"The Land of Unknown" – Mothers Waiting for their
Child's Autism Assessment

By

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PREFACE

This preface will introduce the Counselling Psychology portfolio of my Professional Doctorate, which consists of three distinct pieces of work. It includes a research project, a case study and a publishable article. These pieces of work have equipped me with practical skills and theoretical principles in developing as a Counselling Psychologist. It begins with an outline of the portfolio and I will discuss each piece of work, including a rationale for choosing this work to be included and identify themes. Finally, an overview of my clinical practice is included to reflect on the unique and important beliefs I hold within Counselling Psychology.

1.1. Outline of Thesis

The first piece of work is a qualitative study that I have conducted focussing on the experience of mothers waiting for their child's assessment of Autism. Within the literature, the existing knowledge is gathered retrospectively from parents whose children have been diagnosed at the time of the interview. The research project involves a critical literature review demonstrating theoretical knowledge and understanding of relevant literature.

The next piece is the methodology of the research. I explained the chosen paradigm and philosophical underpinnings of the study, from the theories from Husserl and Heidegger. I explore how these fit with the research design, chosen method and personal and methodological reflexivity. Ethical considerations are explored, along with participant recruitment, exclusion criteria and data collection and analysis.

In the third section, I introduce the three major themes that emerged from the data which were: (1) Developing an understanding of the child, (2) The suffering parent, (3) Focusing on the future. Within the research project, there is a sense of desperation and sadness about being stuck in an experience and having very little control. The mothers were bewildered and confused about how to support their child. The findings provide a rich description on how mothers make sense of the waiting before their child's Autism assessment.

Waiting for a diagnosis has a significant impact on mothers that I feel should be considered throughout the referral to diagnosis phase. Some of these findings link to the stress of having an Autistic child and that this stress is not a result of the diagnosis. It is argued that increased awareness of the parent experience will help clinicians consider their treatment of families while they are waiting to help build better relationships that benefit the child and the family.

The final part of the research project includes a discussion of the theoretical insights and integration of relevant literature, implications for clinical practice, an evaluation of the research, the relevance to counselling psychology, and conclusions from the research overall.

1.2. Client Study/Process Report

The second part of the portfolio includes a case study which is a written summary of the key aspects of a counselling session between me and a client who was suffering with depression, anxiety and grief. The therapeutic model used with the client was Narrative therapy, with a focus on re-establishing the connection with herself and her identity.

I demonstrate my ability to select and apply a specific theoretical model, illustrating several core theoretical principles. I discuss a systemic perspective, paying particular attention to the systems around my client, since these influenced the stories which she gravitated towards to make sense of her experiences.

Next, I give a clear and coherent account of my clinical skills and reflect upon personal and professional self-awareness. The introduction consists of the presenting complaints, history and the client's reasons for approaching therapy. I explained the progression of therapy over the course of the treatment and identify difficulties that arose in the therapeutic relationship and how these were resolved. The use of appropriate supervision is discussed together with what I have learnt overall. I chose this client study to form part of the portfolio because it gives a real sense of some of the difficulties that face individuals in the study and how they identify as parents, especially though loss.

Identity, within the context of the influence of the environment, evolved as a central theme within the case study. The client began to recognise and form connections with herself; her past, significant experience and people in her life. From this, her confidence grew and her ability to articulate her perception of herself allowed her to share her reflections with others and build a deeper understanding of who she was. Moving forward the patient here was able to identify who she was alone and who she was in the context of relationships. She accepted a new narrative that drew her back to her identity after the trauma of losing her husband. She experienced similar feelings to the research participants in feeling stuck in her grief, letting go of a future that she had hoped for and

adapting to a new way of living, whilst still holding uncertainty about what this might look like.

The rationale for including this piece of work within the portfolio is to demonstrate the consistent themes running through my own research and therapeutic work. It examines the theme of identity and its presence in the research and my therapy and concludes how both pieces of work can contribute to the understanding of identity.

