. The burden that once was placed on mothers suggesting that they caused the autism

symptomatology has now manifested into a hyper-focus on expert parenting, which has the potential to leave parents of children with autism strained under the burden of becoming a "warrior-hero".

Furthermore, insecurities associated with the historical perspective of autism are still evident today, with parents experiencing feelings of anxiety about their ability to parent and the perceived social constructions that surround this (Neely-Barnes, Hall, Roberts, & Graff, 2011; Ludlow, Skelly & Rohleder, 2012; Lutz, Patterson, & Klein, 2012; Nealy et al., 2012).

2.3. Autism Diagnosis

Within the U.K., Autism Spectrum Disorder (ASD) is diagnosed using the Diagnostic and Statistical Manual – Fifth Edition (DSM-V; APA, 2013) and is characterised by "the presence of markedly abnormal or impaired development in social interaction and communication, and a markedly restricted repertoire of activity and interest". The DSM–V also states that "the manifestations of this disorder vary greatly depending on the developmental level and chronological age of the individual" (DSM–V, 2013). It is considered to be a spectrum condition with varying presentation. According to the DSM-V (2013), all who receive a diagnosis will experience difficulties in the areas of social interaction, communication and restrictive and repetitive interests

(including sensory behaviours). Symptoms will be pervasive and evident in early childhood.

Autism has related co-morbid conditions including Attention Deficit Hyperactivity Disorder (ADHD), Developmental Coordination Disorder (DCD), Global Developmental Delay (GDD) and Learning Difficulties (LD), which can also impact upon a child's presentation and symptomatology (Mannion & Leader, 2013). Although, not all children will receive a secondary diagnosis. 'Co-morbidity' refers to two or more disorders with distinct core symptoms that simultaneously occur in the same person (Matson & Nebel-Schwalm 2007). Autism-specific symptomatology and related co-morbidities have the potential to impact upon perceptions of demand related to caregiving (Karst & Van Hecke 2012).

Autism-specific symptomatology can lead to challenges in communication, behaviour, personal care, sleep and play (American Psychiatric Association (APA); 2013). Parents report difficulties related to their child's inability to communicate their needs (expressive and receptive language deficits); internalising and externalising behaviours; difficulties in toilet training fuelled by possible hypo-sensitivity to interoception sense; other sensory processing challenges; lack of sleep (e.g. parental fatigue); and reduced awareness of how to engage their child in play and learning opportunities (Armstrong et al., 2005; Rieffe et al., 2014; Mazefsky et al., 2014b; Nuske et al., 2018). All of this can shape parents' perception of their

parenting capabilities and can lead to a reduced sense of self-efficacy, self-determination and perceived locus of control in relation to their parenting skills (Benson, 2016; Harvey, Houser & Cullen, 2018; Weiss et al., 2016).

Potentially, a significant number of parents experience similar difficulties, with the most recent statistics within Wales suggesting that 0.27% of the child population of 663,305 received a diagnosis of Autism in 2011 (Wimpory & Leekam, 2012). Research suggests that having a child receive a diagnosis of autism can feel extremely taxing for many parents, sometimes resulting in depression (Taylor & Warren, 2012), the diagnosis may come after a prolonged period of frustration, anxiety and delay (Crane, Chester, Goddard, Henry & Hill, 2015), with some parents in the U.K. waiting up to three and a half years for a decision (Karim et al., 2014; Crane et al., 2016). Furthermore, waiting for the outcome of an assessment frequently means families receive less early support in 'making sense' of confusing behaviours (Denman, Smart, Dallos & Levett, 2016). Connolly and Gersch (2013) reported that parents find being on the waiting list for a diagnosis particularly stressful; and that interventions, information and support is generally unavailable for these families. A recent Welsh Government report (Holtom & Lloyd-Jones, 2019) and the Autism Spectrum Disorder Strategic Action Plan (ASD SAP; 2016) identifies that:

> "timely access to assessment services is vital for families so that each
> child's needs are understood and appropriate services are put in
> place to support them to lead fulfilling lives. An early diagnosis will

also enable family members to understand their child's needs and to seek appropriate support in their caring role." (p.p.107)

Within most Welsh health boards, diagnoses of Autism are made by a community paediatrician who, via a referral from another health professional, with the support of a speech and language therapist and one other professional (e.g. paediatrician or an educational/clinical psychologist), initiates a process of assessment. However, there continue to be some inconsistencies in regional referral pathways within Wales (Holtom & Lloyd-Jones, 2019). The assessment generally includes the completion of an Autism Diagnostic Observation Schedule assessment (ADOS; Lord et al., 2000). The ADOS assessment is a semi-structured assessment of communication, social interaction, and play (or imaginative use of materials) for individuals suspected of having autism or other pervasive developmental disorders. It consists of standardised activities that allow the examiner to observe the occurrence or non-occurrence of behaviours that have been identified as important to the diagnosis of autism and other pervasive developmental disorders across developmental levels and chronological ages. Generally, families are invited to a second appointment, during which they are informed of the outcome of the ADOS assessment (i.e. ASD or not, and severity of symptomatology).

Welsh Government (WG; Refreshed Autistic Spectrum Disorder Strategic Action Plan, 2016) have introduced a 26-week waiting time target from referral to first appointment for children with autism, although recent

reports suggest that "pressures upon services have increased waiting times" (Holtom & Lloyd-Jones, 2016, p.p.46). Local health boards are now working to meet the expected target of seeing 80% of children and young people within a 26-week window (WG; Autistic Spectrum Disorder Strategic Action Plan Annual report, 2019).

It appears evident that supporting families during and following a diagnosis of autism may be essential in ensuring that sense is being made of the diagnosis and its implications, in sharing of information regarding services and strategy, as well as ensuring the well-being of the family.

3. Autism Research: A different experience

3.1. Introduction

The literature review will now explore theory and research pertinent to autism-related challenges and the suggested impact that this may have on parent well-being, the internal experience of the parent and the process by which parents adapt to the new, ambiguous and unexpected situations.

Parental experiences are as varied as the symptomatology of their child's autism – not one person will experience their child's condition in exactly the same manner. However, there are commonalities within the experiences, which the research has attempted to explore. Those commonalities, for example, include the presence of challenging

internalising and externalising behaviour in the children, finding alternative means of communicating with their child and cognitive deficits; all of which have the potential to impact upon a parent's experience (Hoogsteen & Woodgate, 2013). It is suggested that autism becomes "centred within the family" (p.p.136) thereby affecting how parents parent (Hoogsteen & Woodgate, 2013) other children. Furthermore, parents' internal experiences, including feelings of loss, ambiguity, grief and shifts in identity can impact upon perceptions of difficulty and reduce or facilitate a parent's capacity to gather resources and access support (Boss, 1999, 2006; O'Brien, 2007).

3.2. A Different Experience: Autism Challenges

Autism presents a challenge for parents, which is arguably different to the challenges experienced by parents of typically developing children. A large proportion of the research explores these differences in relation to parental well-being, focusing primarily on levels of stress, parent perceptions of their child's autism and factors which may lead to the adaptation to new experiences.

It is suggested that this group of parents view their parenting role as demanding (Beresford, Tozer, Rabiee & Sloper, 2007), due to the breadth and depth of difficulties experienced by their children who are diagnosed

with autism (Fiske, Pepa, Harris, 2014). Some challenges which have been identified include supporting the development of communication and social interactions (Armstrong et al., 2005; Ludlow, Skelly, & Rohleder, 2012), managing externalising behaviours, including meltdowns, aggressive behaviours, restricted interests, repetitive behaviours and intolerance of others (Myers, Mackintosh & Goin-Kochel, 2009; Fodstad, Rojahn, Matson, 2012; Ludlow, Skelly, & Rohleder 2012; Bearss, Johnson, Handen, Smith & Scahill, 2013); emotion-regulation differences (Cappadocia et al., 2012; Jahromi et al., 2013; Nuske et al., 2018); inflexible adherence to routines (Bonis, 2012); intolerance of uncertainty (Rosen & Knauper, 2009; Hodgson et al., 2017), demand avoidance behaviours (Duncan et al., 2011), chronic fatigue due to sleep disruption (Malow et al., 2014); as well as managing diet and weight of children diagnosed with autism (Curtin, Jojic & Bandini, 2014; Zobel-Lachiusa et al., 2015).

Such challenges are commonly observed among young children diagnosed with autism and are associated with greater autism severity (Matson et al., 2009; Jang et al., 2011). Matson et al. (2009) found that "those with severe ASD exhibited significantly higher levels of problem behaviours than children with mild or moderate ASD" (p.p.29). Autism symptomatology can vary, as can the experience of the parent. We also know that 'functioning' is a social construct. For example, children who are perceived to be "high functioning" still may require a significant amount of

support to function (Burns, 2019), which often falls to the parent (Connell, Halloran & Doody, 2016). From here the terms 'high functioning' and 'low functioning' will be used tentatively.

3.3. Autism Challenges: Impact on the Parent

Autism-related challenges have the potential to impact significantly on parent well-being, including influencing symptoms of stress and depression. Research has identified child-related factors such as autism severity and challenging behaviour as being associated with both parent stress (Falk et al., 2014; Karst and Van Hecke 2012) and depression (Ingersoll and Hambrick 2011; Weitlauf et al., 2014). Parenting stress is defined as an "aversive psychological reaction to the demands of being a parent" (Deater-Deckard, 1998; p.p. 315). The DSM-V (APA, 2013) acknowledges that clinical depression has a significant impact on functioning and presentation may include depressed mood; markedly diminished interest or pleasure in all, or almost all, activities; significant weight loss or weight gain; slowing down of thoughts and a reduction of physical activity, fatigue or loss of energy; feelings of worthlessness or excessive or inappropriate guilt; diminished ability to think or concentrate, or indecisiveness; and recurrent thoughts of death, recurrent suicidal ideation. Those who receive a diagnosis of clinical depression will be experiencing five or more symptoms over a prolonged period of time, and symptoms will be present most of the day, nearly every day.

For nearly all parents, caring for a child comes with challenges and triumphs (Myers et al., 2009), however, much of the research reports that parents of children diagnosed with autism experience higher levels of stress, compared to parents of children with other developmental disabilities (e.g. Downs Syndrome; Griffiths et al., 2010; Hayes & Watson, 2013; Zaidman-Zait et al., 2016; Cohrs & Leslie, 2017). Bitsika, Sharpley & Bell (2013) indicated that more than 80% of parents in their research reported that the demands of being a parent of a child diagnosed with autism meant that they felt "stressed beyond their limits" (p.p.537). Furthermore, it has been suggested that the greater the perceived severity of autism symptomatology (i.e. "higher" end of the spectrum), the greater the impact on parental depression symptoms (Falk et al., 2014). Finally, 'high' autism severity has also been linked to parental reports that their child's daily life was "less normal" and parents' confidence in managing their child's differences was lower than parents of children with lower autism severity (Kimc, Ekasa & Hockb, 2016), suggesting that a parents perception of autism severity has a significant impact on the well-being of parents, as well as feelings of confidence in their own capacity to support their child effectively. Phrases such as "less normal" allude to parents viewing their experience as being different to what was expected.

The demands placed upon parents, including autism-related challenges, which are perceived to be prolonged and pervasive appear to have the most significant impact on parent stress and depression symptoms (Haney, Houser & Cullen, 2018). For example, parents who highlight the pervasive nature of the condition are more likely to report a clinically significant score in relation to emotional and behavioural difficulties in their children. Furthermore, Kim et al. (2016) indicated that parental perceptions of the degree to which their child with autism is impacting upon their family routine and relationships mitigated the effects of children's behaviour on parental stress, suggesting that parents' social constructions of autism and the perception of associated challenges can determine the significance of stress and depressive symptoms that they experience.

This group of parents often report that they are judged unfairly and indicate that their parenting skills are being called in to question by others (Dabrowska & Pisula, 2010; Lutz et al., 2012). They may experience difficulty in relation to explaining behaviours to others (Solomon and Lawlor, 2013) and report experiences of covert (e.g., distancing, subtle condemnation) or even overt forms of exclusion due to autism-related difficulties (Vasileiou et al., 2017). Some parents admit to being negatively confrontational during these times and some admit to 'picking their battles', whereas others choose to ignore negative or erroneous views of their child (Nealy et al., 2012). However, the presence of perceived or actual

judgements and exclusion from social events may lead to feelings of

isolation and loneliness for parents of children diagnosed with autism. Some

parents allude to self-isolating in order to protect themselves and their child

from experiencing challenging situations (Woodgate, Ateah & Secco, 2008;

Ekas & Whitman, 2011). Judgemental views held by others are viewed as

major sources of parental stress (Nealy et al., 2012). Some report (Altiere &

von Kluge, 2009; Knapp, Romeo & Beecham, 2009) the breakdown of

personal friendships which parents attribute to their child's autism-related

difficulties (e.g. challenges in attending social events, disagreements with

friends as a result of misconceptions of their child's behaviour). Therefore, it

appears that autism, vicariously, may have an impact on the social

experiences of the parent. As indicated by several theorists and research

papers, social support can facilitate improved well-being for parents of

children diagnosed with autism (McCubbin & Patterson, 1983; Pozo et al.,

2014; Paynter, Davies & Beamish, 2018). It therefore, appears that parents'

perceptions of demand associated with autism symptoms can impact on

their ability to engage in typical parent experiences.

3.4. Underrepresentation of fathers

Much of the research explored within the literature

review focuses on mothers' experiences, and historically, fathers have been

underrepresented within autism research (Potter, 2016), but their views are

increasingly being sought to understand their experiences of being a parent

of a child diagnosed with autism (Flippin & Crais, 2011; Potter, 2017).

Braunstein et al. (2013) argue that the underrepresentation of fathers

within this field of research impacts upon the effectiveness of service

provision and results in the delivery of erroneous guidance. Reasons for

such exclusions include the notion of men being considered as hard to reach

due to lack of availability to participate in research which is being conducted

during typical working hours (Phares et al., 2010), parenting role gender-

based assumptions held by researchers (Flippin & Crais, 2011), as well as

scheduling of data collection not taking into account employment

requirements (Fabiano, 2007).

It has been a common assumption that mothers of

children diagnosed with autism experience greater levels of stress compared

to fathers (Dabrowska & Pisula, 2010; Jones et al., 2013; McStay et al., 2014;

Falk, Norris & Quinn, 2014; Ozturk, Riccadonna & Venuti, 2014). Recent

findings suggest, however, that fathers may experience levels of stress and

experiences of demand equal to or greater than that of mothers. For

example, Potter (2016) reported that fathers experienced a range of

significant challenges during the diagnostic process, and Rivard et al., (2014)

suggested that fathers experience higher stress than mothers, although

there were limitations associated with sample size. Such data may be in line

with Kayfitz's et al. (2010) study which highlighted that mothers reported

more positive experiences with their children than fathers. They

hypothesised that higher levels of experiences that were perceived as positive were associated with lower stress, thus fathers were viewing their parenting role less positively than mothers.

Gender differences in coping and parenting style are also highlighted within the research. For example, Hill-Chapman et al. (2013) suggested that there are differences between the genders in the acceptance of an autism diagnosis, in management of discipline, and in managing their child's behaviour and caring for the child. Furthermore, Harper (2013) noted that mothers and fathers can engage in conflicting approaches to family management and discipline. Some research suggests that mothers typically use emotional coping and struggle with feelings of incompetence (Dunn et al., 2001) and fathers tend to use avoidance coping to avoid dealing with stressors resulting from managing their child's challenging behaviours (Altiere & von Kluge, 2009a). Finally, it is suggested that mothers will seek local support groups to mediate some of the difficulty (Mandell et al., 2010), whereas fathers will seek respite in the form of work outside of the family home (Gray, 2003).

It is important to consider that responses given within research may not be truly reflective of the parent's internal experience. Parents may be masking their true feelings, for example responses being generated on assumptions and expectations (Järviluoma, Moisala & Vilkko,

2003) in accordance with expectations of their gender-identity (e.g. "mothers are meant to view their child positively"). Furthermore, it is likely that each parent, irrelevant of gender has a very individualised experience, which is impacted upon by an array of complex factors. Thus, hearing individual stories of both mothers and fathers has value in understanding the phenomenological nature of being the parent of a young child diagnosed with autism.

4. Being the parent of a child diagnosed with autism: The Internal Experience

4.1. Introduction

Research which has aimed to explore the experiences of being a parent of a child diagnosed with autism implies that autism-related demands are high and available resources are limited (Bitsika, Sharpley & Bell, 2013; Ludlow, Skelly & Rohleder, 2012). However, the internal experience of being a parent of a child diagnosed with autism has yet to be explored within this literature review. Section 4 will explore the parents' feelings of loss, grief, ambiguity and resultant shifts in identity, as well as the theoretical processes of adaptation.

4.2. Loss, grief, ambiguity and identity

For some parents, realising that their child's development is not as expected can evoke feelings of loss, grief and ambiguity. Aspects of a parents' daily life may change due to the autism-related difficulties faced by their child, which may impact upon familial relationships, disrupt routines and future aspirations (Altiere & von Kluge, 2009a; Dale, Jahoda & Knott, 2006).

Learning that their child's autism is pervasive and life-long has the potential to bring about feelings associated with loss, for parents. Boss' (1999, 2006) Theory of Ambiguous Loss posits that stress results whenever there is change within a family (e.g. the delivery of a diagnosis of autism). According to Boss' theory, the most severe stressors are those changes which are not clear-cut and ambiguous (e.g. uncertainty surrounding the trajectory of the child's development), meaning that resolution of the situation is not possible, and the outcome is not predictable. The challenge for parents whose children receive a diagnosis of autism is to accept their new experiences and the permanency of their child's condition while maintaining optimism about potential development that can be made through early and effective interventions (Boss, 2006; O'Brien & Daggett, 2006). The unexpected challenges associated with being the parent of child diagnosed with autism means that the nature of the parent-child relationship requires some change. In this sense, autism represents a situation of ambiguous loss to parents, e.g. the loss of an

expected parenting journey, loss of an expected child. However, Ambiguous

Loss Theory does not acknowledge the unique quality of experience and

perception. The theory alludes to ambiguous loss being an external

situation that is assumed to be neutral. Boss (2007) argues that how loss is

perceived, however, has valence - the higher the degree of boundary

ambiguity, the more negative the outcomes. For example, O'Brien's (2007)

article on ambiguous loss in families of children with autism spectrum

disorders found that the higher the mother's levels of identity ambiguity,

the higher her depressive symptoms, independent of the severity of

diagnosis. Therefore, it is important to remember that experience is unique

to the person and, therefore, this theory should be applied cautiously.

Where ambiguous situations arise, they can present a

context in which the identities of the child and parent can become unclear

and ambiguous, leading to change within the parent-child relationship.

Some parents respond to this identity ambiguity by taking on responsibility

for all aspects of their child's life (e.g. warrior parent, advocate), blurring the

boundaries between themselves and their child. If parents of children

diagnosed with autism are unable to separate their own life situation from

their child's disability, they can be described as experiencing identity

ambiguity, which has been linked to immobilization, feelings of being

overwhelmed and unable to change the situation, and difficulty adapting to

change (Boss, 1999). Thus, parents of children diagnosed with autism who

experience identity ambiguity would be expected to have difficulty making

decisions about their child's support and also would be ineffective in

analysing their own options regarding such activities as employment,

socialising with friends, and community involvement. As a result, when

identity ambiguity results from the ambiguous loss represented by their

child's autism, parents are predicted to experience higher or increased

levels of personal distress following their child's diagnosis.

This group of parents may also experience feelings of loss

associated with their personal and parental identity. It is suggested that a

person's identity is constructed via the development of cognitive schemas

and processes which are individual to the person, as well as those which are

shaped societally (e.g. being a parent, cultural, family, friendship group)

(Crown, 2009). Cognitive schemas are suggested in this model to include

those relating to personal characteristics; a persons' preferences; their

goals, hopes and aspirations; and behaviour patterns. For parents of

children diagnosed with autism a shift in some or all of these schemas can

elicit feelings of loss, e.g. "I am a calm person" to "I am not able to remain

calm" (characteristics), "I want to go on adventures with my son" to "My

son won't tolerate going on adventures" (goals). Cognitive processes may

include those related to construction, maintenance and change of identities,

as well as personal attribution of blame, causality and responsibility, which

may be shaped by both individual and group perceptions (e.g. Refrigerator

Mothers). Learning that your child has been diagnosed with autism often

does not fit with pre-existing schemas which relate to personal schemas

(e.g. career goals) and parents may begin to attribute blame to themselves

(e.g. "maybe it's hereditary, maybe he got it from me") or to the child.

Crown (2009) alludes to parents placing blame on themselves and suggests

that this maybe due to parents seeking control in an ambiguous situation

framed within 'fate':

> "Mothers comb through their pregnancies and past behaviors to find
> the food they ate, the drink, the flaw in their mothering, the
> imagined crime they are being punished for that explains their child's
> disability. Fathers, too, search for their culpability in their faulty
> genes, their behavior, the time they threw their child up in the air
> with too much exuberance. It's unthinkable that this could just
> happen. At least if it is something the parent did, they can not do it.
> They can stop the illogical falling through the random abyss of fate."
> (p.p.74)

Blame can also be attributed to external sources, which

may or may not be linked to the management of ambiguity. Dale, Jahoda &

Knott (2006) suggest that parents express either an internal (i.e. blame

themselves) or external (i.e. blame an external source) locus of cause. Once

again highlighting the unique nature of experience for this group of parents.

Presenting positive identities may be important to many

parents of children with disabilities according to researchers. Goffman

(1955) proposed that 'saving face' occurs in the event of facing 'threatening'

social situations, where a person can be embarrassed, or their identity is in

some way compromised. Furthermore, in different contexts parents

distance themselves and their child from being responsible, or being 'bad

parents with naughty children' (Farrugia 2009; Lester and Paulus 2012;

Sperry and Symons 2003). The feelings of responsibility for their child's

challenges means that they may reject diagnoses, to reduce feelings of hurt

or 'blame' (Farrugia 2009) or fault being implied through pathology

(Bagatell, 2007). Maintaining a positive identity has been noted to present

difficulty for some parents, even following diagnosis and may impact upon

their well-being.

Furthermore, conflict between the parents view of their child ("I love

him so much") and the challenges associated with autism ("managing his

externalising behaviour is challenging") may be difficult for the parent to

process. Myers, Mackintosh, & Goin-Kochel (2009) argue that a parental

dialectic response to autism is due to attempts to find positive meaning in

their life. They found 15 negative themes and 9 positive themes related to

maternal parenting of an autistic child. Themes were subsumed into five

clusters: Stress; Child's behaviour; Parents' personal well-being, work, and

marital relationship; Impact on the whole family; and Social isolation. The

researchers argued that having a mix of negative and positive themes was

due to a 'dialectical viewpoint of finding positive meaning to life even while

acknowledging the stress and difficulties of having a child with autism' (p.p.

14), suggesting that mothers are searching for balance amongst the

difficulty experienced. However, Myers and colleagues gathered data via questionnaire which limited data to recorded content and may have left out other potential forms of information. They also used a qualitative content analysis methodology which relies upon the subjective conclusions of the researchers. To counteract this, they employed three coders, ensuring the validity of the codes and took an inductive approach to the content analysis.

Factors which reduce the impact of challenges associated with autism for parents have been evidenced in several studies (Manning et al., 2011; Ludlow, Skelly & Rohleder, 2012; Benson, 2014; Pozo and Sarriá, 2015; Zaidman-Zait, 2018). Meirsschaut, Roeyers & Warreyn (2010) explored parenting experiences and cognition in mothers of children diagnosed with autism and in those who had 'typically' developing children. The data highlighted that the parents of children diagnosed with autism experienced loss of spontaneity, they had to make job and career adjustments, and displayed reduced self-efficacy, which was different to the experiences of parents of neurotypical children. This highlights some of the internal processes and challenges which may be associated with being the parent of a child diagnosed with autism, as well as the role of loss and changes in identity. However, the researchers stressed that the small sample (17 mothers) may have resulted in limited power to detect differences in mothers' cognitions. They also highlighted that results may have been somewhat different if fathers had been included within the study, since

different psychosocial outcomes were found when comparing mothers and fathers on their parenting experience (Hastings, Kovshoff, Ward, Espinosa, Brown & Remington, 2005). Therefore, data should be interpreted tentatively and applied cautiously.

Receiving a diagnosis can also elicit a traumatic response within the parent and fracture the existing parenting processes, recipitating a "crisis" (Weiss, Wingsiong, & Lunsky, 2014) and a grief response. Kubler-Ross (1969, as cited in Penzo & Harvey, 2008) describe five stages of grief: denial, anger, bargaining, depression, and acceptance, although the framework is often attributed to death and viewed as a linear process. A typical model of grief alludes to its process having stages which occur in sequential order. However, when considering grief within parents of children diagnosed with life-long and pervasive disabilities, the linear framework is challenged, with evidence of feelings associated with grief being revisited at times of ongoing difficulty (Penzo & Harvey, 2008). For parents of children diagnosed with autism "grief is normally experienced in cycles, sometimes precipitated by stressors, events, crises and missed developmental steps. It can surface each time, at the same intensity, as at diagnosis'' (MacGregor, 1994, p.p.161). One study (Fernańdez-Alcántara, García-Caro, Pérez-Marfil, Hueso-Montoro, Laynez-Rubio & Cruz-Quintana, 2016) has challenged the cyclical nature of grief for this group of parents. This study suggests that resolution of grief can be actualised through the

process of an oscillation between behaviours/coping centred on loss

(processing the emotions associated with grief) and those centred on

maintaining social relationships and carrying out daily living activities

(restoration oriented). Thus, promoting a new relationship with their child

based on who they are now rather than who they were in the past. Although

opinion relating to grief vary within the research, it is important for those

working with this group of parents to neither assume nor dismiss the

presence of grief without understanding the individual experience.

Brown (2016) acknowledges that internal feelings,

including those related to loss and grief, are often not expressed and

attributes this to societal discourses on disability. Brown suggests that

mothers within this study had never spoken of their emotional pain "…as a

result of the complexities of their personal situations, or the prevailing social

construction of disability, or the disability movement's concern over loss

being ascribed to disability…" (p.p.114), thus suggesting that some

experiences are truly internal and are rarely voiced to others. Brown

explored the experiences of six mothers of young adults with intellectual

disability and eight themes emerged from the data: Initial Diagnosis,

Solemnity, Personal, Societal, Pivotal Point, Milestones, The Future and

Meaning Making. The theme of 'Initial Diagnosis' highlighted mothers'

expectation of the past and the newly acquired realisation of the future. The

'Solemnity' captured nuances of the double mourning of the mother and

child 'ideal'. 'Personal' reaction to response highlighted that "Mothers expressed that deep personal grief triggered by their needs and aspirations for their child and them-selves changed them irrevocably" (p.p.117). The 'Societal' theme articulated experiences of exclusion and inclusion of mother and child. 'Pivotal Point' revealed profound turning points through the experience of crisis and resultant coping. 'Milestones' highlighted that parents experienced life transitions being lost or found in relation to understanding of disability. 'Future' theme alluded to the challenge and change in the mothers' caring role. Finally, 'Meaning Making' revealed the subthemes of mothers' identity and agency as women. Literature points to an ongoing process of meaning making of mothers' personal and societal experiences which may lead to transcendent and transformative experiences (Wright, 2002) or post-traumatic growth with increased strength and resilience (Tedeschi & Calhoun 2004; Broberg, 2011).

O'Brien (2007) also posits that parents' ability to tolerate and manage the ambiguity of their child's autism is a key factor in their parent experience and may lead to an identity crisis. The complexities associated with being the parent of a child diagnosed with autism can culminate in feelings of 'failure', 'rejection' and 'loss', which have the potential to impact upon parent well-being and parental perceptions of difficulty. Research, overall, reflects the parental position as one of adversity, with some (Ludlow, Skelly & Rohleder, 2012) highlighting parental

perceptions of negative affect when describing their parenting experiences. Ludlow, Skelly & Rohleder's (2012) participants (mostly mothers) spoke about feelings of 'failure as a parent' and 'inadequacy', with some mothers identifying their experiences in relation to feelings of 'rejection' and 'loss'. Another mother described her parenting experience as one of 'loss', in relation to not being able to hug her child who is unresponsive and sensitive to touch.

As suggested by the Kubler-Ross (1969) stages of grief model and McCubbin & Patterson's ABCX model of family adaptation (1983), it is assumed that parents move towards a place of acceptance, and for some the development of an identity which aligns with their new experiences may allow for this. Nevertheless, there also appears to be a potentially cyclical component to the difficulty which rears its head as new expected milestones are missed (e.g. perceived age thresholds for language acquisition).

4.3. Adaptation: 'Welcome to Holland'

For parents, a shift in perceptions about their child and their own identity, gathering of new information and resources to parent an unexpected child, may begin as they struggle to understand and manage autism-related challenges. Adaptation is defined as 'the action or process of

adapting or being adapted' (Oxford Dictionary, 2019) – a process of change

by which a person becomes better suited to his/her environment or context.

Bowlby (1980) posited that all parents go through a period of

transition, from 'before becoming a parent' to 'as a parent'. For those

parents who learn that their child has autism, transition from one to the

other may take an unexpected route. Furthermore, he suggests that

reorganisation from 'before becoming a parent' to 'as a parent' is

considered an optimal and healthy outcome, and it involves the process of

realignment of the representational world and internal models (as cited in

Main et al., 1985). Transition, coupled with the effort and complexity of

caring for a child diagnosed with autism, may present a different challenge

for this group of parents compared with those who parent neurotypical

children. Adaptation from one internal model to another requires cognitive

capacity, with feelings of loss and grief impacting greatly upon this process,

thus presenting the possibility of increased challenge and reduced capacity

to adapt (Paynter et al., 2013, Harper et al., 2013). According to Lazarus

(1991), negative emotions are appraised in a manner that directs parents to

avoidant coping strategies, and conversely Folkman (2008) and Fredrickson

(1998) suggest that positive emotions are associated with widening focus of

attention, motivation and eliciting social support. Therefore, it might be

assumed that supporting parents' emotional well-being may impact upon

their ability to assimilate their new experiences, their ability to gather

information and resources which allows them to support their child

effectively and facilitates a healthy shift in their personal and parent

identities.

> "This process of adapting to any given reality and working through the inherent tension between the expected and the actual may be challenging to most parents. Yet, this may be much more challenging when parents have to accept and adjust to the reality that their child is not developing typically. These parents have the extra burden of reconciling between the typically developing child they had hoped for and the child with the specific difficulty or diagnosis that they now have...parents experience many feelings and thoughts that need to be integrated and accommodated."
>
> – Yirmiya et al. (2014; p.p. 355-356)

Several psychological models and theories have attempted to explain

the process of adaptation for parents of children diagnosed with autism, e.g.

ABCX Model of family adaptation (McCubbin & Patterson, 1983), The theory

of Cognitive Appraisal (Lazarus & Folkman, 1984), the Risk Resilience Model

(Wallander et al., 1989), the Conservation of Resources (Hobfoll, 1989), the

Caregiving Stress Process Model (Pearlin et al., 1990), the Process Outcome

Model (King et al., 1999), and the family management style framework

(FMSF; Knafl & Deatrick, 2003). All have attempted to explain how parents

adjust and cope with demands and stress associated with autism.

Some theorists argue that adaptation occurs when parents of

children diagnosed with autism perceive that they have an enhanced ability

to support their child's needs and those of their family (Harper et al., 2013) and that the availability of resources can alleviate stress and aid adaptation to the 'autism' experience. For example, McCubbin & Patterson (1983; ABCX Model of family adaptation) describe adaptation within the distinct experiences' pre-crisis, crisis and post-crisis, and highlight factors associated with adaptation, including 'Pile-up', 'Perceptions', 'Resources', and 'Coping' (see Figure 1). They argue that adaptation is dependent on individual and/or group resources (e.g. Internal - self-esteem; external resources - social support).

Figure 1. ABCX Model of family adaptation; McCubbin & Patterson (1983)
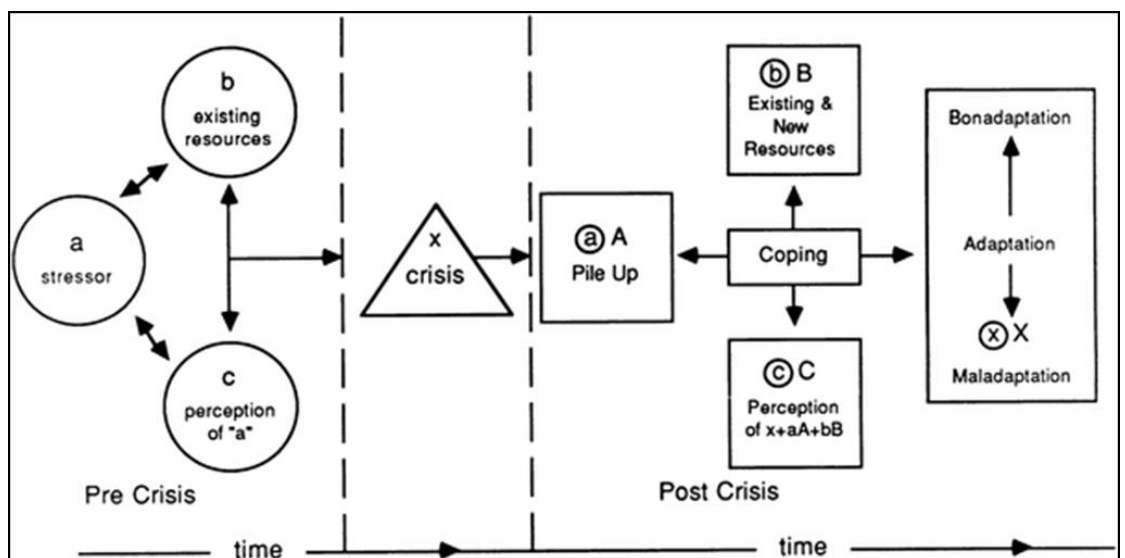
Recent studies have highlighted the possible appropriateness of applying the ABCX Model of family adaptation to families caring for individuals with neurodevelopmental disorders, including autism (Paynter et al., 2013; Pozo et al., 2014; McStay et al., 2014; Paynter, Davies & Beamish, 2018). Paynter et al. (2013) found support for the proposed relationships in

the model, with adaptation outcomes for individuals and families being linked to perceived severity of children's symptomatology (e.g. externalising behaviour), as well as 'pile-up' of additional demands, resources (internal and external) used to cope with these stress-inducing factors, and coping styles. The most recent study (Paynter, Davies & Beamish, 2018) also suggests that the ABCX model of family adaptation may be useful in understanding the experiences of autism families and the process by which they manage autism-related challenges, as well as other family and external factors which impact upon parental experiences. However, the proposed individual nature of a parent's story makes it challenging to have a one-size-fits-all model of adaptation.

Welcome to Holland
by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this......

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says,

"Welcome To Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

Figure 2. 'Welcome to Holland' poem

5. Rationale for Thesis

5.1. Introduction

The body of research in relation to being the parent of a child diagnosed with autism suggests that this group of parents experience an increase in perceived demand, stress and depression symptoms, when compared to parents of neurotypical children and children with other neurodevelopmental disorders (e.g. Zaidman-Zait et al., 2016). Difficulties associated with autism-related externalising behaviours, family functioning, isolation and stigmatisation have all been suggested to impact upon parenting perceptions of their parenting role and their capacity to adapt to the 'unexpected' autism experience (e.g. Myers et al, 2009; Ekas & Whitman, 2011; Paynter et al., 2018). These difficulties are suggested to be evident for parents of children of all ages (e.g. Benson, 2012; Caiozzo et al., 2017). However, the literature is yet to explore the experiences of being the parent of a young child diagnosed with autism using a phenomenological stance. Paynter et al. (2018), gathered phenomenological data relating to the experiences of fathers within this time period.

5.2. A distinct experience

Given that this research focuses on and identifies the experiences of being a parent of a young child diagnosed with autism as

distinct from other periods of time within the overall autism parenting experience, it is important to consider what makes it distinct.

All children will make developmental progress, however, this will be relative to the child's abilities. Children diagnosed with autism will also make progress and their parents will develop skills which align with the new parenting expectations. McGovern & Sigman (2005) suggest that although a diagnosis of autism shows very strong stability over time, improvement is reported by parents in terms of symptoms, adaptive behaviour, and behavioural responsiveness to the emotions of others. Parents mentioned fewer symptoms in adolescence/early adulthood than they remember when the children were 3–5 years of age. Therefore, although clinical symptoms remain fairly consistent over time, according to qualitative findings, the perception of severity changes over time. Gray (2006) suggests that this may be due to the declining degree of emotional distress experienced by the parents - 'children had improved to the point where they were significantly easier to live with, even if they retained many autistic symptoms' (p.p. 972).

For parents, adaptation may be defined by time, resources and capacity, all of which may be reduced within the early stages of the experience due to lack of understanding and access to information related to autism, as well as the trauma experienced by the parent at this

time. With time and a developing capacity to gather internal and external resources, it is assumed that adaptation can take place and thus perceptions of demand may reduce and parental well-being may improve (Paynter, Davies & Beamish, 2018).

5.3. Research Question

Adopting a hermeneutic phenomenological methodology affords the opportunity to explore a group of participants in an in-depth manner, potentially allowing for the removal of researcher biases (Smith, Flowers & Larkin, 2009). Given the research explored in the literature review, the research question will be: What is the experience of being a parent of a young child diagnosed with autism?

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"We very much planned our life with an idyllic sense": Being a parent of a young child diagnosed with Autism

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Abstract

For most parents, caring for a child is an experience full of triumphs and joy, as well as challenges and stress (Myers et al., 2009). However, being a parent of a child diagnosed with autism comes with challenges which may be very different from the expected challenges of being a parent (Perlman and Peplau, 1981; Peplau and Perlman, 1982; Dunlap, Dyler and Koegel, 1983; Lecavalier et al., 2006; Woodgate, Ateah and Secco, 2008; Zaidman-Zait et al., 2016; Ludlow, Skelly, & Rohleder, 2012). Historically, research exploring parent experiences relating to their child's autism has focused on parents of children beyond the age of six years, particularly adolescents (e.g. Smith et al., 2012; Benson, 2012) and little is known about the parent experience for those who are a parent of young (i.e. younger than six years old) child diagnosed with autism. Using semi-structured interviews, it aimed to explore the experience of six parents (four mothers and two fathers) of young children diagnosed with autism. Using Interpretative Phenomenological Analysis, four superordinate themes emerged from the data: *Diagnosis hit me like a train; I thought I'd have a little girl and we'd go shopping together; I wanted something to pin it on; This is my adventure*. Themes suggest that being the parent of a young child diagnosed with autism is experienced as receiving a diagnosis, loss, blame, taking control and adaptation to a "new normal". The research highlights the role of strength-based support in aiding adaption for these families.

1. Introduction

Parents of children diagnosed with autism are reported to experience elevated levels of stress and frame their parenting role within the context of difficulty and demand (Peplau and Perlman, 1982; Dunlap, Dyler and Koegel, 1983; Lecavalier et al., 2006; Woodgate, Ateah and Secco, 2008; Zaidman-Zait et al., 2016; Ludlow, Skelly, & Rohleder, 2012). Both autism-related challenges and the parents' internal experience are reported to impact upon parent stress and depression, which has implications for the parent, the child diagnosed with autism, siblings, spouses and extended family members (Falk et al., 2014; Zaidman-Zait et al., 2018; Howell et al., 2015; Sikora et al., 2013; Altiere & von Kluge, 2009a).

Factors such as autism-related differences (e.g. externalising behaviours, lack of sleep), parent-related differences (e.g. self-efficacy, coping style), family factors (e.g. having more than one autistic child, single parent family), external factors (e.g. judgement from others, access to support), are all suggested to impact upon parental well-being and perceptions of difficulty (e.g. Myers et al, 2009; Ekas & Whitman, 2011; Paynter et al., 2018). The internal experience of being a parent of a child diagnosed with autism is suggested to be one framed within difficulty (Myers, Mackintosh, & Goin-Kochel, 2009). Parents report feelings of loss, ambiguity and grief (O'Brien, 2007; Boss, 2004, 2006; Poslawsky etal., 2013).

1.1. The Current Research

Much of the current literature focuses on parents of older children and adolescents diagnosed with autism. Given current research it is assumed that early parent experiences are distinct, thus there is a gap in the literature which would be useful to explore. This study posits that experiences related to being the parent of a young child with autism may be better understood through exploration of those which are internal to the parent, i.e. those which are rarely voiced. For example, feelings associated with loss of identity (Poslawsky, Naber, Van Daalen & Van Engeland, 2013; Cashin, 2003; Dale, Jahoda & Knott, 2006), loss of the expected child and parenting experience (Walter & Smith, 2016), sense-making of the ambiguous nature of the condition (Aylaz, Yılmaz & Polat, 2012), and acceptance and adaptation (Paynter, Davies & Beamish, 2018).

This study aims to explore the experience of parents of young children (under six years old) with a diagnosis of autism to understand the possible distinct nature of this lived experience, exploring the unspoken. It is concerned with the quality of those experiences and with what they might mean for participants.

1.2. Aims and Research Questions

Adopting a hermeneutic phenomenological methodology (Interpretative Phenomenological Analysis; IPA) allows the opportunity to explore perceptions held by this group of participants in an in-depth manner, potentially allowing for the removal of researcher biases and encouraging the lived experience to be heard (Smith, Flowers & Larkin, 2009).

The research question was:

• What is the experience of being a parent of a young child diagnosed with autism?

2 Methodology

2.1. Ontology and Epistemology

The researcher holds a relativist ontology, thus assuming that reality as we know it is constructed inter-subjectively through the meanings and understandings developed socially and experientially (Smith, Flowers, & Larkin, 2009; Willig, 2008). Furthermore, the researcher's epistemological stance is framed with a subjectivist lens (Chamberlain, 2014), assuming that we cannot separate ourselves from what we know. The researcher and the object of investigation are linked such that who we are and how we understand the world is a central part of how we understand ourselves, others and the world.

Research that explores experiences of parents of children diagnosed with autism varies in its methodological, ontological and epistemological perspectives. Variants of research that focus on the experience of the parent of a child diagnosed with autism include, quantitative methodologies (e.g., Dabrowska, & Pisula, 2010; Benson, 2014), longitudinal quantitative methodologies (e.g., Zaidman-Zait et al., 2017) and qualitative methodologies (e.g., Griffith et al., 2012; Luong, Yoder & Canham, 2009; Lai & Oei, 2014). All of the aforementioned studies add value to our understanding of the experience of this group of the parent. However, the researcher assumes that applying a self-conscious and systematic approach to interpretation of these experiences will allow for a more robust qualitative research design, via an interpretive and iterative process that accounts for the constructions of the participant and the researcher in a reflective and reflexive manner (Smith, Flowers & Larkin, 2009).