The process report highlights a particular aspect of the therapy, where the client and I were thickening the client's story about herself. Since the death of her husband seven years prior to seeking bereavement counselling, the client felt that she had lost her own identity and felt uncertain about who she was. The report documents part of the therapy where we began to think about where she came from, where she felt her life was now and the skills and strengths that she possessed. The thesis focused on mothers who were waiting for their child's assessment of Autism and how they made sense of the experience of waiting. One of the sub-themes found was that the mothers identified themselves as bad parents and struggled with feeling responsible for their child's mistakes and behaviours. They were uncertain about their future, possibly including their identity as a parent.

In the process report, my client's identity had changed since her husband's death. Whilst he was alive, they took part in activities as a couple and socialised with other couples in their community. Following the loss of her husband, she felt that she did not fit in with her previous social circle. She struggled to adapt to her new way of living alone and was unable to share this with other people. She felt that others expected her to "get over" the grieving of

her husband and pretended that everything was okay to her friends and family. She feared that others would judge her and so chose to disconnect emotionally and sometimes physically from others. This was similar to the experience of the mothers in my study. Many felt unable to share their concerns or their understanding of the child with others in fear that they would be seen as bad parents, which often led to a feeling of isolation and responsibility for their child. Some mothers were vigilant in recognising difficulties in advance and adjusted their behaviour to prevent their child from "failing" in social interactions. The mothers feared that expressing their concerns to professionals about the child would not be taken seriously or that they would be seen as liars, overexaggerating the child's difficulties.

The fear of being judged appeared to be influenced by cultural norms for mothers and my client in the process report. Western culture dictates that parents are responsible for their children and their children's behaviours that are socially unacceptable are due to poor parenting. In the same way for my client, the expression of emotions in Western society are expected to be concealed. Cultural influences seemed to exacerbate their difficulties with their identities and apply additional pressure in them asserting a new identity.

The struggle for my client in establishing a new identity was distressing and she attempted to manage this by disconnecting with her emotions and delaying her grieving process for seven years. For the mothers, their identity shifted to being a bad mum, unable to cope with their child, and increased their isolation. It also may decrease the advocating they are able to do for their child. I completed a piece of work in therapy with my client, allowing us to make sense of

who she was by creating an alternative story, helping her to feel more grounded

in her identity and increased her confidence in sharing this with others.

From these two pieces of work, I was able to gain a better understanding

of the impact of traumatic events on the identity of individuals and the influence

of culture. Trauma for these individuals was the loss of a significant person or the

trauma of waiting for a diagnosis to understand and support the child. It can lead

to a significant negative change in identity or loss of identity all together. There is

a strong sense of isolation associated with this change that can reinforce

unhelpful identities. Isolation reduces the access that individuals have to other

stories and explanations to make sense of their experiences. When working

therapeutically with clients under stress and pressure, it could be helpful to

understand that the difficulties with identity can impact on their mental

wellbeing, within the context of their culture.

1.3. Publishable Paper

The third piece of work will be a publishable research article which reports the

findings from my research project. The article was written for the Journal of

Counselling Psychology. My particular focus was the findings I identified as they

were both useful and interesting. I believe these will contribute to the

understanding of parents' experiences of waiting for an Autism Assessment for

their child.

2. Personal Statement

Five years ago, I started working with a mother with two Autistic sons and

built a close rapport. She spoke of struggling to cope, accept the difficulties that

her sons experienced and understand that they each had different needs. Over

time, I saw her start to understand that Autism presented in a different way in her two children and she needed to support them with different interventions. Her sons also began to change, with their needs being met, and the relationship with their mother improved. From working in the Child and Adolescent Mental Health Service (CAMHS), I have worked with young people on the Autism Spectrum. I have often perceived parents being desperate to support their child and not having the understanding. This had moved me and fuelled a desire to understand and support these parents. Working alongside these parents sparked my interest in how they experience this period of time where they do not have a label and are uncertain about their understanding of their child.

From working with families that were affected by Autism, I began to notice similar dynamics in my own family. Two members of my close family exhibited Autistic traits, which sometimes created situations that I found difficult to understand. After sharing this with my family, we noticed how acknowledging the traits influences how we acted and reacted to each other. A greater understanding of these members and the triggers for their distress led to more preparation around stressful events to create a containing environment. Reflecting on my own part in the family dynamics led me to feel ashamed and guilty for not seeing it sooner, and a sense of responsibility of missing the signs, as a mental health practitioner.   Now, I am able to appreciate the progress that we have made by understanding the needs of each other and feel that it has brought us closer together as a family. Whilst there are still conflicts, we are able to think about patterns to the distress and identify strategies to negotiate these more easily.