2.2 Research Design

A semi-structured interview approach was selected to explore the lived experiences. Participants were asked to take part in a semi-structured in-depth interview exploring their experiences. A semi-structured interview methodology was chosen because of its potential for generating rich data, gaining insight into participants' perceptions and values, contextual and relational aspects which are viewed as significant to understanding others' perceptions (Newton 2010) (Appendix 2). Active listening skills supported

the establishment of a rapport between researcher and participant which was regarded as important to the success of the process (Egan, 1982). The participants were informed that the interview may be a lengthy process (up to 90 minutes). The participants were viewed as "experiential expert[s]" (Smith et al., 2009, p.64), and thus the questions were designed to be open and encourage participants to talk at length with interruptions kept to a minimum. The interview schedule was memorised and followed flexibly so participants frequently guided the flow of the conversation and chose which aspects of their experiences to discuss.

The research question was answered solely through the Interpretative Phenomenological Analysis (IPA) of qualitative data (i.e., semi-structured interview transcripts; see appendix 7). IPA (Smith, 1996) is a relatively new approach to qualitative enquiry. It examines how people make sense of major life experiences, for example, being the parent of a young child diagnosed with autism. Its three theoretical underpinning principles are Phenomenology; how people examine and comprehend lived experiences, Hermeneutics; theory of interpretation, and Idiography; commitment to detail and how experiential phenomena have been understood from the perspective of particular people, in a particular context (Smith, Flowers & Larkin, 2009). The researcher used the process of IPA to better understand the experiences associated with being the parent of a young child diagnosed with autism.

The use of alternative methods such as focus groups or questionnaires were considered, however these approaches were disregarded because it was felt that they may have imposed a rigid structure that hindered reflective thinking and would not have aligned with the epistemological and ontological stance taken by the researcher. Furthermore, it was felt that these methods may also result in increased feelings of ambiguity and offer less flexibility to the participant in the choice of their responses (Gillham, 2000).

3 Method

3.1 Sampling

The sample for this study were self-selected (Robson, 2011) (i.e. those who have volunteered to participate) and included both biological mothers and fathers of young children diagnosed with autism. All children had received a formal diagnosis of Autism Spectrum Disorder (ASD) by a paediatrician and by means of an Autism Diagnostic Observation Schedule (ADOS; Lord, et al. 2000). Six participants were recruited, including four mothers and two fathers. Smith, Flowers and Larkin (2009) suggest that four to ten participants is appropriate for qualitative research and Sanelowski (1995) suggests five as being the optimum number of participants. Therefore, six participants offer a good sample size for this qualitative research.

A gatekeeper letter (sometimes included in an instant message) was sent to the chairperson/ administrators (Appendix 3) of each online parent support group from which participants were recruited. A consent form was completed by the gatekeeper (Appendix 4) before the researcher made contact with any potential participants. Parents were recruited on a voluntary basis through an advert, which included the research information. This was shared within three local autism parent-support online groups via the gatekeeper. Prior to the commencement of the interview the researcher shared the participant information sheet (Appendix 5) and obtained written consent (Appendix 6). The interviews were conducted in English, which participants agreed to, due to this being the first language of the researcher.

Ethical approval was obtained from the Cardiff University School of Psychology Ethics Committee. Procedures followed for recruiting participants and conducting research in line with ethical practice are detailed in Part Three of the thesis (p.p. 128-130).

3.2. Participants

Participants were located within urban areas of Wales and were contacted via local online parent support groups. Parents whose children were older than 5 years 11 months were excluded due to the focus on experiences of parents of young children diagnosed with autism. Parents of children who were yet to receive an official Autism diagnosis were also

excluded due to possible alternative explanations for their presentation and thus experiences would be related to a different phenomenon. Participant details are provided in Table 1.

Participant Pseudonym	Mother /Father	Child diagnosis	Child's needs	Age at diagnosis	No. Years since diagnosis	Age	Child's gender	Number of siblings (diagnosis of ASD or other condition)	Known to the researcher Y/N
Andrew	Father (Biological)	Autism (verbal)	Social communicat-ion Sensory Anxiety	2 yrs	3 yrs	5 yrs	Male	1 brother (diagnosis of autism – non-verbal and learning difficulties)	Y
Rhodri	Father (Biological)	Autism (Verbal) Viewed as More Able and Talented	Social Behavioural Attention Change is difficult	2 yrs	3 yrs	5 yrs	Male	1 sister (being monitored by parents and HV) and 1 brother (no present concerns)	Y
Tiffany	Mother (Biological)	Autism (Pre-verbal)	Behavioural Social	2 yrs	1.5 yrs	3.5 yrs	Male	No siblings Auntie with epilepsy and other needs	Y
Julie	Mother (Biological)	Autism (Pre-verbal)	Behavioural Sensory needs	2 yrs	2 yrs	4 yrs	Male	3 older brothers 2 have a diagnosis of autism	N
Rachel	Mother (Biological)	Autism (Pre-verbal)	Hyperactivity Attentional skills Risk taking behaviour Sensory overload	3 yrs	3 mths	4 yrs	Male		N
Deb	Mother (Biological)	Autism (Pre-verbal)	Behavioural Pre-verbal	3 yrs	2 yrs	5 yrs	Male	2 siblings – 1 older sister (autism pathway)	Y

Table 1. Details of participants

3.3. Procedure

A pilot interview was undertaken with two participants, the purpose of this being to ensure that the research questions and prompts were appropriate and that the researcher was able to develop the responses of the participant through, for example, further gentle probing. The data gathered from the first pilot interview is not included within the empirical paper. However, the data gathered from the second pilot interview is included and has formed part of the analysis process. Interviews were conducted in the participant's home and were between 40 and 90 minutes in length.

Interviews were transcribed verbatim, using pseudonyms. Some personal information was changed or redacted to maintain anonymity. A full key to the interview transcripts is given and symbols and styles relevant to quotations within the body of the thesis are shown in Table 2.

Style	Meaning	Style	Meaning
( )	Round brackets indicate words, pauses, noises etc. of the participant	[]	Square brackets indicate the researcher's explanatory comments/observations
XXX	Redacted words/ very brief phrases	[…]	Longer redacted or edited passages
(.)	Very short pause typical of connected, flowing speech	((pause))	A longer pause
?	Used to indicate a questioning tone	!	Used to indicate and exclamatory point
Underlining	Used to indicate emphasis	Dash-	Cut-off speech

Table 2. Key to symbols and styles used in quotations

Analysis followed the steps suggested by Smith et al. (2009),

these were as follows: reading and re reading; initial noting;

developing emergent themes; searching for connections across

themes; moving to the next case; looking for patterns across cases.

Further details are given in Table 3. The IPA steps were iterative

(Eatough & Smith, 2011) and regular exploration of the transcripts

and recordings helped to keep interpretations grounded in the data.

The literature review was written after data analysis, which is in

keeping with the principles of IPA.

Step	Description
Reading and re-reading	Recordings were listened to and transcripts read through at least twice to increase familiarisation.
Initial noting	The first transcript was read through carefully and notes made of anything interesting or significant (Smith & Osborn, 2008). Smith et al. (2009) note that this is "the most detailed and time consuming" (p.83) stage of analysis and can be done at three levels: descriptive, linguistic and conceptual. For earlier interviews, each of these stages was done in turn to encourage closer analysis; for later interviews, when the technique was more familiar, they were done in parallel. An example is shown in Appendix 7.
Developing emergent themes	Initial notes on the first transcript were explored at a higher level of abstraction, mindful of the initial notes that had been made on the transcript as a whole, and emergent themes were recorded. An example is shown in Appendix 8.
Searching for connections across emergent themes	A list was made of emergent themes within the first transcript, together with key quotations. These were reordered to establish links, patterns and contrasts and eventually grouped into superordinate themes at a further level of abstraction. An example is shown in Appendix 9.
Moving to the next case	This process was repeated with each subsequent transcript whilst being mindful of the way in which on-going analysis of each transcript was changing the researcher's preconceptions. This and other reflection were recorded in a diary to enable them to be "bracketed off" (Smith et al. 2009) Extracts from the reflective diary are shown in Appendix 10.
Looking for patterns across cases	Themes were compared between participants, leading to a re-ordering of themes until a set of

	super- and subordinate themes was developed to represent the transcripts as a whole. This re-ordering continued to a minor extent throughout the writing of the results and analysis. The participants' own words were used to label the themes to reflect their often emotional experiences in preference to using more neutral labels.

Table 3. The six steps of IPA

4. Results and Analysis

This section explores super- and subordinate themes recurring (each theme was present within at least three interviews): these are summarised in Table 4. Table 5 shows the recurrence of each theme across participants. It is recognised that these are the researcher's interpretation of what was said rather than a hypothetically neutral analysis (Smith et al., 2009); theme labels are derived from quotations but remain the researcher's choice. Theme labels are tags drawn from the words of participants as a dramatic symbol of experience but contain semantic variations from the tag itself e.g. "hit me like a train" is far away from denial and ambiguity.

Superordinate themes	Subordinate themes	Illustrative quotes
"Diagnosis hit me like a train"	• Something was wrong (Intuition)	"…you notice something not normal about your child and he's-he's developing differently and it's just this instinct. This gut feeling." (Rachel)
	• I was in denial	"I think I panicked and was in a bit of denial-- that it was just her speech and it would-- it would-would-would happen once she started talking. and obviously it hasn't…" (Deb)
	• Expecting it	"So, my expectation for a diagnosis was there. And I accepted it straight away. I just didn't know that he would be classed as severely autistic…" (Tiffany)
	• Diagnosis – loathing and learning	"…diagnosis hit me like a train, then I was just like Jesus… "…getting the diagnosis early-- it was changing my mindset in you know, may be the neurotypical play isn't enough…" (Andrew)
"I thought I'd have a girl and we'd go shopping together"	• Loss of expected child/parent experience	"And then actually, reality is you can't do all of those things and you can go to a place--with your friends--but you don't spend one minute--talking to your friends--because you can't take your eye of your child because they're gonna strip or they're gonna--smack another child…" (Deb)
	• Loss of identity/selfhood	"I've just quite my job, which you know, broke me really, because I'd worked since I was 14, you know, whilst still in school. Prided myself on working all my life! You know took years and years to get to a really good position in my career, where I really loved my job and was actually, for once, going somewhere. Then all of a sudden, I had to call HR and tell them, I have to give this up. And that broke me a little bit (emotional). Umm (pause and crying)" (Andrew)
	• Loss of expected future	"I've got big-- I had big, sort of, career dreams and big plans and I-I'd like to be the director of a company, the organization. I- I've pretty much given up on that for- for- for the short term anyway, because I just think there's no way-- I think I'm capable, but capacity-wise, mentally I just don't think there's anyway that I could…" (Rachel)
	• Loss of control	"I think if you're out and about, you have to try and put that front on that everything's all right--and you-you're in control. Whereas, actually deep down, you're thinking, "Oh my god. I just don't know how to deal with this." (Deb)
"I wanted something to pin it on"	• Ambiguity – looking for something tangible	"The future is-is- I think can be terrifying. We don't know. We don't--It could be wonderful. It could be- who knows?" (Rachel) Yeah, and I had to think to myself, why? Why-why three of my kids got autism and what caused it. I don't know. Why is my-- Is it genetic? "Is it my fault…" (Julie)
	• Attribution of blame (guilt)	"I felt like it was my fault, first. Um like, I just felt awful for R, like, he's gonna struggle through his life with it… My brother got diagnosed when he was, like, well, 14, 15, so he struggles with through life… Um, yeah, and he struggles with that. I just didn't want R to have the same situation so" (Rhodri)
"This is my adventure"	• Acknowledgement and acceptance of new normal	"It's just maybe because like I wanted R to be comfortable with who he is - And start accepting who he is - Not like he's a little brat and like he's got autism and-- he's gonna need all the help he can get that's why I'm gonna be there for him to help him. Yeah, I think that's what it was - accepted." (Rhodri)
	• Seeking new skills and new situations	"I'm not an expert on his triggers yet, but again, I-I-- It's just a learning progress every day." (Tiffany)
	• Assimilation of new identity and future aspirations	"-at the same time-yeah I love it, I do love it. I mean with what we've done since the diagnosis is that we've - the community that's out there and the wonderful people that we've met as well. You know we wouldn't, potentially we wouldn't know them now had autism not taken us down this path-" (Andrew)
	• Taking control	"I made a choice to I can- I can either force, you know, continue to force to going down this-this one track of expectations and forcing them to go swimming. Or-or working with L, working with his needs, what he wants and-and having a happier life for everyone." (Rachel)

Table 4. Recurrent superordinate and subordinate themes

Superordinate themes	Subordinate themes	Andrew	Rhodri	Tiffany	Julie	Rachel	Deb
"Diagnosis hit me like a train"	• Something was wrong (Intuition)			☑	☑	☑	☑
	• I was in denial	☑	☑				☑
	• Expecting it			☑		☑	
	• Diagnosis – loathing and learning	☑	☑	☑	☑	☑	☑
"I thought I'd have a girl and we'd go shopping together"	• Loss of expected child/parent experience	☑		☑	☑	☑	☑
	• Loss of identity/selfhood	☑		☑	☑	☑	☑
	• Loss of expected future	☑	☑	☑	☑	☑	☑
	• Loss of control	☑			☑	☑	☑
"I wanted something to pin it on"	• Ambiguity	☑		☑	☑	☑	☑
	• Looking for something tangible			☑	☑	☑	☑
	• Attribution of blame (guilt)	☑	☑	☑	☑	☑	☑
"This is my adventure"	• Acknowledgment and acceptance of new normal		☑	☑	☑	☑	☑
	• Seeking new skills and new situations	☑	☑	☑	☑	☑	☑
	• Assimilation of new identity and future aspirations	☑	☑			☑	
	• Taking control			☑	☑		☑

Table 5. Recurrence of themes across participants

As will become apparent, there was evidence of divergence

and convergence within the data, as expected with the individuality

of people's experiences (Smith, Flowers & Larkin, 2009; Tuffour,

2017). Convergence was observed, and it was assumed that this was

due to all participants being parents of young children diagnosed with autism, e.g. initial challenges in understanding child's externalising behaviours, concerns for the future, etc.

Divergence was observed in Rhodri's experience - he had a very different experience from that of other participants. His experience of parenting a young child diagnosed with autism alluded to greater positivity compared to the other participants. The obvious difference for Rhodri was that his son is perceived to be 'higher functioning' - he is verbal and is viewed as being More Able and Talented (MAT; WG, 2013) in some areas of learning. He also has previous experience of autism (his brother has a diagnosis of Asperger's Syndrome), which possibly, in part, facilitated a process of acceptance and adaption that was different to the other participants.

There was other evidence of divergence with half of the participants (Andrew, Rhodri and Deb) experiencing denial prior to receiving their child's formal diagnosis. Tiffany, Julie and Rachel shared that they knew that there was something different about their child and expected to receive a diagnosis.

Analysis is structured by superordinate theme with each subordinate theme explored in turn.

4.1 Superordinate Theme: "Diagnosis hit me like a train"

This superordinate theme highlights the experiences of intuitively knowing that something was different about their child's development, denial, expectation of their child receiving a diagnosis, and the loathing and learning that follows the receipt of a diagnosis.

4.1.1 Subordinate theme: Something was wrong (Intuition)

Participant	Quotations
Tiffany	• "…I'm lucky that I noticed the signs-- I've been around 10 other kids-- but his behaviour was completely different- so I knew that there was something-" (Pg9) • "So, we went to see Dr. D, Paediatrician, again, he did a test and even in that test I knew. And in my head, I knew-- already-- that he was autistic." (Pg9)
Julie	• "I remember that when they gave the diagnosis, and we partly knew-" (Pg5) • "So, I already knew, um, and I've seen doctors about that and he told me he's 99% sure it's autism." (Pg6)
Rachel	• "I knew he needed support. So I- I pushed for that for for what he needed, not for my benefit for I knew he had to go through this process. And I knew it was coming-" (Pg4) • "Maybe it's mother's intuition. Maybe it's some basic training I'd had in the past. Um, and I said he's autistic. I said, "That- that is just not normal."" (Pg14) • "I knew he was and I-I wanted that- I-I needed that sort of- sort of pursuing." (Pg20)
Deb	• "I knew he was autistic-" (Pg2) • "-Because I knew he was autistic so I was prepared for him being autistic-" (Pg34) • "-you know your child and deep down I knew-" (Pg35)

This subordinate theme was exclusive to the mothers within the research and was labelled by participants as "Mother's Intuition" or "Mother's Instinct". It alluded to the experience of having previous experience of supporting children (their own children, children within the extended family, or training/work experience) and comparing their child's development to this. The parents

described their child's development as "not normal" or "wrong",

which suggested expectations of a 'typical' child development.

4.1.2 Subordinate theme: I was in denial

Participant	Quotations
Andrew	• "I was very much a denial dad in the early days that, there's nothing wrong. Even for a short period of time after L's diagnosis, I still didn't quite understand or believe what the issues were." (Pg9) • "I was, I was absolutely 'Denial Dad'. Completely didn't, you know, mum saw the autism in L, god at ten months old." (Pg13) • "I mean as I say, I'd get up in the morning, I'd feed him, I'd go to work, I'd go home and put him to bed, but I didn't see any of that (autism traits) and (inhalation of breath) and very much-I think part of that then turned into, sort of, denial – the whole, 'There's nothing wrong', 'He's just slow', 'he's just a boy'" (Pg15)
Rhodri	• "I was in denial at first." (Pg7) • "It was Rachel first, I thought Rachel was just looking for it, because I thought she was just-- I was just denying, I was like, "You're just looking for the signs," I thought that's because the way he was lining up cars and stuff, I just thought that was being a boy." (Pg7)
Deb	• "Um, I think I panicked and was in a bit of denial-" (Pg1) • "And I think I was still in denial a lot about-" (Pg9)

The theme 'I was in denial' was experienced by both fathers

and one mother and indicated that parents attributed their concerns

or the concerns of others to their child "being a boy" or "slow". It

also indicated that the fathers acknowledged that the autism was

first noticed by their spouse.

The divergence in this theme came in the form of Deb

experiencing denial. However, she also expressed that she "knew

deep down" that her son was on the autism spectrum, possibly

suggesting that she was suppressing her fears as this did not fit with her expectation of her child and her parent experience.

4.1.3 Subordinate theme: Expecting it

Participant	Quotations
Tiffany	• "So, my expectation for a diagnosis was there--I just didn't know that he would be classed as severely autistic, I just thought it was like a borderline. And then to be told, "He won't do this. He may not work when he is older, he may not do this, that." Rather than tell me what he can do and what his capabilities are, that was very disheartening." (Pg9) • "I went in with the expectation of him saying, "It's just borderline." And that I knew he had global development de-delay. So, I was just expecting them to say, "It's borderline autism."" (Pg16)
Rachel	• "So I don't know, I never expected to- you know, and I never knew I was gonna be an autism mother, I never knew this was, you know, this was- the-the path I was going down-" (Pg11) • "Um, yes, so I was expecting it. I had pushed for it. I was pushing for it for a good eight months, and-and knew I had to get this diagnosis to get anywhere-" (Pg19)
Deb	• "-he's, um, quite severely autistic. You know, it-it-it's very, you know, it was really clear. And I think that I wasn't expecting that, I thought he would be on the lower end where, you know, actually as he gets older it's probably, you know, it's-it's-it's not gonna be so bad. Um, so that kind of was a little bit different to what I expected, but, yeah, I just came home and cried and if-- I just-- reality really hit then." (Pg35)

'Expecting it!' alluded to the experience of the expectation that the parent held when receiving their child's formal diagnosis of autism. Parents expressed that although they expected their child to receive a diagnosis of autism, they had not anticipated the severity noted by the ADOS (Lord, et al. 2000) assessment - All parents noted that they had anticipated the outcome of the assessment would indicate a lesser severity than it did. This may be indicative of parents' hopes for their child's development and their parent

experience, e.g. lower autism symptomatology equates to higher

likelihood of a level of independence as the child reaches adulthood.

Parents also alluded to the emotion of the experience of learning

that your child is on the autism spectrum.

4.1.4 Subordinate theme: Diagnosis – loathing and learning

Participant	Quotations
Andrew	• "But I think with the diagnosis especially, it definitely (emphasised intonation) helped me understand him more." (Pg4) • "-you hear the term 'early intervention' at such an early stage of the child's life. You're delaying that early intervention by so many months/years, that then that child is potentially missing out on learning, or not even learning of the child, but the parent learning about the child. Umm, so yes early intervention is key, but then don't delay the early intervention." (Pg10) • "-getting the diagnosis early, it sort of made me (pause) and obviously with L already having his diagnosis as well, it was changing my mindset in you know, may be the neurotypical play isn't enough to settle M or meet his needs-- it's learning more about him through the diagnosis that's delivered-" (Pg5) • "-diagnosis then hit me like an absolute train-" (Pg13) • "-guilt hit me like a train, Because, I felt that as a parent I should have maybe seen it quicker, I should have seen it sooner, I probably should have listened to my wife sooner, umm, and not palmed her off, as in 'Aw, love, you know you're talking rubbish, he's fine'." (Pg15)
Rhodri	• "Yeah. Because, as I say, if he was in school, and if he didn't have a diagnosis, he probably would've been thrown out by now." (Pg15) • "[Diagnosis] was a relief, because, as I said, if-- I know it's a limbo, but it's nice to have it because you can say, "well, you've got to-- Like, in the school, you've got to meet his needs and you've got to help him." (Pg15)
Tiffany	• "The doctor did say to me in the diagnosis, Dr. D, -- um, his traits of autism may disappear as he grows up. That was my understanding that autism can't be cured- So, that was- that confused me because it was conflicting information-- from what I was reading into." (Pg9 & 10) • ""This is the spectrum. This is mild, this is modest, and this is severe-- and this is where C is. This is severe autism." And I said, "Well, what's that even mean?"" (Pg16) • "I didn't know anything about autism at all. There was very limited help and very limited information on it. So, I think I'm just learning." (Pg25)
Julie	• "[Diagnosis] it's helped to get certain things." (Pg10)

	•	"Well, I do meet people who're going through diagnosis, and it's- it is hard, and it is- it's like a roller coaster ride. You have one minute down, the next minute, you've got to fight for everything." (Pg30)
	•	"Like-like I had been punched in the stomach…" (Pg6)
Rachel	•	"-when we had the diagnosis, I mean, just it was just like, "Oh, my God, my life just- just-" it just fell apart. So I went through counselling and marriage is on the rocks because of it- not because of it probably both." (Pg4)
	•	"-getting assessed, getting diagnosed and once he was diagnosed, it was like, "Right, here's the diagnosis, have fun," and-- I just didn't know where to go with it." (Pg32)
	•	"It's a constant learning process, constant learning." (Pg32)
	•	"Well, everything just hit rock bottom." (after receiving diagnosis) (Pg47)
Deb	•	"I was scared about what would happen to her I guess. And- and the same with H, I- my biggest concern- my biggest concern with them being diagnosed was would they have to move schools-" (Pg34)
	•	" that-that official diagnosis was still hard even though I knew." (Pg36)
	•	"And one thing I've realised with, um, having H diagnosed is it's only through the diagnosis then and then kind of delve into more things that actually you can access and that-that there is access to things." (Pg37)

This theme conveyed the dialectic nature of having a child receive a diagnosis of autism, that is, the emotional pain experienced at this time and the perceived value of a diagnosis. The pain experienced was expressed as metaphors, for example "hit be like a train", "like being punched in the stomach" and "like a rollercoaster ride". These suggest that parents felt extreme physical pain that has the potential to be life-changing. Emotion was experienced as feelings of being scared, feeling like their world was "falling part" and "hitting rock bottom".

Despite the personal pain experienced, parents acknowledged that receiving a diagnosis would help their child. They

highlighted that diagnosis brought about a process of learning for themselves and helped others to understand their child's needs. Parents alluded to the diagnosis facilitating access to services and support mechanisms, for example access to specialist schools, receiving learning support, and support through early intervention programmes, which was viewed by the parents to be of high importance to their child's development of skills and future outcomes.

4.2 Superordinate Theme: "I thought I'd have a girl and we'd go shopping"

This superordinate theme illustrates parents experience of loss, including feelings of loss of an expected child and typical parent experience, loss of their identity, loss of an expected future and loss of control of their lives.

4.2.1 Subordinate theme: Loss of expected child and parent experience

Participant	Quotations
Andrew	• "you do have this pre-conceived notion of child care and what parenting and what family life is gonna look like. You do have this idyllic, perfect outlook of life and we very much planned our life with an idyllic sense, in that we were gonna still be working, we even chose a nursery that they were gonna go to, we had rotas and schedules of what our days were gonna look like going forward (pause and sigh) and then when you throw that rule book and that, that picture out the window to be something absolutely polar-opposite, completely different than what you planned or what you thought (emphasised)

		was gonna be in your naïve, pretty little outlook of life…” (Pg16) • “-when you plan on having children--“we are going to have two children and a dog” and “They are going to go to a-“, you know and arguably let's face it, we did choose relatively up-market nurseries, going onto a relatively well to do Primary School, onto a very well to do Comprehensive School. You have such a detailed-and that was very much instilled to what I was brought up like.” (Pg27)
Tiffany		• “-I was told he wouldn't be. He's not gonna be able to understand human emotion. He's not gonna be, um, as you would expect a normal child to be. And yet he's one of the most loving little boys I've ever experienced.” (Pg1) • “To get him to play was really, really, difficult, and again, I just felt like I was failing. It felt like my child didn't want a relationship with me.” (Pg10) • “-although he can't verbally tell me that he doesn't want to go, he'll use violence as a way to communicate.” (Pg19) • “And you can see that the bond and the love is there. But I think this is hard just to look at your own situation and recognise that actually, it is there.” (Pg23)
Julie		• “I wouldn't call it a grieving process because I haven't lost him. He's still J, you know.” (Pg6) • “Well, the first bit is the worry, and of worrying about the future, the effect it's gonna have on the family, and-and I don't know, the feeling that you want him to be a typical kid-“ (Pg7) • “Well, J is more to do with care. And, you know, he-he does need a lot of care, a lot of supervision, things like that.” (Pg20)
Rachel		• “-But again, looking back and you just-you just walk past sort of like this group of children are doing all these sort of the typical things-“ (Pg23) • “mothers on the Facebook page, you know, "Oh God, Oh Sean has been coming home singing carols". And I'm going, “Oh my God." Um, you know, this moments where ago, like that's how different life is you know. Moments of comparison, yeah-yeah and I'm sort of, “Oh God, oh Charlie doesn't wanna wear his Christmas jumper," and like, "Oh my God, I mean it's been blowing my mind, that must be awful for you, I'm so sorry for this." You know.” (Pg65)
Deb		• “I thought about, you know, I'd love to have a little girl--who could be my best friend--and we can go shopping together,- -and do all these wonderful things, and you know. It w-it would be great--if it's, you know,- -there's my friend for life.” (Pg15) • “And, you know, it will be---and-and then we can-- I can go out with my friends who's got children--and we can go to all these lovely--places. And, you know, I'm gonna-- I'd-I'd give a child a lovely life. We could do loads of things. And then actually, reality is you can't do all of those things and you can go to a place--with your friends--but you don't spend one minute--talking to your friends--because you can't take your eye of your child because they're gonna strip or they're gonna--smack another child, or, you know. And-and you're just so--concerned or they're gonna-- you're scared that the gate is gonna open when someone's gonna go out and your child's that quick that they'll just go…” (Pg15 & 16)

This subordinate theme highlighted the experience of loss of the expected, "typical" child and the loss of expected child-parent experiences, e.g. going shopping, having a movie and pizza night. Expectations were established based on past experiences and planning for the expected child. The reality was a "polar-opposite" of this and parents found themselves having to re-align their expectations with the new experience, which made them feel out of control.

Instead of the 'idyllic' expectation of the parent experience, they found themselves learning to manage loss of expected interactions with their child, their child's externalising behaviours including, physical aggression, self-harming behaviours and smearing of faeces. This shift in expectation was difficult for parents and they found themselves experiencing feelings of guilt and failure in relation to meeting their child's needs, alluding to the role of grief within their stories. Parents also compared their experience to the experience of others, which intensified feelings of loss.

4.2.2 Subordinate theme: Loss of identity

Participant	Quotations
Andrew	• "-I've just quit my job, which you know, broke me really, because I'd worked since I was 14, you know, whilst still in school. Prided myself on working all my life! You know took years and years to get to a really good position in my career, where I really loved my job and was actually, for once, going somewhere. Then all of a sudden, I had to call HR and tell

	them, I have to give this up. And that broke me a little bit (emotional). Umm (pause and crying)-" (Pg14) • "I mean any parent anyway does lose their identity a little (Pause)- and I'm very - so much more a different person now to what I was seven-eight years ago, that I've, I've lost my Identity so much (Pause). Even down to the very core of who I am as a person and what I believe in as a person. That yeah- it's kind of – "Who am I again?"- do you know what I mean? What-what-what did I enjoy doing? I mean I -we had a conversation a few months ago of "what did we do before we had kids?". "What-what did we do before we had autism in our lives?". You know you do really lose sight of who you are." (Pg25) • "That you-you lose identity of the path you were on. You lose the identity of who you thought, who you are and who you thought you were going-going to be. And then you have to change who you are very quickly then because then you have to learn about all these different things." (Pg29) • "-my identity because I think some days I struggle with that-- there's days where I'm probably more a pare- more a carer-- much more a carer-- than I am a parent." (Pg30)
Tiffany	• "But then sometimes I feel like I'm losing myself." (Pg27) • "And then, sometimes it makes me feel guilty because as much as I love being C's mum, I enjoyed that hour away and it makes me feel horrible. [sobs]" (Pg27)
Julie	• "Uh, I used to put on a bit of lippy in the morning. I mean, sometimes I don't even brush my hair and I was never like that. Uh, prim and proper-proper, girly. Like my hair- my hair was always perfect. Always dyed it and-and slimmer you know-" (Pg16) • "I don't. I'm always last. I don't- I don't put myself anywhere. You know, I make sure everyone else is okay." (Pg23) • "I honestly think he's meant for me. I do. And I'm meant for him." (Pg7)
Rachel	• "I've got big-- I had big, sort of, career dreams and big plans and I-I'd like to be the director of a company, the organization. I- I've pretty much given up on that for- for- for the short term anyway, because I just think there's no way-- I think I'm capable, but capacity-wise, mentally I just don't think there's anyway that I could fo- give-- Give what I needed to a- to a job like that, you know? So again, it comes back to finances, self-fulfilment." (Pg64) • "-you're having to adapt to a child with a-a condition- - disability, whatever you-you know, however you want to sort of define it, becoming a carer- -you know? Becoming identified as a carer by-by professionals-" (Pg42)
Deb	• "you know, it's-it's just tiring and it's really tiring. And-and sometimes-- Again, I go through the different emotions of, "Do you know what? This is just life and you just got to get on with it." And sometimes I feel really sorry for myself and think, you know, "Gosh, why can't I just, like, go somewhere and have five minutes break." And-and-and I- and I guess I use their activities as my break." (Pg44)

'Loss of identity' reflects the parents experiences of losing themselves whilst supporting their child's needs. Andrew highlighted that all parents "lose their identity a little", but he also indicated that for parents of young children diagnosed with autism, the shift from who they were before coming a parent, to who they became following the birth of their child, followed by a quick shift to the role of parent-carer, takes place very abruptly and with little control for the parent.

In line with parents view of their parent-carer role, feelings of guilt were expressed when they took time for themselves, which was interpreted by being related to a view held by the parent that they are the "only one" who fully understands their child's needs. This might be attributed to the blurring of identities of the child and the parent (Identity Ambiguity, Boss, 1999; O'Brien, 2007). Julie prioritised herself last within the family system, often going days without a cooked meal and had little time to brush her hair – this was a stark contrast to her view of herself prior to having her son when she would often "put lippy on" (Julie, Pg 16).

Some parents also spoke about loss of a career or future career. For Andrew, this was framed as a devasting blow to his identity and changed "the very core" of who he was. Rachel expressed that she was very ambitious before she learned of her

son's autism diagnosis, but now her plans for being "the director of a company" were put on hold, as she felt that her capacity to care for her son and to work affectively towards her career goals were not compatible at this time. She alluded to the ambiguity of the future in relation to her aspirations - "The future is-is- I think can be terrifying. We don't know. We don't-- It could be wonderful. It could be- who knows?" (Pg29).

4.2.3 Subordinate theme: Loss of expected future

Participant	Quotations
Andrew	• "-I was going to grow up, I was going to have a really good job. It was going to be really well paid I was going to be this, it's silly looking back now but this-this strong independent, strict-- person, parent, adult-" (Pg27)
Rhodri	• "-he's gonna struggle through his life with it… My brother got diagnosed when he was, like, well, 14, 15, so he struggles with through life… Um, yeah, and he struggles with that. I just didn't want R to have the same situation so" (Pg8) • "I mean like I, uh, like yeah we'll have to care him." (Pg36)
Tiffany	• "And even though I try to take it day by day, I'm a full on worrier. So, I worry about, "Will he need me when he's older? Will he be able to drive? Will he be able to cross the road on his own?" Because at the moment, his safe- safety awareness is just non-existent." (Pg14) • "My worry is like 20 years down the line." (Pg43)
Julie	• "I was really worried about his future-- and about the-the typical things, you know, and-- what it's gonna hold, uh-- what it would mean for J, you know. (Pg5) • "You know it's- like I know J is probably gonna have troubles with J when he's older - But the moment now, he's still very toddler-like and- And we got a buggy if he's dropping to the floor, I'll put him in the buggy, you know." (Pg21)
Rachel	• "God, um, I think that-that kind of- what brought me to- tipped me over the edge, where- -when L was diagnosed because it was like you know you never want to have to think about you know being there for your child not-not because you want to be there- -but because you don't know who else is gonna look after them- -and they'd-- it's just the thinking of the future so you're thinking about you're having to adapt to a child with a-a condition- -disability--"Gosh- gosh I-I really need I need- I have to be here for- -for L. Put things in place.""（Pg42)

| Deb | • "Um, and actually, I think I think more about the future now- rather than, what the past… I think more about like, what's gonna happen in five years? How-how am I gonna help them in 10 years' time? Are they- are they gonna be living with me forever? You know, I need to give them the best--possible environment. To like kind of, for them to flourish and to--to help them for the future." (Pg31 & 32) |
| | • "H can be quite violent sometimes. So, you know, my-my worry is as he gets older he's gonna get stronger. You know, right now as a five-year-old - You-you can deal with him-- hitting and kicking, uh, but as a 10,11, 12-year-old, that's going to be very difficult. Because he's going to be a lot stronger." (Pg38 & 39) |

'Loss of expected future' suggests that parents experience loss in relation to their child's future, as well as their own. The discussions alluded to the lifelong and pervasive nature of the condition, but parents also expressed a sense of ambiguity in relation to the future, for example '**Will** he drive?', 'He'll **probably** have troubles', '**Who** else will look after them?', '**Are** you going to be living with me forever?'.

Parents also alluded to the intensity of fears for the future (e.g. "I'm a full on worrier", "Tipped me over the edge"), maybe partly exacerbated by perceptions of the unpredictability of the development trajectories of children diagnosed with autism (Singh, 2016)

Andrew expressed loss in relation to his quality of life, shining light on his aspirations for the future, "-I was going to grow up, I was going to have a really good job. It was going to be really well paid-".

Andrew's experience is interpreted to mean that the loss of his

career will have a significant impact on his expectations of quality of

life, reducing opportunities to have nice possessions (e.g. house,

cars, gaming equipment, etc).

Parent experiences also alluded to loss of the child's future.

Rhodri shared that he was concerned that his son would struggle

throughout his life, meaning that his son would struggle to function

without support. It appeared that Rhodri's past experiences of

supporting his younger brother were influencing his expectations of

supporting his son. This alludes to the role of social constructions

and past experiences on parents' expectations.

4.2.4 Subordinate theme: Loss of control

Participant	Quotations
Andrew	• "-and I sometimes lose control. I feel like I've lost control in respect of if they do something that I deem to be inappropriate or not necessary in that moment - I'm trying to discipline but they're not getting it-" (Pg23) • "I just think that there are days when I just think "Who is the parent in this house? --Is it me or is it you?" I feel sometimes like the child in the house --That everything of my day consists of me having to nurture you so much (emphasised), that I've got no real control over you and no way of disciplining…" (Pg24) • "-everything of my day consists of me having to nurture you so much (emphasised), that I've got no real control over you and no way of disciplining, that -that when I do potentially go off and game then everything you (I) do in that moment you're (I'm) in control of- You know (breath in). So, it's a bit of escapism, a bit of me being able to- yeah, maybe regain control my sort of life a little, um." (Pg24)
Tiffany	• "He likes being in control of everything that you do." (Pg2)
Julie	• "It's just I get my head down, keep ploughing through it, and I [crosstalk]--Keep going, different day tomorrow, [crosstalk]." (Pg29)

Rachel	• "You don't expect it and that's probably, it's-it's- you've got no control over it. Loss of control, you know, and you think you're on this path and then this happens. And you're like, "Oh, okay. Right. So now we're going down this path." And you are having to change so quickly--and adapt so quickly to a life that you perhaps hadn't agreed to sign up for and, you know, you're on this different path-" (Pg26)
Deb	• "And I think if you're out and about, you have to try and put that front on that everything's all right--and you-you're in control. Whereas, actually deep down, you're thinking, "Oh my god. I just don't know how to deal with this."" (Pg21)

'Loss of control' relates to the experience of being directed by the needs of the child which were unexpected (i.e. shifts in power, not being able to engage in activities of choice), loss of the ability to parent in a typical manner (e.g. discipline), a forced change (e.g. "I didn't sign up to this") and creating an illusion of being in control to fit with perceived social norms.

Tiffany alluded to the experience of being controlled by her son – "He likes being in control of everything you do", and made the suggestion that early support from a specialist playgroup had little effect on his apparent innate need to control his world. Tiffany's experience of trying to intervene often leads to her son having a meltdown, resulting in self-harm and the use of physical aggression towards her. Tiffany perceives that she does not have the skill or capacity to shape this characteristic of her son's autism, which encourages her feelings of loss of control.

Andrew alludes to his frustration at not being able to parent in the manner which he expected to, i.e. using discipline to change his children's behaviour. Andrew's experiences of his own childhood have shaped his constructions of what fatherhood is, i.e. my use of discipline will make my children well behaved. The loss of the expected child (i.e. a child who responds to typical parenting strategies) impedes his ability discipline his child in the way he expected to, resulting in ambiguity of his role, which is indicated in this rhetorical question, "Who is the parent in this house?".

Parents expressed feelings of loss associated with managing their child's behaviour in public and the challenges associated with the actual or perceived judgements from others ("control your child"). Deb shared that externally she often portrays signs of control, but internally she is often feeling very much out of her depth and not in control. Tiffany alluded to not wanting to change her son, but hoped to change the views of others, which was sometimes expressed as frustration and challenging of their views. Although, Deb and Tiffany's responses to the judgements made by others is different, they both highlight the role of social norms in their experience of being a parent of a young child diagnosed with autism.

4.3 Superordinate Theme: "I wanted something to pin it on"

The superordinate theme "I wanted something to pin it on"

indicates parents' feeling of ambiguity of their child's autism, looking

for something tangible to change or control, and attributing blame to

something in order to better understand their child's condition.

4.3.1 Subordinate theme: Ambiguity - Looking for something

tangible

Participant	Quotations
Andrew	• "Umm, because I just couldn't bond with him because he was such a difficult, what I felt in my sort of clueless mind was a difficult, moody child." (Pg3) • "When you're being told that (pause), you're just (pause), you're just looking for autism--which is really frustrating and upsetting to think that I'm not in it for, I'm not in it for the diagnosis, not in it for (pause) the badge to say that my second child is now autistic or looking for autism, but I'm noticing traits that possibly relating to autism, that are, that are affecting him in different ways and then to be told that, "Oh, he's just copying his brother" is so patronisingly--Ignorant, that, that isn't fair." (Pg9)
Tiffany	• "And even though I know- not to touch him, I'm still letting my instinct take over. But as a mother, when you see that your child is upset, your first instinct in any situation is just to pick them up and hold them and let them know that it'll be okay." (Pg6) • "And then again, it's just that I'm feeling a failure of -You don't know your own child." (Pg22) • "I didn't know anything about autism at all. There was very limited help and very limited information on it. So, I think I'm just learning." (Pg24) • "No, and it's that in that moment that I'm like, "Why don't I know what's triggered this? Why don't I understand him?" And that I'll, literally for days, I will torment myself trying to figure out what happened in that moment and it can literally just be, uh, C, just, was having one of those days." (Pg40)
Julie	• "Yeah, and I had to think to myself, why? Why-why three of my kids got autism and what caused it. I don't know. Why is my-- Is it genetic? Is it - J had genetics done and they were just borderline-- uh, genetics, you know." (Pg28) • "But I always just thought my kids were hard work, 'cause nobody would babysit them all together. They'd only have one at a time and things like that." (Pg18) • "I say it's a good thing mind, and sometimes I just think, "Oh, good God."" (Pg27)

	• "I took him to the doctors, and they did all the test and they said, "Oh, he's fine." And I said, "No, he's not." So, I started taking pictures and videos of him, and then I showed the doctor, and he said, "Oh, that's not fine. He needs to see someone.""" (Pg3)
Rachel	• "Uh I didn't know what to do. I just thought he was a naughty child. I knew he couldn't understand, you know, that because I'd be speaking to him like I'm speaking to you and there would just be- it's awful to say, nothing there, nothing coming back." (Pg17) • "You want- you want to- I wanted something to pin it on, like it's coming from somewhere, um, even if it was my fault, at least we could sort of trace it back. I'm starting to learn that, you know, that it could come from- it could be spontaneous, it probably doesn't run in families." (Pg17) • "Am-am I doing the right thing by him? Am I--? It's just this doubt. This-this, um." (Pg22) • ""Gosh, this-this could happen when he's 14, 15." And you know, sometimes you do go into that what- what does the future hold?" (Pg29)
Deb	• "-what probably one of the hardest bits was I didn't understand my children. Um, the-they were non-verbal, th-they can't tell me--how they're feeling, they can't tell me why they won't go into this room--and why they're screaming and-and hitting and kicking me. Um, because I think they just can't--physically tell me-" (Pg18) • "I had bad births with them both--and I thought, "Was it something to do with that?"" (Pg27) • "Went through the whole like MMR thing--with O and I didn't give it H--um, and-- 'cause I thought I might, you know-- Was it that?" (Pg27 & 28) • "Um, and- and I just wanted to-- I-I think I went through a stage where I just wanted to get to the bottom of why. Um, which you're never gonna get to the bottom of. You know, and-and-and, I think until you realise that. And I- I think I spent a lot of time focusing on-on that. Um, which was a lot of wasted time to be honest." (Pg29)

'Ambiguity' alluded to many things, including the parents'

perception that they lacked understanding of their child's needs,

exacerbated by the feeling that there was very little support to aid

their understanding and acknowledgement that their child could not

voice their needs; not knowing the trajectory of their child's

condition or their skill development; and perceptions that

professionals were not listening to their concerns. All of which set

the tone for feelings of an uncertain future and resultant feelings of ambiguity.