Being part of a family that has benefited from an understanding of Autistic traits, and supporting families and young people without this understanding, provoked my thinking about how parents make sense when waiting for their child's assessment of Autism. I have spent much of my career working to understand the young people with Autism that I work with and seeking to share in their understanding of the world in a therapeutic context. I was drawn to the parents' perspectives because I believe that they remain the experts on their own child and are a protective factor in their child's mental health. I was aware that my own experience of living with family members with Autistic traits gives me some insight and expectations. Since the Autistic traits in my family do not have a significant impact on their functioning, they would not meet criteria for a diagnosis of Autism. I expected to find that the parents in the study would find this more negative as the behaviour of their child was likely to be more extreme than my experience of Autistic traits at home. Perhaps the assumption that the experience of waiting for an assessment would be negative affected the literature searching and selection. By selecting papers that support this assumption, the literature review possibly emphasises how negative and distressing the experience of waiting is for parents. I was aware of this bias and attempted to minimise this through the study by carefully considering and reflecting on the decisions that I made about the study.

Being a woman, with the hope of having children in the future, I consider what responsibilities may come with this. This has led to me consider how developmental conditions can influence the lives of parents and the family. Whilst deciding on the focus of my research, I wondered about how I would experience having a child with additional needs and how this might change my

relationships with others? This is not a question I can answer but highlights to me how parents feel about facing challenges with their child.

As a Counselling Psychologist, I identify as working with individuals rather than working with labels. The humanistic approach of my training has promoted being a pluralistic practitioner, whereby I view all therapeutic approaches as equal. Through my training, I have valued the concept of self-actualisation (Maslow, 1954) and have built my identity of being a Counselling Psychologist as perceiving difficulties with reference to the impact that they have on an individual's potential. My experience of working with individuals on the Autism Spectrum has helped me to understand that an individual's potential is subjective and cannot be defined by others, including family members. Whilst it is important to me that this is recognised, this can also be difficult for family to understand. This can be a struggle of a parent with an Autistic child where I feel Counselling Psychology can support families.

PART A: THESIS "The Land of Unknown" – Mothers Waiting for their Child's Autism Assessment

ABSTRACT

The majority of research in this field focuses on the diagnosis of Autism and parents' satisfaction with the diagnostic process, with a relatively small contribution from pre-diagnostic experience of parents. Of the studies exploring this, many have used retrospective data (Ryan & Salisbury, 2012; Braiden, Bothwell & Duffy, 2010) leaving a limited understanding of parental experience while waiting for a diagnosis. The study aimed to explore the experiences of mothers waiting for their child's assessment of Autism and a sample of mothers with a child on the waiting list were recruited. Semi-structured interviews of 6 mothers were conducted and Interpretative Phenomenological Analysis (IPA) was used to analyse transcripts. Three master themes were highlighted; Developing an understanding of the child, The suffering parent and Focusing on the future. Other themes conveyed the importance of having a shared formulation of the child between home and school, the impact of waiting on the mothers' mental health, and feeling uncertain and stuck in their current predicament, due to the lengthy waits of Autism assessments. The study provides a deep and valuable insight into parental experiences during this stressful period, with the added complication of parenting a child with additional needs. This provides implications for how the parents cope and the knock-on effect on the family system and the child.

CHAPTER 1: LITERATURE REVIEW

1. Introduction

This study investigates how parents experience waiting for their child's assessment of Autism. Children and Adolescent Mental Health Service (CAMHS) have waiting times of up to 2 years for a child's assessment across the UK. During this time, parents have limited support for themselves and the child and without any certainty that their child will be diagnosed. The rationale for this study is to identify whether families need support during this waiting period, to avoid deterioration in the family's mental health. Understanding how parents experience this period of time would be valuable to identify how best to support them. The literature review will explain the strategy used for the literature research, further details on the context of the study, the definition of Autism and background information on parenting children with Autism. The critical examination of the research examines the experiences parenting a child with Autism, diagnosis process of Autism, having a child with Autism and the impact on parents and the pre-diagnosis experience.