This ambiguity led to fears relating to "doing the wrong thing", which led parents to seek support from others (professionals) to understand their child's autism. The apparent lack of support led parents to seek information from other sources, such as Google, books, charities and other parents. "Doing the wrong thing" also led to feelings of failure.

Parents shared that the experience of expressing their initial concerns about their child's delayed and atypical development with a professional (e.g. GP, Paediatrician) was often one of not feeling listened to ("overbearing parent"; Andrew, Pg 9), resulting in feelings of ambiguity. Ambiguity relating to their child's atypical development continued as parents awaited information from the doctor. Andrew and Julie alluded to having to present evidence of their concerns before the doctor would initiate a pathway assessment. Accessing a pathway assessment was viewed as a means of beginning to understand their child's needs.

4.3.2 Subordinate theme: Attribution of blame (guilt)

Participant	Quotations
Andrew	• "Because, I felt that as a parent I should have maybe seen it quicker, I should have seen it sooner, I probably should have listened to my wife sooner, umm, and not palmed her off, as in 'Aw, love, you know you're talking rubbish, he's fine'." (Pg15) • "-I just didn't have it in me to develop or even want to develop that bond with him, because of, potentially, L and (sigh and pause) and that again, looking back now, was the guilt of 'Why the hell, why the hell would I do that as a parent?'. Why would I even (sigh and pause), subconsciously, want to do that to a child? Or to the two children (pause) that I just can't be bothered. You know, I-I, guilt is really, really hard, because in the moment, in that absolute moment you don't, you don't choose to be that cold-hearted person to push someone aside, you don't choose to be that person, it's just in, in that moment of heightened stress of (pause) the diagnosis and learning about the diagnosis and learning about L and having to quit the job and everything else, and becoming his primary carer- then a newborn and all of the, the things that come along with that, that I didn't choose to do that. It's just, it was how my mind coped with it at the time." (Pg16)
Rhodri	• "I felt like it was my fault, first. Um like, I just felt awful for R, like, he's gonna struggle through his life with it… My brother got diagnosed when he was, like, well, 14, 15, so he struggles with through life-" (Pg8) • "-it was like guilt as well. Like I did it. Like it was my fault just because of my side of the family." (Pg15)
Tiffany	• "It's difficult because I feel like I'm doing something wrong-- instantly in my head, I'm 'failing'" (Pg4) • "And I just felt- I felt like he didn't like me--And I was doing something wrong." (Pg 7) • "I am saying to him, "I know it's frustrating. I'm sorry, I put you into that situation" But because it was a quiet day, I didn't really think anything of it. And I'm saying I'm sorry." (Pg21) • "Um, it got to the point where I so-- I-I wasn't going to work. I did get very suicidal, because just having the thought of leaving him, [sobs] made me feel like I was a failure anyway." (Pg11)
Julie	• "But why, what caused it, why were three of my-- Is it my fault that I've done?" (Pg28) • "I always thought something-- I don't know, I can't put my finger on what it was-- but I always thought, um-- The-the earliest things was like, um, he didn't have the, the basic instincts of leaning out, and like it's my fault-" (Pg2)
Rachel	• "Um, I felt intense guilt. I thought there was something that I had done to him. I thought, "Oh, my God, it- was it the C section, was it-- Did I eat something when I was pregnant? Did I take- did I take a tablet that was-- You know, you just think of all these horrendous things." (Pg17)

Participant	Quotations
Deb	• "There was a big blame on myself, -I think--and a lot of guilt." (Pg27) • "Yeah, I-- It just made me feel a failure. It-it made me think it was all my fault." (Pg29) • "-as far as I'm aware there's-- there was nothing in the family--you know, and I was-- I guess I was looking for a blame, you know. What a-- How, you know-- why-- what causes it? I think I was looking for the cause more than a solution--to help them. A blame, you know." (Pg26)

4.4. Superordinate theme: "This is my adventure"

The superordinate theme "This is my adventure" alludes to the acceptance of the new experience, seeking new skills and experiences which align with the assimilation of a new identity, changes to future aspirations, and taking control of the situation. These processes are viewed as a healthy and necessary shift from pre-parent to parent of a child diagnosed with autism.

4.4.1 Subordinate theme: Acknowledgement and acceptance of "new normal"

Participant	Quotations
Rhodri	• "That's, kind of, why I accepted it as well, like, okay he's autistic it's fine" (Pg8) • "And, like, I know you're not supposed to compare, but I used to, like, at-at least he's not, like, a low functioning child. He's high functioning, which is good, but at least he's not, like, we don't have to help him every day, every minute. I mean, like, we do at home. It's going to have to be different, but I'm hoping that he can have his own independence." (Pg8) • "It's just maybe because like I wanted R to be comfortable with who he is - And starts accepting who he is - Not like he's a little brat and like he's got autism and-- he's gonna need all the help he can get that's why I'm gonna be there for him to help him. Yeah, I think that's what it was accepted." (Pg36)
Tiffany	• And I accepted it [autism diagnosis] straight away." (Pg9) • "I don't want him to get rid of the autism. - It's not C that I would change. It's everyone else's understanding of the

	•	situation that I would change. But I think that it's just my personality." (Pg15)
Julie	•	"-- But I think I'm at the place now where J-J is-- this is our life and-He makes me happy." (Pg7)
Rachel	•	"And, you know, I feel a bit, I don't know, embarrassed, I guess, to think that I wanted to make everything okay because everything is okay, you know, we're just living. We're just having a different parenting experience to what other people are having." (Pg19)
	•	"You just- you-you-you should be happy with your--with your lot, and I think that's how I-I've sort of taken things a lot with L you know. It's autism, yeah, it's-it's a life-long disability--but we can make that the best as possible and, you know, its'-it's not horrendous. You know, it's not the worst thing. And I did feel like it was the worst thing in the world. But it- it really isn't, you know? And he's still L, he's still the amazing little boy we've always had. (Pg37)
Deb	•	"And-and-and so I think I just started to change-change my life, really. Um, and it just took a lo-- it just took a lot of time-- and I think once I-- I think it took me to accept the children-- and autism--before I could get over it--to be honest." (Pg17)
	•	"It's definitely a journey, um, and yeah I think- I think it's just the acceptance I think really helps… Yeah, my acceptance." (Pg32)
	•	"I just want them to be accepted by everybody, um, for who they are because I think that's whe-where I am now. I've accepted them for who they are. I know I want them-- I-I hate the thought of-of them feeling like they're different." (Pg33)

This subordinate theme highlights parents' acknowledgement of the permanency of their child's autism and their acceptance of this. It highlighted a process of sense-making that the parents navigate to reach a point of acceptance of their child's autism and the perceived changes to their own life.

Parents' expressed a move towards viewing autism differently to how they had previously. For example, Rachel alluded to once feeling that having a child diagnosed with autism was "the worst thing in the world" (Pg 37) but after a period of sense-making shifted to a view that it was "just a different experience" (Pg 19).

Parents also indicated that this transition was influenced by the passing of time, the development of skills (parent and child), and opportunities to make sense of the new experiences.

Rhodri alluded to the role of comparison within his shift to acceptance. For example, he shared that he found himself looking to parents of children with severe autism to demonstrate how "lucky" (Pg 1) they were to have a child whose autism presented lesser challenge. Comparison was viewed as a sense-making strategy which has the potential to influence hopes and aspirations for the future; "He'll be okay", "We're in a better position" (Rhodri, Pg 8).

For parents who had children whose autism had greater symptom severity, their transition to acceptance took the form of acknowledgement of their child's positive attributes; for example, "He makes me happy", "He's my happy place" (Tiffany, Pg 3), "He is the most loving child" (Rachel, Pg 2), "He's so easy going", and "he's a wonderful little boy" (Deb, Pg 2). They also spoke about "being happy with your lot" (Rachel, Pg 37) and "flipping it on its head" (Rachel, Pg 4) meaning that parents were reframing the perceived challenges to being to view positive nature of the situation. This was viewed as post-traumatic growth (Zhang et al., 2015) following a period of experiencing grief associated with the unexpected and ambiguous situation.

4.4.2 Subordinate theme: Seeking new skills & new situations

Participant	Quotations
Andrew	• "There's a, you know, there's something affecting him in the moment that I need to work out, to help him not be moody or be crying. Umm, and may be, you know, settle my patience down and (pause) and help more, find a way of helping him-- and becoming a detective, more than just this typical throw away 'Oh he's just crying', he's probably crying for a reason. "" (Pg5) • "-diagnosis, sort of, came along and then I started to research and look in to autism and-and-and his version of autism and the severity of his autism-" (Pg15) • "With any parent it's difficult to be able to drop everything and just do what you want to do, but with children with additional needs it's even harder again to not have any babysitter--on speed dial or any family member on speed dial to just go 'Come and look after the kids' while I go out and have drinks with a friend, or go out to a party--you know, you don't have that ability full stop. So (pause), I've probably taken that part of my life and translated it into something like gaming-" (Pg21 & 22)
Rhodri	• "We used to go out to the park, we'd go for walks, through like, P woods (local wooded area). But you can't walk-" (Pg5) • "So I've got to use the car to pick him up at night and I like walking." (Pg26) • "I-I-I like I said, I like going for walks, don't we? We like going everywhere? - when he's at school." (Pg27) • "I don't think it really makes me angry anymore. R, I just let him get on with it, like he's um, having one of his moments where he just something he wants he can't have." (Pg19)
Tiffany	• "I'm not an expert on his triggers yet, but again, I-I-- It's just a learning progress every day." (Pg2) • "So, like I said, I think it's just learning or recognising that I am my own worst enemy when I live in my head." (Pg26) • "And I just find that [Zumba] helps relieve a lot of stress." (Pg26)
Rachel	• "He is always, like, the rough and tumble, the squeeze and the, um-- Yeah, that sort of thing, but I would take him into, like, outdoor play group, so I'd source places where I thought, "Right, well, he likes to be outside, um, the freedom, let's do that."" (Pg16) • "So, my job now is-is, sort of, completely rethinking the way I think and-and teaching him, "Well, you know, this might not make sense, but--this is what we do."" (Pg18)
Deb	• "Um, I think-- We-we've put a lot of measures in for H. Um, in terms of vis-- Everything's visual. Um, He needs to know what's being expected of him. He needs to know what's happening. He suffers really bad with anxiety. Um, so-- He needs a visual calendar. He needs social stories. He needs pecs (augmented communication system). You know, that's the way we have to communicate--with him for everything. Um, I think, you know, just going into the car. H needs to know where we're going. Because that can cause a-a huge meltdown--of-of him not knowing anything." (Pg39 & 40)

	• "I think once I've-- I-I think my-my mindset has changed in terms of, um, I would have seen that as challenging behaviour, that he's not listening, he doesn't- he's not doing what, you know, when you eat, you should sit at the table. Um, and actually, to shift my frame of mind of why is he doing that. And, you know, even with the, I guess, the hitting and kicking, instead of focusing on that-that behaviour, I'm focusing now on what's happened to cause that and how can I stop that happening again." (Pg49)

'Seeking new skills and new situations' is indicative of the parents' move from 'typical' to 'atypical' ways of supporting their child, which was facilitated by the gathering of information and the seeking of situations which aligned with their atypical journey.

Parents alluded to the ongoing process of their learning about autism, due to the changeable nature of their child's needs. They sought information about the aetiology of their child's condition, strategies to support, and information about professionals, agencies and charities who could offer advice and support. Learning was viewed as a mechanism for shifting the perception of the parent role and the execution of strategies (e.g. remaining calm when my child is showing externalising behaviours).

This theme also indicated that parents were learning about themselves within the context of the new situation, i.e. the development of new personal interests or shifts in expectation about old personal interests. For example, Andrew shared that he has found new activities to meet his need to be sociable. He was once

able to go to the pub with friends but is no longer able to due to

struggles in seeking a babysitter. New activities included online chat

with fellow gamers. Rhodri highlighted that he enjoys walking, but

his son struggles with this due to hypermobile joints and demand

avoidant behaviours. Instead of ceasing this activity, Rhodri now uses

time when his son is in school to engage in a favoured activity.

Three of the mothers (Rachel, Tiffany and Julie) in study

alluded to seeking support to maintain their mental health, e.g.

counselling, spiritual therapy, and weight management.

4.4.3 Subordinate theme: Assimilation of new identity and future aspirations

Participant	Quotations
Andrew	• "But thankfully there is a little bit of social aspect to it as well, because you know like the six members of our friendship group, 'Clan' as it's called, are from different walks of life, different parts of the world, different stories--the friendship's built to such a point now where we actually met up and have gone to Germany to a games convention. We're in person together. I mean It's become such a brilliant friendship. But, it's just that I haven't had that non-autism friend for so long that I think (pause) I enjoy it. It's nice to just not have to talk about it or think about it." (Pg24)
Rhodri	• "volunteering with NAS [National Autistic Society]--And I'm looking for a career in that, so." (Pg21)
Rachel	• "It's not a great way to be because you're constantly on alert. But, you know, if I don't fight for him--I think, "Well, who else is?" You know, I have to be his voice, I have to be his-his advocate and-and there's- nobody gonna walk over him or us as a family because he will-- And he's not the best, I mean, he's not better than everyone else, but it's-it's kind of through L and I'm saying, you have to treat children with autism better, this is just not acceptable--so perhaps a bit of a-a mission-" (Pg30) • "you need to be resilient, you need to persevere. You need to be a parent warrior." (Pg65)

'Assimilation of a new identity' alluded to a transition from the 'who I used to be' to 'who I am now' and highlighted parents' drive to regain their personal identity and social identity following a period during which they perceived that they had lost their identity.

Some assimilated a new personal identity based their child's autism diagnosis. For example, Rhodri indicated that he now works for the National Autistic Society and hopes to seek a career in supporting children with additional needs. Julie, Tiffany, Rachel and Deb viewed that they had now become advocates for their child and this formed their new identity. In essence they became 'Warrior parents'.

Social identity also shifted for this group of parents. Feelings of judgement and challenges associated with externalising behaviours led to parents isolating themselves, fracturing their social identity (e.g. friendship group) and led to an assimilation of a new social identity (e.g. gaming clan, member of a parent support group).

4.4.4 Subordinate theme: Taking control

Participant	Quotations
Rhodri	• "-you want to tell people he's only five. I find, I do that as well--And they're like, "What? He's only five?"-" (Pg5) [Becoming an advocate] • "It's just maybe because like I wanted R to be comfortable with who he is-" (Pg36)
Tiffany	• "At that point, you have parents making comments, you know, "Control your child." So that's added to the stress-" (Pg20) • "Yeah, so I decided to ignore it and, obviously, I can't control how other people think. I can't control other people's opinions. I can only control how I react to it." (Pg34)
Rachel	• "Perhaps it was a really redefining the moment. Even though it [son smearing] made me feel, quite frankly, like shit. It made me really- it made me sort of re-evaluate and think, "You know what, you're not doing that bad". You know, you've-you've like 4, 5 hours already before even starting work covered in poo, you know, having to drive an hour - And it was- it was like, you know what, you're doing okay. Just, just so it's even though it brought me down, you sort of flip it around and I think it's a choice about the way you think about things as well." (Pg29) • "I think you, um, I've adapted, I've had to adapt to go. This is-this is what I do now. This is-this is my adventure." (Pg23)

'Taking control' alluded to parents need to take control of a situation which once felt out of their control (e.g. "I didn't sign up to this" to "It's a [my] choice"). Taking control took the forms of being an advocate and changing the negative views of autism held by others, making informed choice about how they support their child, controlling how they react to the judgements of others, and actively redefining their view of autism ("flipping it on its head").

5 Discussion

This thesis aimed to explore the lived experience of parents of young children (i.e. younger than 6 years old) diagnosed with autism as there is little phenomenological research relating to this. The research posits that parent experiences at this stage of a child's development may present some distinct features, possibly relating to adaptation to an unexpected parent experience and perceptions of not being equipped to manage some of the associated challenges. This section will discuss the research questions in relation to previous research, using psychological theory to propose tentative links between themes.

5.1. The Research Question

Largely, parents perceived that their experiences of being the parent of a young child diagnosed with autism was 'difficult' and this was contextualised by the experience of receiving a diagnosis, feelings of loss and a sense of ambiguity resulting in the parents seeking information, skills, situations and new identities, leading to adaptation to a 'new normal'. It is assumed that this experience is unique to this group of parents and this was alluded to within the subordinate theme 'Loss of identity', which acknowledged the unique nature of the experience of a quick succession from a pre-parent identity to a parent identity, abruptly followed by a transition to a parent-carer identity.

Parents alluded to the experience of seeking, receiving and learning from their child's diagnosis. They expressed feelings of fear, denial, frustration and illustrate the juxtaposition between the emotional experience and their drive to seek out a diagnosis. The diagnosis was viewed as a means of learning about their child's needs and reducing ambiguity relating to their child's atypical development. It was also viewed as a starting point and a transitional experience.

Parents experiences of loss related to loss of the expected child and the parent experience, loss of identity (personal and social), loss of an expected future (e.g. hopes and aspirations for themselves and their chid), and loss of control. Expectations of their child and being a parent - social constructs and norms exacerbated feelings of loss for these parents.

The ambiguous nature of autism resulted in parents searching for something tangible to pin it on, with them attributing blame to external factors such as genetics and injury following MMR vaccinations (Brown, et al. 2012). Parents also attributed blame to internal factors (i.e. those relating to themselves), such as lack of ability to bond and being a "shit parent" (Andrew, Pg 36).

"Hitting rock bottom" (Deb, Pg 8) was viewed as a catalyst for adaptation. However, parents within the cohort varied in the outcome of their adaptation. Some acknowledged that they still struggled with feelings of loss (Andrew) three years after the receipt of their child's diagnosis and others indicated that they had made an active choice to "flip it on its head" (Rachel, Pg 4)) meaning that they were creating a new life framed within 'difference' as opposed to 'difficulty'. The transcripts reflected differences amongst the perception of difficulty and the framing of being the parent of a young child diagnosed with autism. This is somewhat different from the findings of previous studies and alludes to the potential for strength-based support for this group of parents. Some parents within this study sought new skills, situations and identities and took control of the new experiences. Viewing autism through a strengths-based lens appeared to improve hopes and aspirations for the future, which is in line with the findings of Kapp et al. (2013). Kapp et al. (2013) suggest that recognition of the negative aspects of autism and endorsement of parenting practices that celebrate and ameliorate but do not eliminate autism have the potential to improve outcomes for autism families.

5.2 Previous Research

Consistent with the research, the lived experience of these parents suggests that challenges become easier to deal with over time, as parents learn to adjust to an atypical parenting role (Barker et al., 2011; Resch et al., 2012). The perception of the severity of their child's symptoms shifts as the child's increasing independence in participating in daily activities (Resch et al., 2012). Parents' increase their acceptance of their child's autism diagnosis and appreciation of his or her strengths (King et al., 2006; King et al., 2009). Finally, there is improved familiarity in navigating support systems (Resch et al., 2012).

However, in line with the individual nature of peoples' experiences and sense-making, not all participants reported acceptance and adaptation to the same degree. It was assumed by the researcher that differences in the degree of adaptation were attributed to the parent's perception of severity of autism symptomatology, and 'pile-up' of demands, as well as coping strategies. This is in line with Paynter's et al. (2013) exploration of the ABCX Model of Family Adaptation when an autism diagnosis is received.

5.3. Implications for Educational Psychology Practice

The work of EPs is often involves exploring hypotheses based on psychological knowledge (Beaver, 2011) and in this respect these findings are useful. In addition to holding knowledge about the experience of being the parent of a young child diagnosed with autism, it is important for EPs to find ways to talk about the complexity, for parents of learning that a child has a diagnosis and moving towards adaptation, and to help identify barriers to implementing support. Even where the diagnostic journey appears relatively smooth there remains a role for EPs in helping schools support parents on that journey.

6 Contribution to Knowledge

This thesis brings together many ideas reflected in the literature and places them within the context of parents' lived experiences of being a parent of a young child diagnosed with autism. This experience is viewed as distinct from parenting an older child diagnosed with autism. This group of parents experiences a quick succession from pre-parent, to parent, to parent-carer, which requires a degree of adaptation. Adaptation relies upon the parent's ability to accept that their child is developing atypically, make adjustments to expectations of parenting and their child, and seek out skills and experiences which align with the new situation.

By using IPA to analyse in-depth, personal accounts of parents' experiences, this thesis offers detailed understanding of the experiences of accessing a referral pathway and receiving a diagnosis for a child, the conflict which is experienced at this time (i.e. "diagnosis hit me like a train" and "-it helped me understand him more), the resultant feelings of loss, ambiguity and grief, for some leading to acceptance and adaption.

Furthermore, it highlights the role of reframing of autism, making use of strength-based approaches to support families to adapt to their new experiences.

7 Strengths and Limitations of the Research

A strength of the current research was the use of IPA both to produce a rich account of participants' experiences and through the associated use of semi-structured interviews to allow participants to guide data-collection rather the researcher deciding important areas for discussion. This allowed for a detailed examination of the impact of learning that your child has a diagnosis of autism on parents within the early years. However, in keeping with the principles of IPA, the research findings presented here are ideographic and cannot be generalised (Smith et al., 2009); also, analysis remains subjective (Smith, 2004).

A further limitation arose from using six participants, producing an abundance of data. Analysing the experience of six participants within a short report risks losing much of the detail and it requires a particularly attentive reader to appreciate the individuality of each participant's experience.

8 Suggestions for Future Research

The current study did not unpack the complexity of autism severity, gender of child with the diagnosis, the dyadic nature of parenting (i.e. joint contribution of two parents), which were noted by the researcher to have possibly impacted upon parents' stories. This may have added to the complexity of the lived experience and the resultant adaptation. Therefore, further research might explore these factors in closer detail for this group of parents.

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"We very much planned our life with an idyllic sense": Being a parent of a young child diagnosed with Autism

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2019

PART THREE: CRITICAL APPRAISAL

(Word Count: 5389)

1 Critical Account of Research Practitioner

1.1 Rationale for Thesis

1.1.1 Inspiration

The inspiration for this thesis developed out of personal experience – my son was diagnosed with Autism at the age of three years old and the transition from what I had expected as a new parent to the challenges and triumphs that autism presented were poles apart. For me, being the parent of a child diagnosed with autism was initially difficult. This was partly due to the perceptions and expectations that I held about being a parent and the difficulty I experienced in supporting my son's development. This was due to his lack of ability to communicate, socialise and play. However, as time passed, as I developed skills, as my son developed skills, as I became used to being a parent of a child diagnosed with autism, my perception of difficulty changed and I adapted. I began to think about what the experiences of others might be and whether they too experience difficulty followed by a period of adaptation or whether the experience of being a parent of a child diagnosed with autism was quite different for other parents.

However, it was not only personal experience guiding my research idea. Working with several families as a trainee educational psychologist (TEP) highlighted to me that the experience of being the parent of a young child diagnosed with autism was challenging and often impacted significantly on their well-being. I also noticed that although the experience

continued to be difficult for parents as time passed, the initial feelings of

loss of expectation were lessened over time. It appeared that this was for

several reasons including: parental acceptance of the condition and what

this meant for the parents' hopes and aspirations for themselves and their

child; the capacity to implement atypical parenting strategies; the child's

trajectory of development (including noticing small yet significant

milestones); and access to support from others. Of course, difficulty can be

experienced throughout the span of the parent experience. However, it

appears that the quick succession of threats to the parents' identity (i.e.

from pre-parent, to parent, to parent-carer) makes this period of time

somewhat unique.

1.1.2. Initial literature search

An initial literature search highlighted that researchers have largely

focused on parental stress for this group of parents, with factors such as the

cognitive functioning, communication deficits, and atypical behaviour of

children on the autism spectrum being highly correlated with both maternal

and paternal stress (e.g. Davis & Carter, 2008; Zaidman-Zait et al., 2017;

Ludlow, Skelly, & Rohleder, 2012). Both quantitative and qualitative

research has highlighted the impact of being a parent of a child diagnosed

with autism on parental well-being (e.g. Armstrong et al., 2005; Rieffe et al.,

2014; Mazefsky et al., 2014b; Nuske et al., 2018).

Some researchers exploring the views of this group of parents make use of phenomenological research methods. For example, Marshall & Long (2010) completed qualitative research exploring coping processes for mothers of children (aged 6-11 years) with a diagnosis of autism. This research focused on the stories of five mothers. The child's age was used as a cut-off - children enter 'middle school' (Secondary education) at age 11 years at which time it was assumed that the social demands on the mothers change dramatically, which was highlighted by two mothers during the researcher's pilot study. However, no reason was given for excluding participants with children below the age of six years. It is assumed that this may be due to a reluctance of health professionals to diagnose or label children too early (Mitchell & Holdt, 2014), thus reducing the number of children with a formal diagnosis within this age range. Research suggests that age at diagnosis within the UK tends to fall within 6.8 years (Williams et al., 2008) to 7.4 years range (Crane et al., 2016). Furthermore, Griffith et al. (2012) conducted research which explored the experiences of parents of adults diagnosed with autism, in which they reported that mothers highlighted the need to be able to support their child. Beyond this, there is little phenomenological data which captures the views of parents, and particularly those of parents of young children. According to Alase (2017), phenomenological studies, and particularly Interpretative Phenomenological Analysis (IPA) allows an approach that elicits a bonding relationship that enables the researcher to develop with their research participants. Furthermore, as a qualitative research approach, "IPA gives researchers the

best opportunity to understand the innermost deliberation of the 'lived experiences' of research participants" (p.p.9). As an approach that is participant oriented, IPA also allows the participants to express themselves and their 'lived experience' stories the way they see fit without limited distortion or judgement.

Some studies have explored the experiential phenomena of being the parent of a child diagnosed with autism and this once again has focused mostly on parents of children beyond the age of six years and adolescents (e.g. Ludlow, Skelly & Rohleder, 2012; Fontil and Petrakos, 2015; Vasileiou et al., 2017). Few have explored the earlier experiences of this group of parents (of children below the age of six years) and none, to the researcher's knowledge, view that there are distinct experiences within this period. However, one study (Paynter et al., 2018) did explore the earlier experience of being the parent of a young autistic child and viewed this period of time as distinct. This study used questionnaires and telephone interviews to gather data. It focused on the lived experiences of fathers and suggested that this group experienced elevated levels of psychological distress (stress and depression symptoms). Paynter and colleagues stated that much of their stress emanated from the challenges of raising a child diagnosed with autism, including their behaviour, pile-up of additional stressors, and the parent responses to these (e.g., using avoidance).

Following exploration of the literature, it was felt there was a gap in the field relating to the experience of being the parent of a young child diagnosed with autism.

1.1.3. Personal position

For me, as a parent, the early experience of parenting my child with autism was framed by difficulty which resulted in acute feelings about my ability to parent and my son's future. I experienced feelings of denial (e.g. "Maybe he's just a late developer") and isolation (e.g. "nobody is understanding why my son is crying"), anger (which impacted on my relationships, marital and familial), bargaining (e.g. guilt about not accessing support sooner), depression (e.g. hitting a low point, catastrophising) and acceptance (I needed support to reframe 'autism' and our future), inline with Kubler-Ross's (1969, as cited in Penzo & Harvey, 2008) Stages of Grief Model. As I began to increasingly understand my son and his needs, and as my son developed skills, the difficulty seemed to lessen. It felt like there was something distinct about my experiences of being a parent of a young child diagnosed with autism, when compared to those of parents who parent neurotypical children, but also compared to our later experience of being parent to our son.

Given my personal position, the development, delivery and analysis required careful consideration as to how to reduce any unnecessary biases. For example, the use of professional and research supervision of a reflexive kind was helpful in challenging my thinking at all stages of the research process, which is suggested as a useful strategy in developing the necessary qualities of an effective IPA researcher (Smith, Flowers and Larkin, 2009). Furthermore, we know that inevitably the data has a subjective quality, however, the iterative nature of the IPA process allows for bracketing and careful consideration of the 'part' and its relationship to the 'whole' (Smith, Flowers & Larkin, 2009). Bracketing and the use of critical friends (Yin, 2015) allowed me to be reflective and reflexive in my interpretation of the transcripts and the resultant themes, resulting in the improved reliability of my sense-making of the participants' sense-making (double hermeneutics, Smith & Osborn, 2003). It was also assumed that the iterative nature of IPA allowed for reflection and consideration of the contribution of my own experiences, as a researcher and as the parent of child diagnosed with autism, to the analysis of the data. One assumption of IPA is that we bring preconceptions to the phenomena we interpret. As researchers, we cannot know the entirety of these preconceptions and must engage in a cyclical process of reflection, reflexivity and re-engagement with the phenomenon. This increases our awareness of preconceptions and minimises their impact on our interpretations and can be achieved through an iterative process, receiving professional and research supervision of a reflexive kind, making use of a critical friend, as well as a research diary. Furthermore, Smith

(2007) alludes to the role of the hermeneutic circle and the use of

psychological theory in developing robust interpretative research:

> "-theory helped me to see more clearly what was happening in my
> research project, and my research project helped me to see more clearly
> what was going on in the theory." (p.p.11)

Some of the challenges of holding multiple roles (parent and

researcher) included portraying the views of the parents sensitively and in a

way that empowers the autism community (parents, children, young people

and adults). I was also concerned with the use of autism-related terminology

which reflected the socio-political stance (i.e. neurodiversity) held by adults

with a diagnosis of autism, whilst still being sensitive to parents' perceptions

of difficulty. For example, Kenny et al. (2016) alludes to "deep differences in

the preferences people hold regarding the terms they use to describe

autism and how to understand the relationship between that language and

the identity of 'autistic' people" (p.p.444). However, following some debate

with my supervisor, it was decided that 'diagnosed with autism' felt like the

most neutral terminology to use. Discussions relating to language use

continued as I considered the sharing of information with potential

participants. It was decided that 'difficulty' would be used tentatively and

only shared with the participant if they were framing their experience this

way. Language used by the participants was paraphrased to allow the

participant to make new connections in their thinking and to reduce

instances of me inappropriately influencing the participants responses

(Louw, Todd, & Jimarkon, 2011).

1.2. Methodological Considerations

In line with the phenomenological method used to gather data, a relativist ontology was adopted. I positioned myself within the view that a person's 'reality' is constructed inter-subjectively through the meanings and understandings developed socially and experientially. There are therefore no absolute truths, just those that are based upon knowledge gained from a context and the individuals' interpretation. Given the closeness of my experience to the topic being explored, it felt appropriate to position myself within the philosophical view that experiences are relative to differences in perception – my experience may or may not reflect that of other parents of young children diagnosed with autism. Alternative ontological perspectives were considered, including interpretivism. However, my research was not concerned with asking 'how' and 'why' questions (Kroeze, 2012), but was concerned with understanding experience and viewed this group has having distinct and individual experiences (Smith et al., 2009).

I judged that a subjectivist epistemology was most appropriate, that is, we cannot separate ourselves from what we know. I, as a researcher, am linked to the object of investigation and how I understand the world is a central part of how I understand myself, others and the world. Gergen (2015) suggests that perceptions held by participants will be influenced by the cultural and social context in which they occur. Therefore, it is assumed that the experiences shared by participants will be influenced by their

experience of engaging in a semi-structured interview and that my interpretation will be influenced by the experiences shared by the participants. This epistemological position allows for the possibility that participants' experiences may change over time and context, and highlights that no experience is objective. Once again, alternative epistemological stances were considered, including Social Constructionism. This is the notion that meanings are developed in co-ordination with others rather than separately within each individual (Leeds-Hurwitz, 2009). However, it was felt that a subjectivist epistemology was better suited to my personal position within this research.

Interpretative Phenomenological Analysis (IPA) was adopted to ensure that individual lived experiences were paramount to the research aims (Smith, Flowers, & Larkin, 2009; Smith, 2015; Gray, 2018). IPA is derived from the doctrine of hermeneutics, phenomenology and idiography (Smith et al., 2009). Phenomenology suggests that we are intertwined with our experiences which "shapes the fundamental character of our knowing about the world" (Smith et al., 2009, p.p.19). IPA implicates the role of hermeneutics (Smith et al., 2008) within robust qualitative research which suggests that participants interpret their own experiences through their accounts and the researcher interprets these accounts. This involves my sense-making or their sense-making.

The process of IPA and this research were underpinned by idiography which alludes to the value of viewing cases individually. It is suggested that this can be important as "a means of troubling our assumptions, preconceptions and theories" (Smith et al., 2009, p.30). Although viewing cases as individual stories is seen as an optimal practice within IPA, there were challenges in relation to ensuring that stories were treated as such, but also noting any convergence across stories. The conflict between convergence and divergence felt difficult to navigate at times throughout the analysis process. Time to consider each person's experiences and reflective practices reduced some of the feelings of difficulty relating to presenting information accurately and sensitively.

1.2.1. Alternative methodologies

An alternative methodology considered was thematic analysis which, like IPA, draws on phenomenology, and is suited to the epistemology of the thesis and seeks to explore lived experience (Braun & Clarke, 2006). However, thematic analysis was viewed as not having the ability to take account of the personal views of the researcher (Smith, 2010) and thus, IPA offered a greater iterative component which allowed for a process of reflection and accountability that thematic analysis did not.

1.2.2. Semi-structured interviews

As a method of data collection, interviews offer a way to understand the world from the other's point of view, in an attempt to ''unfold the meanings of their experiences, to uncover their lived world prior to scientific explanations'' (Kvale & Brinkmann, 2009, p. 1). The semi-structured interviews were used to enable parents to tell their stories and to account for their lived experience of being a parent of a young child diagnosed with autism in their own way. However, there are some challenges, particularly in relation to the sensitive and emotive topics being discussed (Dickson-Swift et al., 2007). These challenges include how best to involve parents fully in research, how to access them, the skills required during interviews and how to exit relationships that have been developed during the research study.

One of the most challenging aspects of the interview for me, and one which may have contributed to the delivery of the interview and data-gained, was the extent to which emotion was expressed by participants. It was anticipated that stories would have emotional content, but the intensity of the emotions which were expressed during the interviews was not. One interview was stopped to allow the participant time to recover from the emotion that he felt, however, the semi-structured interview continued with little adaptation. A second participant spoke about her role as a parent and highlighted thoughts of self-harm and suicide. In line with ethical

considerations, this interview although useful and insightful, required some

adaptation to the structure to allow for the delivery of support, where it was

appropriate to do so.

As a parent of a child diagnosed with autism, I empathised with the

emotion that these participants felt and found myself comforting them,

offering some normalisation of what was being expressed to me. As a

researcher, this made me concerned about the influence of my attempts at

reassurance had on the remainder of the interview. This placed me a

position of fellow parent and not a researcher. Reflective consideration of

'me as a parent' was employed to reduce the impact that this would have

on the analysis of the themes which emerged from the data.

Reflecting upon these challenges, ultimately, it was felt that given

the ontological and epistemological stance of this research, as well as the

theoretical underpinnings of IPA, semi-structured interviews were an

appropriate method of data collection. Research posits that interviews

enable dialogue between the researcher and the participant (Smith &

Osborn, 2008), acknowledging the subjective nature of its meaning.

Furthermore, participants were able to direct the discussions taking place,

whilst I was able to encourage a focus on what was of "significance to the

person" (Smith et al., 2009, p.33). The structure offers opportunities for

clarity and to maintain focus on the research question, as well as allowing

for some comparisons across the participant group.

1.3. Selection and Recruitment of Participants

1.3.1. Inclusion and exclusion criteria

The full inclusion and exclusion criteria for participants are given in Table 6.

Criteria

Mothers and fathers (biological) were recruited based on the following criteria:
• **They are parent of a young autistic child (below the age of six years)**
• **Their child had received a formal diagnosis of autistic spectrum disorder (ASD)**
• **The child did not have a diagnosed or suspected co-morbid condition that may account for some of the challenges experienced**

Table 6. Criteria for participation

1.3.1.1. Parents

Homogeneity was created through the inclusion of biological parents of young autistic children (below the age of six years) and through the exclusion of those parents whose children were beyond the age of six years, as well as parents of children who had not received a formal ASD diagnosis (Smith et al., 2009; Smith & Osborn, 2008). The criteria allowed for homogenous qualities within the group of participants.

Non-biological parents were excluded from the study due to findings in previous studies which suggest that the experience of becoming a parent for biological and non-biological parents may be different. Becoming an adoptive or step parent is less stressful than the adjustment to biological parenthood (Ceballo, Lansford, Abbey & Stewart, 2004). Thus, excluding adoptive and step parents increased homogeneity within the study.

However, homogeneity was not the only consideration when planning participant inclusion and exclusion criteria. Initially, I had considered including only mothers due to the differences that I had noticed between my experience as a mum and my husband's, as dad, i.e. The diagnosis and autism-related challenges appeared to have a far more negative impact on my well-being, compared to my husband. The perceptions which I held about the differences between mine and my husband's experience were bracketed through my review of the literature. It

appeared that processing may be different, and the experiences may be different, however, it also highlighted that 'difficulty' was perceived by both genders (e.g. Davis & Carter, 2008; Ludlow, Skelly, & Rohleder, 2012; Paynter et al., 2018).

Including both genders may have affected the study's homogeneity. However, fathers are hugely underrepresented within this field of research (Braunstein et al., 2013) and very little is known about fathers within the period of time being discussed (except for Paynter et al., 2018). They also fit the experiential definition of 'being a parent'. Therefore, it was felt that the inclusion of fathers within this thesis was useful in understanding their experiences further.

However, in hindsight I may have explored the views of mothers and fathers separately, as it has been argued that men's and women's modes of narrative telling differ (Conway, 1998, as cited in Freeman, 2007; Gergen, 1997). Mary Gergen (1997) argued that men's autobiographies tend to be linear and women's autobiographies are more complexly woven. However, the stories of Andrew and Rhodri suggested that their narratives differed based on perceived demand and perceptions of their child's autism severity. The differences appeared to not be based on gender, which is in line with research findings from Carpenter & Towers (2008), Hayes & Watson (2013) and Paynter et al. (2018). Furthermore, denial was experienced by both mothers and fathers within this study and was not unique to fathers, as

suggested by Rhodri: "-all I know is that dads are the worst for denying it" (Pg 36).

1.3.1.2. Defining 'early' experiences

Within this study, 'early' experiences are those relating to parents of young children diagnosed with autism, where the child is under six years of age. Previous phenomenological research has not considered the significance of this time period.

It is assumed that it is important to understand 'early' experiences firstly because, much of the research focuses on parents of children older than 6 years and secondly because, children are being diagnosed at a younger age (Buescher et al., 2014). Research suggests that the median age at diagnosis ranges from 6 years 8 months to 7 years 4 months of age (Williams et al., 2008, Crane et al., 2016), with Buescher et al., (2014) suggesting that only 10% of children with an ASD diagnosis are aged 0-3 years. There is widespread variation in clinical diagnostic services within the UK, resulting in initiatives such as the National Autism Plan for Children (NAP-C; 2003) and the Welsh Refreshed Autistic Spectrum Disorder Strategic Action Plan (WG, 2016) publishing recommendations around the identification, assessment, diagnosis and access to early intervention for preschool and primary school age autistic children.

Therefore, given the potential for an increase in 'early' diagnosis, exploration of parental experiences has value for those supporting parents to understand and empower them in navigating some of the difficulties explored.

1.4. Analysis of Data

One of the biggest challenges for me was analysing the volume of data. The iterative nature of the research is thorough, yet time consuming. The richness of data also meant that not every aspect of the parents' stories was included in the final analysis, which sometimes felt uncomfortable, as I viewed that much of the data had value. However, the decision was made to focus closely on the most salient aspects of the data to ensure that the research question was explored. On reflection, I could have included fewer participants and could have stopped at five interviews in order to explore more of the emerging themes. For example, I would have liked to explore the 'connection' or 'bond' theme that was highlighted by some of the participants. Some viewed that the they "struggled to bond" with their child, due to lack of understanding about their needs. Others viewed that they had a "deeper connection", one that was beyond language. However, this was subsumed within several of the themes which emerged from the data and was not analysed as a distinct theme.

In line with previous research and my personal experiences, the framing of difficulty permeated my analysis at the outset. However, as I became more familiar with the transcripts and reflected upon the themes, I began to contrast this with a strengths-based approach. This idea informed my final analysis. The superordinate theme "This is my adventure" highlights the experience of framing autism by strength, although this does not necessarily remove the experience of difficulty for this group of parents. As described in Kapp, et al. (2013), the recognition of the negative aspects of autism and endorsement of parenting practices that celebrate and ameliorate but do not eliminate autism have the potential to improve outcomes for autism families.

1.5. Other Ethical Considerations

The proposal for this thesis was written with the British Psychological Society (BPS) ethical guidelines in mind (British Psychological Society Ethics Committee, 2009) and ethical approval was obtained from the Cardiff University School of Psychology Ethics Committee. However, BPS guidelines acknowledge that ethical practice involves on-going decision-making in changing contexts.

1.5.1. Informed consent

All of the potential participants received the participant information sheet (Appendix 5) which outlined the nature of the research. This information sheet included the researcher's contact details so that a private telephone conversation could take place in which informed consent, confidentiality and maintaining anonymity could be discussed – two out of the six participants contacted the researcher to request a copy of the empirical paper once complete. All participants signed a written consent form (Appendix 4).

1.5.2. Anonymity

Anonymity was of paramount importance in writing this thesis. I had recruited via online parent support groups, some of which I am a part of. I wanted to ensure that data gathered was fully anonymised, reducing the chance of participants being identified. Any information which alluded to the identity of the participants was excluded from quotations. This occasionally influenced the choice of quotations but not so as to alter the analysis.

Use of recordings: The interviews are confidential and were transcribed and anonymised two weeks after the completion of the interview. The participants had the right to withdraw their data up until

transcription. This was verbally explained by the researcher and was clearly outlined on the consent form.

The interviews were recorded by the researcher using a Sony audio recording device, which remains protected by a unique password known only to the researcher. The application Sony Sound Organiser was used. Once transcribed, the original data was destroyed and the transcript will be kept indefinitely in accordance with Cardiff University policy.

Distress to participants: Participants were reminded that they were not required to answer all questions and were free to terminate the interview at any time. One participant needed to temporarily suspend the interview due to the emotion that they felt whilst talking about their experiences. Another participant became upset but wanted to continue the interview. In order to reassure participants that their parenting was not being questioned, participants were reminded that they volunteered and were not been targeted to participate. At the end of the interview, the researcher offered appreciation and gratitude to the participant. The introduction, interview and debrief was concluded at least ten minutes before the end of the allocated session so participants did not feel hurried and allowed time for any questions. One interview raised difficult and personal issues for the participant, the researcher shared information relating to available support and the interview schedule was altered to support the participant.

2 Contribution to Knowledge

2.1. Contribution to the Literature

This thesis has contributed to the literature by exploring a distinct period of time, unlike previous research (Ludlow et al., 2012; Zaidman-Zait et al, 2014). It focuses on the experience of being the parent of a young child (below the age of 6 years) diagnosed with autism, exploring how they experience the journey rather than what they experienced, providing a rich picture of the impact on parents. It offers a British perspective of this experience, paying consideration to the parents' internal thoughts and processes (i.e. the unspoken voice) which impact upon perceptions of difficulty and resultant adaptation. Furthermore, it offers an in-depth interpretative phenomenological analysis within the context of the UK. It is felt that this thesis is unique in taking a broad view of the experiences related to being a parent of a young child diagnosed with autism, bringing an often-neglected period of time into focus.

2.2. Contribution to Future Research

This thesis has contributed by firstly viewing this period of time as distinct and valuable. It highlights the desire to seek new skills and new experiences to align with a new, ambiguous and somewhat unexpected reality. For this group of participants, understanding their children's needs and shifts in their personal and social identity can lead to shifts in their

perceptions of difficulty. Offering a glimpse of these lived experiences allows professionals the opportunity to begin to understand some of the challenges faced by parents at this time, in order to support them effectively. However, with such a small sample, generalisability is not possible. This thesis instead, offers a starting point to begin to think about the distinct nature of this period, with further research having potential to explore the lived experiences of other members of this group, thus generating a deeper understanding of the unique nature of being the parent of a young child diagnosed with autism.

Understanding the challenges associated with receiving a diagnosis ("Diagnosis hit me like a train"), feelings of loss ("I thought I'd have a girl and we'd go shopping together"), the experience of ambiguity and self-blame ("I wanted something to pin it on") and the experience of adaptation ("This is MY adventure") offers insight to ignite interest within this distinct context with the aim of encouraging future research.

2.3. Contribution to Professional Practice

As previously stated, it is not possible to make claims of generalisability for the findings of this thesis. This is in line with the ontological and epistemological basis of this research, coupled with the theoretical bases of IPA, i.e. hermeneutics and idiography. Therefore, it is

not claimed that the experiences of this group of participants are representative of all parents of young children diagnosed with autism and that it should influence practice without careful consideration of systemic factors (e.g. Bronfenbrenner, 1979). However, as Yin (1989, cited in Smith et al., 2009) noted, a case study "is intended to demonstrate existence, not incidence" (Smith et al., 2009, p.30), and thus it is to be used as a consideration within individual cases. The data offers the opportunity for reflective practice, which Tarrant (2013) suggests can move us from the position of novice to expert. Therefore, the contribution to my own professional practice is that of developing my reflective and reflexive skills in relation to supporting parents of young children diagnosed with autism.

In the process of completing this thesis, I have reflected on aspects of my personal practice. Firstly, it has made me reflect upon how I support others to understand some of the challenges faced. Secondly, it has made me re-evaluate my personal view of 'difficulty' and how I apply this to the experiences of other parents, i.e. not all parents perceive the same level of difficulty. Finally, it has opened my thinking to the factors which lead to adaptation and how I can support families to reach this point.

My practice has been heavily influenced by the reading of research and the analysis of data. Time to reflect upon my findings and those within other research has allowed me to be far more open to the breadth and

depth of experiences of autism parents. I have shifted my thinking from a position of assuming that all early experiences are framed by some difficulty to a position where I am paying close attention to the individual experiences of the parent. Thus, reducing the chance of developing erroneous hypotheses during consultation which illustrate my own experiences.

2.3.1. Within educational psychology services

The themes derived from the data allude to the emotional experience of being the parent of a young child diagnosed with autism, feelings of loss and ambiguity leading up to, during and following the receipt of a diagnosis, as well as potential learning and adaptation that takes place. The adoption of a strength-based approaches within practice has the potential to help the parent reframe some of the perceived difficulty (Kapp et al., 2012). Identifying strengths, through endorsement of parenting practices that celebrate and ameliorate but do not eliminate autism have the potential to improve outcomes for autism families.

The need for strength-based approaches was alluded to within the theme "This is MY adventure". It highlighted parents' acceptance of a diagnosis, the development of new identities and adaptation which aligns with being the parent of a child diagnosed with autism. It is suggested that educational psychologists may wish to work with parents to facilitate

effective adaptation, considering their future aspirations (Hodgetts,

Nicholas, Zwaigenbaum & McConnell, 2013). Working in this manner may

also allow for assimilation of a new identity for the parent which is framed

by strength (Hays & Colaner, 2016).

Educational psychology services can work closely with parents and

nurseries/schools to allow them to understand research, theory and

strategy, which acknowledges the emotions experienced by parents at this

time and offers practical support for parents. Krakovich et al. (2016) found

that school-based support had a positive effect on parents' perceptions of

difficulty at this time and highlighted the role of the parent-teacher alliance.

This can be achieved through the process of consultation, the delivery of

professional supervision of a reflexive kind for nursery/school staff, and via

information sharing and training.

3. Conclusions

This thesis aimed to provide in-depth and ideographic accounts of

the lived experiences of being the parent of a young child diagnosed with

autism. It has shown that perceptions of difficulty can be varied, but that

parents go through some form of adaptation and realign their preconceived

views of parenting with their new reality. However, this presents a level of

difficulty for parents. Mechanisms, such as support to understand their

child's autism and related behaviours, seeking information and support, as well as the assimilation of a new identity, are perceived to support adaptation for parents of young children diagnosed with autism.

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Appendix 1 – Details of Electronic Literature Searches

PsycINFO, Orca and Google Scholar. Combinations of the following sets of search terms were used: Autism, Asperger's, ASD; parent, family, parenting, mother, father; coping, managing, difficulty, challenge, challenge faced; adapting, adaptation; mental health, well-being; and qualitative, quantitative, phenomenological, experience, experience of, perception, perception of, lived experience. Chosen literature was restricted to that published in English, in peer-reviewed journals, since 2008.

Search Terms	Articles
PsycINFO searches	
(autism OR ASD OR autism spectrum disorder OR autism disorder OR Asperger's) (1)	49357
(Parenting OR parent OR family OR mother OR father) (2)	459959
(Difficulty OR Challenges OR coping OR manage) (3)	592934
(1) AND (2) AND (3)	19407
(1) AND (2) AND (3) * Those which were peer reviewed and English Language	793 (4)
(Experience OR Experience of OR Perception OR Lived experience) AND (4)	286 (139 appropriate)
Orca Searches	
Autism (all forms) AND challenges AND parents AND peer reviewed *past 10 years	2251
Google Scholar searches	
1. Autism (all variations)	1, 280, 000
Autism challenges	410, 000
Autism challenges faced by parents (5)	82, 100
(5) AND 2008-2019	17, 900
2. Autism (all variations)	1,240,000
Experience	892,000
Autism Experience of parent (All variations of parent) (6)	290,000
(6) AND 2008-2019	84, 000
All searches amounted to 104 useful articles	

Appendix 2 – Semi-Structured Interview Schedule

1. Tell me a little bit about (your child who has a diagnosis of autism….…..

2. Tell me about when you first noticed signs of autism

3. Tell me about when began looking for advice/support

4. Tell about receiving the diagnosis

5. Tell me about [child] at home

6. Tell me about [child] when you're out and about

7. Tell me about [child] when he's at school/nursery

8. What would you tell someone else about parenting a child with a diagnosis of

   Autism?

   - Paraphrasing was used to reflect the participants experience
   - Questions like "Tell me more about that…" were used to help the participants spend more time thinking about their experiences

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27.05.2018

Dear……………,

I am a postgraduate student in the School of Psychology, Cardiff University undertaking a Doctorate in Educational Psychology. As a third year student I am required to undertake a thesis. I have chosen to explore the experiences of parents of young autistic children (aged under six years). I am writing to enquire whether you would be willing to share the attached information regarding this research.

Under the supervision of Dr Ian Smillie, course tutor, this research will explore experiences of parents of children diagnosed as being on the autism spectrum, under the age of six years. In order to do this, I will ask participants to take part in an interview, which will be arranged at their convenience. The interview should take no longer than 90 minutes.

Participation in this study is entirely voluntary and participants can withdraw at any time without giving a reason. A risk assessment of the study has suggested there are minimal potential risks involved in participation. Before, during and after the study, participants will be free to discuss any concerns about this research with Claire Prosser, or with her supervisor Ian Smillie, at Cardiff University.

All data resulting from the study will be kept confidentially and will not be accessible by anyone other than the researcher. Data will be anonymised and as such will not be traceable to any individual.

This research will be conducted using open questions through individual semi-structured interviews which will last up to ninety minutes with a minimum of five parents of young children on the autism spectrum. Once your consent has been granted, I would ask that you distribute the participant information sheet so that potential volunteer participants can be informed about the research and make contact with myself.

All of the participating parents will have the project carefully explained to them including the rationale, recording of the interview, confidentiality, anonymity and the transcription process, the right to not answer a question and withdrawing of her data. Participants will also be made aware that findings may be published or presented at conferences, but only in the anonymised state.

The volunteering parents will be asked for their consent and will be chosen at random to be participants; this process will also be explained.

Furthermore, the confidentiality and anonymity of the participants that take part in this research is assured, no one will be identified within the write up or in any work that may follow from this research. This research is conducted with the appropriate ethical approval and is supervised by a member of the university doctorate course. Thank you for your consideration of this project. Please let me know if you require further information. Furthermore, if you wish to discuss this research with the ethics committee the contact email ispsychethics@cardiff.ac.uk.

Regards,
Claire Prosser
Educational Psychologist in Training
JonesCL6@cardiff.ac.uk

Claire Prosser	Ian Smillie
Postgraduate Student	Tutor
School of Psychology	School of Psychology
Cardiff University	Cardiff University
Centre for Human Developmental Science (CUCHDS)	Centre for Human Developmental Science (CUCHDS)
Park Place	Park Place
Cardiff	Cardiff
CF10 3AT	CF10 3AT
Tel: 07815790416	Tel: 029 20875474
Email: JonesCL6@cardiff.ac.uk	Email: Smillie@Cardiff.ac.uk

Appendix 4 – Consent Form (Gatekeeper)

Consent Form

-I give permission for the trainee educational psychologist to speak with members of this NAS branch.

-I understand that this research will involve individual interviews with parents of young children on the autism spectrum in relation to experiences of parenting.

-I understand that participation is voluntary.

-I understand that information will be confidential and held securely up until it is transcribed, at which point it will be anonymised.

-I understand that the information collected will be used to write a report for the university and may be used for publication purpose, but only in an anonymous form, from which no individual or area in Wales can be identified.

I...consent to participate (name)

Signature...

Date...

Participant information letter

Thank you in advance for your possible interest in this research. My name is Claire Prosser and I am a third year trainee on the doctorate in educational psychology at Cardiff University. A course requirement is that I undertake a thesis. I have chosen to explore the experiences of parents of young children on the autism spectrum (aged under six years). I am writing to enquire whether you would be willing to take part in this project.

If you are interested in taking part in this research you will be required to contact the researcher, during which time you will be able ask questions relating to the research and participation.

Prior to the commencement of the interview the researcher will share the information sheet once more and obtain written consent from you. The interviews will be conducted in English so participants will need to agree to this.

This research will involve asking open questions through an individual interview. The questions are designed to gain insight into your ideas and experiences around parenting your child. Clearly there are no right or wrong answers and this research is not concerned with assessing individuals but rather understanding their experiences. You will have the right not to answer any questions. You can withdraw from the interview process at any time. The interview will last a maximum of ninety minutes which will include time for a debrief.

The interview will be confidential and you will have the right to withdraw your data up until the point of transcription (a maximum of two weeks from the date of the interview) after that the data will have been anonymised and cannot be withdrawn. The results of the research will be made available to you in the form of a summary sheet. The researcher would also be contactable to discuss the outcome of the research. The researcher appreciates your time in considering whether you might like to be a possible participant. Participation is completely voluntary and participants will be selected randomly so it is possible that you might not be selected.

Some of the benefits of this research include gaining an understanding of some of the experiences of parents following their child's diagnosis, and for parents of young children, in particular. Constraints of this research include, an inability to generalise the data to other groups of parents (e.g. parents of adolescents on the autism spectrum) and, due to the emotive nature of the topic, participants may opt out which could prevent a deeper understanding of parental perceptions. Although the data gathered during this study will inform the researcher's future practice, participation will not necessarily lead to service changes, but is primarily a training procedure for the researcher.

If you feel that would like to be considered as a participant or require further information please contact me using the information below. You may also like to contact the

professional university supervisor involved with this research and/or the ethics committee. The contact information for each is also listed.

Claire Prosser: JonesCL6@cardiff.ac.uk **or 07815790416**

Ian Smillie: Smillie@Cardiff.ac.uk or 029 20875474

The Ethics Committee: psychethics@cardiff.ac.uk

The data controller is Cardiff University and the Data Protection Officer is Matt Cooper CooperM1@cardiff.ac.uk . The lawful basis for the processing of the data you provide is consent.

N.B: If you email personal information please be aware the email addresses are not secure

Appendix 6 – Consent Form (Participant)

Participant consent Form

The aim of this research is to explore the experiences of parents of young children on the autism spectrum. You have been asked to participate in this research as you are a parent of an autistic child under the age of six years. There are no direct or instant benefits to you from taking part in the study. However, gathering an understanding of the experiences of caring for a child who has been diagnosed with autism is hugely beneficial to the professionals who support them.   There are no foreseen risks from participating in the research.

If you do consent to participate:

I understand that my participation:

- Involves completing an interview with the researcher.
- Will take a maximum of ninety minutes.

I understand that:

- My participation is voluntary;
- I do not need to answer any questions that make me feel uncomfortable;
- I can withdraw at any time from the interview without giving a reason;
- I am free to ask any questions;
- I am not being asked to comment on any named others but may choose to use examples from my own experiences in order to answer the researcher's questions.
- The information I give is held in strict confidence and all data will be made anonymous;
- I can withdraw my data to the point of anonymity (two weeks from the date of the interview);
- That the interview will be audio recorded for purpose of transcribing the interview. Once the interview has been transcribed (up to two weeks after the interview date), the recording will be destroyed and the anonymous transcript will be kept indefinitely, in accordance with the policy of Cardiff University;
- The recording tapes will be kept, encrypted and only accessible to the researcher (Claire Prosser).
- The interviews will be conducted in English – If I wish to take part I will need to agree to this.

If issues arise during or following the interview, a participant can seek support from one of the following:

- National Autistic Society - http://www.autism.org.uk/get-involved/about-us/contact-us.aspx
- ASD Info Wales - http://www.asdinfowales.co.uk/parents-and-carers
- SNAP Cymru - http://www.snapcymru.org/
- Parent to Parent Service - 0808 800 4106
- Contact your GP

I...consent to participate (name)

Signature...   Date: ....

Appendix 7 – Example of initial noting of transcripts

Interviewer: Okay, so we'll do the formal bit. So as you're aware, we're exploring, um, experiences of parents of children, young children in particular, on the autism spectrum. Um, and, um, I suppose first I wanna ask you some some kind of background questions really. Um, so, um, it's R, isn't it?

R's Dad: Yep.

Interviewer: Um, is it EU, or UE?

R's Dad: Uh, EU.

Interviewer: Um, and how old is R?

R's Dad: He is five years old.

Interviewer: And when was he diagnosed?

R's Dad: I think it was when he was around two.

Interviewer: Two?

R's Dad: Yeah.

Interviewer: Okay.

R's Dad: Quite lucky well, I think.

Interviewer: Yeah?

R's Dad: Two. Yeah.

Interviewer: Okay.

R's Dad: It's, you know what I mean by lucky, know what I mean?

Interviewer: No I know what you mean that early, an early diagnosis.

R's Dad: It was called early and–

Interviewer: Yeah. Um, and then, um, what else do I need from you? Um, has he got any siblings who also have a diagnosis?

R's Dad: Um, no as of yet.

Interviewer: Okay.

R's Dad: But some are we, um, we did the uh, um, there was a test.

Interviewer: Okay.

R's Dad: Um, I cant remember what she did but apparently being back there's no signs yet–

Interviewer: Okay. Okay.

R's Dad: - so it's something like that.

Interviewer: Okay so like monitoring process, or?

R's Dad: Kind of, yeah. So, um, no way of assuming, 'cause apparently girls hide it better.

Interviewer: Yeah, girls tend to mask, don't they? Okay. So it's something that's just under observation. Okay. That's fine. And what else, um, where did you hear about this research? What- where did you see the post?

R's Dad: R (wife) told me.

Interviewer: Okay.

R's Dad: Yeah.

Interviewer: And where did you see it, R (wife)? Was it on- on the NAS (National Autistic Society Facebook page)?

R (wife): Yes.

R's Dad: I just scan them I do see, some of them, like if my name's tagged in I will look because–

Interviewer: Yeah, yeah, yeah. Yeah.

R's Dad: - obviously it's something to do with you.

Interviewer: I mean interestingly I think that is something about possibly– I think mum's may be engaged in some of the groups a bit more than dads do. Yeah, yeah.

R's Dad: Mm.

Interviewer: Um, okay, um, thank you that's amazing, and even in a Costa cup!

R's Dad: [chuckles]

Interviewer: Um, and then just- obviously I know this, but just for the purposes of the recording, what's your relationship to R?

R's Dad: I'm his dad.

Interviewer: Biological dad?

R's Dad: Yeah.

Interviewer: Okay, that's amazing. So okay then, so let's start off with, um, can you just tell me a little bit about R?

R's Dad: Um, let me see what can I say about him - He's really busy.

Interviewer: Okay.

R's Dad: Talks a lot.

Interviewer: Okay.

R's Dad: But- it's fine, like he talks a lot about something he, like the things he's doing.

Interviewer: Yeah.

R's Dad: - it's like he'll play, he's obsessed with the game Roblox you know?

Interviewer: Right, okay.

R's Dad: And we're trying to limit that, and if you limit it then, yeah, he's like, "No, I wanna play."

Claire Prosser
Behaviour - obsessive

R's Dad: He won't— he doesn't want to go out, he'd rather just stay in. He won't— he used to love going out to like, walks. We used to go out to the park, we'd go for walks, through like, P woods (local wooded area). But you can't walk, basically he'll get to the top of the steps, walk a bit down the road and he'll say his legs are hurting him.

Interviewer: Yeah.

R's Dad: So, you know, we'll carry him. But we were thinking he's um, hyper is it? Hypermobility because he's always complaining about aches-

Interviewer: Okay.

R's Dad: -in his legs and his arms.

Interviewer: Okay.

R's Dad: Yeah, and he's a big boy so trying to carry him-

Interviewer: Yeah, it's difficult.

R's Dad: Yeah, and that's one thing he struggles with. And I wish he was more, a bit more sociable, I wish he had more friends isn't it?

Interviewer: Okay.

R's Dad: And he was, he's usually friendly with all the people. Kids his own age even, it's weird, it's like they're, babyish to him aren't they?

Interviewer: Yeah.

R's Dad: Like the way he talks, it's like, none of the kids his own age talk, and then like wow, we're different.

Interviewer: Yeah, different.

R's Dad: And you want to tell people he's only five, I find, I do that as well-

Interviewer: Mm-hmm.

R's Dad: And they're like, "What? He's only five?"

Interviewer: Mm-hmm.

R's Dad: I'm like, "Yeah." 'Cause-

Interviewer: Yeah.

R's Dad: Because he's tall and talks really ahead of his time.

Interviewer: Yeah, yeah, yeah.

R's Dad: Kind of a little overwhelmed.

Interviewer: Okay. Tell me more about that, tell me about being overwhelmed.

R's Dad: Like, because I have, like any situations he just cries, I mean he breaks down.

R (wife): He can't go to town or something.

5

Claire Prosser
Finding new ways of being a family
Hurdles to overcome - walking

Claire Prosser
Hypermobility is a comorbid condition with autism – sensory sensitivity?

Claire Prosser
Challenge and adaption as he gets bigger

Claire Prosser
Wishes for son or for family/dad?

Claire Prosser
Helping others to understand
People's perception of R

Claire Prosser
Managing and supporting his son when isn't coping

R's Dad: Oh yeah, he can't go to town with me, he's crazy in a shop. He will not go shopping either, it's too much for him. And you've-you've had 'him in the trolley—

Interviewer: Mm-hmm.

R's Dad: -That'll help. And then we get remarks off people-

Interviewer: Yeah.

R's Dad: -Like, the trolley's not for children.

Interviewer: Yeah.

R's Dad: And, yeah, things like that and like, because we have a blue badge-

Interviewer: Yeah.

R's Dad: -Cause where we are, um, we've had some sarky remarks, haven't we?

Interviewer: Okay.

R's Dad: Like people saying, "Oh you, is there anything wrong with your kids?"

Interviewer: Okay, yeah.

R's Dad: And then you go to tell them, obviously. That's the one thing I don't like about people's view on Autism as well. Like, sad they think a Rain Man, and they think he's gonna be repeating himself-

Interviewer: Yeah.

R's Dad: And he's gotta be rocking and—

Interviewer: Yeah, yeah, yeah.

R's Dad: Yeah.

Interviewer: And that's-and that's been difficult for you as-as his dad, would you say?

R's Dad: Yeah, yeah, I get angry about-

Interviewer: Yeah.

R's Dad: I-I-I wasn't used to it, I just let it go over my head now.

Interviewer: Yeah. So what's kind of, helped you to, kind of, allow that to just pass while they're-

Interviewer: Okay.

R's Dad: They don't mean anything.

Interviewer: Okay.

R's Dad: These people they're just people.

Interviewer: So change your perspective for you, you maybe?

R's Dad: Yeah, like, they're- if they want to be ignorant. They can't imagine what they're like in real, situations so-.

Interviewer: Yeah, so change of perspective for you?

R's Dad: Yeah.

6

Claire Prosser
Perceptions of others – R in trolley – others perceiving that it isn't age appropriate – others not understanding invisible disability

Claire Prosser
Others perceptions

Claire Prosser
Comments from others, not understanding invisible disability - difficulty

Claire Prosser
People's narrow view of autism – R not fitting people's perception of autism presentation

Claire Prosser
Change – "Let it go over my head" – adaption?

Claire Prosser
Dad gets angry when others pass comment on his son

R's Dad: He won't— he doesn't want to go out, he'd rather just stay in. He won't— he won't— he used to love going out to like, walks. We used to go out to the park, we'd go for walks, through like, P woods (local wooded area). But you can't walk, basically he'll get to the top of the steps, walk a bit down the road and he'll say his legs are hurting him.

Interviewer: Yeah.

R's Dad: So, you know, we'll carry him. But we were thinking he's um, hyper is it? Hypermobility because he's always complaining about aches—

Interviewer: Okay.

R's Dad: -in his legs and his arms.

Interviewer: Okay.

R's Dad: Yeah, and he's a big boy so trying to carry him—

Interviewer: Yeah, it's difficult.

R's Dad: Yeah, and that's one thing he struggles with. And I wish he was more, a bit more sociable, I wish he had more friends isn't it?

Interviewer: Okay.

R's Dad: And he was, he's usually friendly with all the people. Kids his own age even, it's weird, it's like they're, babyish to him aren't they?

Interviewer: Yeah.

R's Dad: Like the way he talks, it's like, none of the kids his own age talk, and then like wow. We're different.

Interviewer: Yeah, different.

R's Dad: And you want to tell people he's only, five, I find, I do that as well—

Interviewer: Mm-hmm.

R's Dad: And they're like, "What? He's only five?"

Interviewer: Mm-hmm.

R's Dad: I'm like, "Yeah." 'Cause—

Interviewer: Yeah.

R's Dad: Because he's tall and talks really, ahead of his time.

Interviewer: Yeah, yeah, yeah.

R's Dad: Kind of a little overwhelmed.

Interviewer: Okay. Tell me more about that, tell me about being overwhelmed.

R's Dad: Like, because I have, like any situations he just cries, I mean he breaks down.

R (wife): He can't go to town or something.

Claire Prosser
Finding new ways of being a family
Hurdles to overcome – walking

Claire Prosser
Hypermobility is a comorbid condition with autism – sensory sensitivity?

Claire Prosser
Challenge and adaption as he gets bigger

Claire Prosser
Wishes for son or for family/dad?

Claire Prosser
Helping others to understand
People's perception of R

Claire Prosser
Managing and supporting his son when isn't coping

R's Dad: Oh yeah, he can't go to town with me, he's crazy in a shop. He will not go shopping either, it's too much for him. And you've-you've had 'him in the trolley—

Interviewer: Mm-hmm.

R's Dad: -That'll help. And then we get remarks off people—

Interviewer: Yeah.

R's Dad: -Like, the trolley's not for children.

Interviewer: Yeah.

R's Dad: and, yeah, things like that and like, because we have a blue badge—

Interviewer: Yeah.

R's Dad: -Cause where we are, um, we've had some snidey remarks, haven't we?

Interviewer: Okay.

R's Dad: Like people saying, "Oh you, is there anything wrong with your kids?"

Interviewer: Okay, yeah.

R's Dad: And then you go to tell them, obviously. That's the one thing I don't like about people's view on Autism as well. Like, sad they think a Rain Man, and they think he's gotta be repeating himself—

Interviewer: Yeah.

R's Dad: And he's gotta be rocking and—

Interviewer: Yeah, yeah, yeah.

R's Dad: Yeah.

Interviewer: And that's-and that's been difficult for you as-as his dad, would you say?

R's Dad: Yeah, yeah, I get angry about—

Interviewer: Yeah.

R's Dad: I-I-I wasn't used to it, I just let it go over my head now.

Interviewer: Yeah. So what's kind of, helped you to, kind of, allow that to just pass while they're—

R's Dad: They don't mean anything.

Interviewer: Okay.

R's Dad: These people they're just people.

Interviewer: So change your perspective for you, you maybe?

R's Dad: Yeah, like, they're- if they want to be ignorant. They can't imagine what they're like in real, situations so-.

Interviewer: Yeah, so change of perspective for you?

R's Dad: Yeah.

Claire Prosser
Perceptions of others – R in trolley - others perceiving that can't see appropriate – others not understanding invisible disability

Claire Prosser
Others perceptions

Claire Prosser
Comments from others, not understanding invisible disability – difficulty

Claire Prosser
People's narrow view of autism – R not fitting people's perception of autism presentation

Claire Prosser
Did gets angry when others pass comment on his son

Claire Prosser
Change – "Let it go over my head" – adaption?

Interviewer: About them?

R's Dad: Yeah that's it.

Interviewer: So let's kind of, shift to then thinking about particular moments in time. We'll do it a bit like a timeline, really, kind of, start off with the early days and progress up if that's okay. And, so tell me about when you first noticed R's differences.

R's Dad: It was R (wife) first, I thought R (wife) was just looking for it, because I thought she was just- - I was just denying, I was like, "You're just looking for the signs," I thought that's because the way he was lining up cars and stuff, I just thought that was being a boy. Um, but, yeah, and signs on the, was it-- road signs and stuff--

R (wife): Road signs yeah. And-

R's Dad: Obsessed, yeah with number plates, oh my God, remember that? He'd want to read every number plate and he'd remember them.

Interviewer: Mm-hmm.

R's Dad: He'd come up just say it, wow. He knew, his uncle's as well, he always knew his uncle's number plate. Then he'd count, um, yeah and it was things like that. And then obviously--

R (wife): Also buses he'd see.

R's Dad: Buses, as well, and the purple bendy bus -- that was his first words.

R (wife): And his first words, sentence was, "I want to go on to the 20 bus with you."

R's Dad: Cause he stopped talking didn't he?

R (wife): Yeah.

R's Dad: That's what it was, he talked, he said a few words and then he stopped. He mumbled and, yeah--

R (wife): It got to be grunting.

R's Dad: Ahh the grunting wasn't it, when he was eating he'd grunt a lot and then "nmn-mm."

Interviewer: Okay.

R (wife): And he spoke, when he spoke it was in a really low-- like the cookie monster.

Interviewer: Okay.

R's Dad: Yeah, he had the really like, low voice.

Interviewer: Yeah.

R's Dad: Yeah, like he was trying to find his right pitch, wasn't he.

Interviewer: Okay-- aw, bless him.

R's Dad: But yeah, I was in denial at first.

Interviewer: Okay, so when did you start, kind of, seeing-- when did you-when did it become real for you?

7

Claire Prosser — Disagreement between Dad and mum -- why?

Claire Prosser — Did not agree about R's differences -- why?

Claire Prosser — Did not agree with mum's concerns

Claire Prosser — Difficult time?

Claire Prosser — Stopped talking -- regression -- perceived as difficult?

Claire Prosser — Dad in denial when signs first noticed by mum

---

R's Dad: Um, probably after, I'd probably say after the assessment was given, the um, diagnosis.

R (wife): Diagnosis, yeah.

Interviewer: Okay.

R's Dad: Literally, then.

Interviewer: Okay.

R's Dad: Like when it was-- when professionals saw it.

Interviewer: Okay.

R's Dad: Um, yes, from then, I think.

Interviewer: What was the difference for you, kind of, at that moment? Some, a professional, kind of, sharing that information. What was the change for you? What did that feel like?

R's Dad: I felt like it was my fault, first. Um like, I just felt awful for R, like, he's gonna struggle through his life with it.

Interviewer: Mm.

R's Dad: and-- But now he's got it, hopefully he'll get all the help he needs.

Interviewer: Mm.

R's Dad: Like I know there, my brother. My brother got diagnosed when he was, like, well, 14, 15, so he struggles through life with it.

Interviewer: Okay.

R's Dad: My younger brother has got asperger's.

Interviewer: Okay.

R's Dad: Um, yeah, and he struggles with that, I just didn't want R to have the same situation so.

Interviewer: Yeah.

R's Dad: That's, kind of, why I accepted it as well, like, okay he's autistic it's fine.

Interviewer: Yeah.

R's Dad: And, like, I know you're not supposed to compare, but I used to, like, at-at least he's not, like, a low functioning child. He's high functioning, which is good, but at least he's not, like, we don't have to help him every day, every minute. I mean, like, we do at home. It's going to have to be different, but I'm hoping that he can have his own independence.

Interviewer: Yeah, yeah.

R's Dad: It sounds awful saying that, but yeah.

Interviewer: It's thinking about kind of the hopes that are [crosstalk]

R's Dad: Basically, yeah. Yeah, I feel like, yeah, he's been diagnosed with it, but I could-- It could be worse. His diagnoses could've been worse. Like, he might've been-- He may not have been able to use the toilet.

Interviewer: Yeah.

8

Claire Prosser — Categorical data shifting thinking -- how? Why?

Claire Prosser — Distinct and definite shift in that moment?

Claire Prosser — Reliance on knowledge of professionals to shift thinking -- no moving away from an expert opinion?

Claire Prosser — Blaming himself -- why?

Claire Prosser — Life time of struggle -- difficult situation

Claire Prosser — Reliance on others for support -- control within family Hope, but some uncertainty

Claire Prosser — Previous experience of autism -- experience of struggle -- shaping thinking around his son

Claire Prosser — Previous experience helpful -- "he's autistic -- it's fine"

Claire Prosser — Comparison with other children helped adjustment for Dad No need for help every day -- care role -- some independence

Claire Prosser — Some feelings of uncomfortableness re: comparison with other/ more 'sever' children

Claire Prosser — Care (toileting), speech, bright -- perceptions of son's ability to be independent

R's Dad: He might not never have been able to talk, but I think he's doing awesome. As I said, he's not doing very well socially, so-so what?

Interviewer: Okay.

R's Dad: He'll get it one day.

Interviewer: Yeah.

R's Dad: And if he doesn't, he doesn't.

Interviewer: Yeah. Okay, so then, um, so do you, kind of, now that you've got that diagnose, you've got that information, you kind of- Would you- Would you say you've accepted it? Would you-?

R's Dad: Yeah.

Interviewer: Yeah?

R's Dad: Yeah. I-I volunteer with the NAS now and-

Interviewer: Okay.

R's Dad: It's nice to be around that. Like I said, we joined those groups because it's nice to be around other people who are in the same- In our situation that who are understanding. Yeah.

Interviewer: Yeah.

R's Dad: Um, it's, like, it's nice to talk to other people who have the same, who have trouble with autism, because you always have, like, uh, you always have similar things to talk about, you know, as well?

R (wife): They're all like, "Are you tired, yeah?"

R's Dad: Yeah, as I said the same thing. There's other parents who said, "Yes, my kid does the same, he's obsessed."

Interviewer: Yeah.

R's Dad: But it's nice to talk to other people about them, how to get support.

R (wife): You don't worry about them being called weird or-

R's Dad: Yeah, because you're just with people who other people.

R (wife): Instead of, you're just with people who are nice.

Interviewer: Yeah. So, sounds to me, kind of some-is there something I'm not-you know-you as R's dad, do you-do you like that sense of community that you- That you-

R's Dad: Yeah.

Interviewer: Yeah? Tell me more about that? What does it- What does it give you?

R's Dad: As I said, it's just-it's just nice to be able to talk to other parents with, like, they've got autistic children and it's nice that R will have somewhere to go and he does have some violent outbursts. He can be angry, can't he?

9

Claire Prosser
Social engagement viewed as a lesser concern than ability to talk and self-care, independence

Claire Prosser
Hope for progress

Claire Prosser
Sitting with feelings of uncertainty

Claire Prosser
Finding a social group – support

Claire Prosser
Understanding of others is important

Claire Prosser
Relatability with others – new social group – adaption

Claire Prosser
Sharing experiences – normalisation of challenge
Social norms for this group

Claire Prosser
Social norms within this group – normalisation

Claire Prosser
Knowledge of others – support

Claire Prosser
Concerns about the perceptions of others

Claire Prosser
Safe and understanding environment – challenging behaviour/meltdown

---

R (wife): It's nice for you, as a dad to do be able to do do stuff with him that as it to foster some relationships. Going swimming and going away travelling, and not having to worry about again what other people are going to say.

R's Dad: Or he's bumped into another kid and then-

R (wife): And having to explain. They're not always understanding.

R's Dad: And then when you say they've got autism, they always seem to be patronizing.

Interviewer: Okay.

R's Dad: You're like, "Oh, my God." I don't wanna-

Interviewer: Yeah. So then going to events that are put on by organizations like The National Autistic Society?

R's Dad: They're amazing.

Interviewer: So, tell me more about that? What does it- You know, what does that- What does that feel like for you in that situation?

R's Dad: Um.

Interviewer: Like you say, you can go to father and dad things.

R's Dad: It feels amazing, like, it's just nice to, like, I won't feel anxious about going, because if we go to say, like say, like, swimming. Swimming and stuff.

R (wife): Put it back.

R's Dad: [chuckles]

Interviewer: Pausing the tape just for a second.

[laughter]

R's Dad: Yeah, we go swimming and there's, like, loads of people there, and it's just, uh, it's not-it wasn't organized by the National Autistic Society.

Interviewer: Okay.

R's Dad: And they had, like, here this things were, like, R will point at people. He'll comment on people.

Interviewer: Okay.

R's Dad: And you've got to explain to them, "Sorry, he's autistic." Like, there was a man before who had his t-shirt on and he was, like, a big guy and is there looking at his fat belly. And like uh.

Interviewer: Yeah.

R's Dad: But he's a kid at the end of the day, as well.

Interviewer: Yeah. Yeah, of course.

R's Dad: You know, kids say it how it is as well. Yeah, it's just it's a relief if anything.

Interviewer: Okay.

10

Claire Prosser
Opportunities to develop a bond with his son in a safe and understanding environment

Claire Prosser
Avoiding the negatively perceived comments of others
Lack of understanding from others

Claire Prosser
Reduced anxiety for dad at autism events

Claire Prosser
Grateful for support of NAS

Claire Prosser
Normalisation of R's behaviours – seeking some semblance of normality?

Claire Prosser
Relief from having to respond to and scaffold R's social needs

Appendix 8 – Example of Theme Grid (Iteration1)

Participant 2 – "Rhodri"

Emergent Themes	Original Transcript	Exploratory Comments
Diagnosis	"I think it was when he was around two…. Quite lucky well, I think… It was called early" (Pg1)	*Language suggests he has assimilated the views of others rather than this being a construction of his own*
	"I know it's a label, but it's nice to have it because you can say, "well, you've got to-- Like, in the school, you've got to meet his needs and you've got to help him." (Pg15)	Social constructions – social learning
Child behaviours ("Obsessed" & "relentless talking")	"it's like he'll play, he's obsessed with the game Roblox you know?.... And we're trying to limit that, and if you limit it then, yeah, he's like, "No, I wanna play"….and he'll just go on, and on, and on about it… And then if he's not playing now, he'll wanna watch videos about it …. Um, yeah, he, I say- would say he's quite obsessed…" (Pg2 & 3)	*"obsession" and "relentless" suggests that it comes with challenge, as does "He'll go on, and on, and on"*
	"Very clever. His reading is amazing … Like in school, he's on what level, eight-nine? Wow he's on stage nine but, um, he's only now in- he's not even year one, is he? He's in reception… Yeah, and his maths is amazing as well like, um, what'd he say the other day? He's 42 months old. And he was right. I googled that, I had to google it. It was like, I mean like" (Pg3)	Positive attributes of son balance the "obsession" and "relentless talking"
Perceived difficulty/Comparison to other children	"But, I mean he does struggle" (Pg4)	*"Amazing" & "Wow" suggests that dad views his son as academically high achieving*
	"Yeah, and that's one thing he struggles with. And I wish he was more, a bit more sociable, I wish he had more friends…" (Pg5)	Over-compensating or genuine perception?

Appendix 9 – Example of Theme Grid (Iteration 2)

Emergent Themes	Original Transcript	Exploratory Comments
Diagnosis	"I think it was when he was around two... Quite lucky well, I think... It was called early" (Pg1) "I know it's a label, but it's nice to have it because you can say, "well, you've got to— Like, in the school, you've got to meet his needs and you've got to help him." (Pg15)	Highlighting perceived importance of "early" support for Rhodri "Quite lucky well, I think..." views himself differently to others who haven't been lucky (i.e. received an 'early' diagnosis "I know it's a label..." suggesting that Rhodri understands that others view labels negatively??? (Labelling Theory View that a diagnosis validates his needs and leads to greater support.
Child behaviours ("Obsessed" & "relentless talking")	"it's like he'll play, he's obsessed with the game Roblox you know?... And we're trying to limit that, and if you limit it then, yeah, he's like, "No, I wanna play"...and he'll just go on, and on, and on about it... And then if he's not playing now, he'll wanna watch videos about it ... Um, yeah, he, I say- would say he's quite obsessed..." (Pg2 & 3)	"obsession" and "relentless" suggests that it comes with challenge, as does "He'll go on, and on, and on" "try and limit it and then..." alludes to perceived battle between doing what's 'right' and not entering conflict with child
Perceived difficulty/Comparison to other children	"Very clever. His reading is amazing ... Like in school, he's on what level, eight-nine? Wow he's on stage nine but, um, he's only now in– he's not even year one, is he? He's in reception... Yeah, and his maths is amazing as well like, um, what'd he say the other day? He's 42 months old. And he was right. I googled that, I had to google it. It was like, I mean like" (Pg3) "But, I mean he does struggle" (Pg4)	Suggests that Rhodri views his son's strengths positively Son's development in line with or better than expected Dialectic response – sense making of strengths and needs

Colour key: Descriptive comments; Linguistic comments; Conceptual comments

Appendix 10 - Examples of Bracketing

(07.04.18) Reflections

Something within me that wants
to be the voice of parents?

- Advocating for others
- In a position to share this
  voice with others.
- Motivated
- Voicing hardship?
  - My own
  - others.

23.06.2018

Framing experience as difficult
- why?
  - This is my experience, maybe
    not experience of other parents
  - 'Difficult' Coping
                    ↑
              loaded words!

(07.07.18)

How do I navigate interviews
without influencing
  - Consider use of language
  - Paraphrase
  - Make use of exploratory
    questioning, e.g. tell me
    more about that
  - Keep exploration broad
  - Use of words should be
    tentative.

Difficult   Coping
              Mindset

Managing   Change

         adaptation   Grief

                   loss.

P1   18·07·18 · Interview

- Trying to remain impartial
- Emotional experience
    - How did this impact on me?
        - Familiar emotions
        - Careful not to collude with his experience

- Keep Q broad as possible
- Acknowledge upset.

- Influence of previous relationship w/ participant
    - Does this improve the dialogue / narrative?
    - Will he assume I know aspects of his experience / relate to it e omit from story?

    - Continue w/ exploratory Qs.
    - "Pretend you don't know me e I don't know you".

(P3)   - v. emotional experience
     - Interview schedule
       shifted to support P
     - Talk of self-harm e
       suicide
     - Impact. this had on data/
       experience
     - Was I shaping her narrative
       as a result of normalising
       some of the emotion.

?   ↑

Think about this
when analysing????

Smith, Flowers + Larkin (2009)

* IPA is concerned with the detailed examination of human lived experience

* Experience to be expressed in its own terms (no predefined category systems / life given), rather than predefined category systems

* Selective work required to facilitate the coming forth.
  - make sense of it.

* Reflective practices ; cyclical approach to brackets.

* Hermeneutic circle of the research process
  - 'Whole researchers ongoing biography
  - 'part' is encounter with new participant

IPA → (once ins record preconceptions, acknowledge precondition, more position, uncovering of experience engagement with them, facilitate attentiveness, interpret conversation; continue, started, hermeneutic circle become more

experience, bracket, research participant

Home - (cognitive) space

Double Hermeneutic
→ Researcher making sense of the participant making sense of X.

Researcher as both like + unlike participant.