1.1. Search Strategy

The literature search was conducted using online databases such as Google Scholar, Psych Info and City University library article search. "Waiting for Autism assessment", "Pre-diagnosis experience" and "Parents" and "Autism", "parents" and "impact" were used as search terms in the databases to gain background information. The terms "Autism", "ASD" and "ASC" were then added to generate the majority of papers in the review. Papers were excluded if they were not written in English or if qualitative methods were not used in the study.

Additional references and articles were found in the reference sections of articles. This allowed for the discovery of more recent articles related to this area of research.

1.2. Diagnostic Process within CAMHS

Within the setting of the present study, the process of assessing Autism is rigorous. Data is collected about the child using screening questionnaires, such as the Social Communication Questionnaire and the Children's Communication Checklist from the parents. The Children's Communication Checklist is also completed by the school to establish the consistency of the child's behaviour across different settings. Qualitative information is also obtained from parents and teachers to express their main concerns about the child. The parents complete a detailed developmental history with a clinician and the Autism Diagnostic Observation Schedule (ADOS) with the child. On occasions, school observations are carried out by an assistant psychologist. This process can take over two years due to the waiting times for this oversubscribed service. It may be important to support parents during this process, as well as after a diagnosis.

After a child is diagnosed with Autism, schools can apply for Education Health Care Plans to receive additional funding to meet the needs of the child. They can also access services in the public to make outings less stressful, for example, being able to jump queues in busy places or attend Autism friendly screenings at the cinema.

1.3. Definition of Autism

In this particular setting, the definition of Autism Spectrum Disorders (ASD) follows the criteria outlined by the International Classification of Disorders (ICD-10). According to the National Autistic Society, Autism affects around 700,000 people in the UK. ASD consists of symptoms, which are separated into three categories: deficits in social communication, social interaction and restricted and repetitive patterns of behaviour (American Psychiatric Association, 2013). Other common symptoms can be difficult to define because there can be wide ranges of ability within the Autism Spectrum, for example, intelligence.

Autism was first identified as a disorder by psychiatrist Eugene Bleuer who linked it with a subgroup of schizophrenia. Since this time, the definition has been redeveloped to describe a separate condition associated with emotional and social problems.

Much of the existing research focuses on brain imaging (Stanfield, McIntosh, Spencer, Philip, Gaur & Lawrie, 2008) to identify different structural and neurological differences in the brains of people with Autism; the outcome of different behavioural interventions to manage socially undesirable behaviour associated with Autism (Virués-Ortega, 2010; Eldevik, Hastings, Hughes, Jahr, Eikeseth & Cross, 2009; Bellini, Peters, Benner & Hopf, 2007); and further understanding of the symptoms of Autism (Uljarevic & Hamilton, 2013; Ben-Sasson, Hen, Fluss, Cermak, Engel-Yeger & Gal, 2009).

It is important to acknowledge that Autism does not just affect an individual but also the family around them, since parents can be a protective factor for their children to cope with difficulties. The literature indicates that

having a child with Autism is stressful for families (Saunders & Morgan, 1997) and how the families cope with this pressure (Tarakeshwar & Pargarment, 2001; Schaaf, Toth-Cohen, Johnson, Outten & Benevides, 2011).

Many of these studies focused on people that had been diagnosed with Autism. From my experience in working within an Autism diagnostic service for children and young people, I found that many families were struggling with life on a day-to-day basis before their child had been diagnosed.

Crane, Chester, Goddard, Henry and Hill (2016) surveyed 1047 parents who had children that had been assessed for Autism. Questionnaires were used to gather data from parents, excluding parents who were still waiting for their child's assessment. They found that parents waited for an average of 3.5 years after contacting a healthcare professional about their concerns for the child. However, most parents also waited for a year before making contact with the professionals, hence they waited for around 4.5 years for a diagnosis of Autism for their child. Parents were unsatisfied with the process of gaining a diagnosis for their child. Reduced satisfaction was found to be associated with a more lengthy diagnostic process, diagnosis of their child at a later age, a lack of information about support for the family and child, the involvement of professionals that parents perceived as unfavourable, and poor support after the diagnosis. However, this study provides limited information about the reasons that parents are dissatisfied and can only make correlational links with other factors, such as the length of wait and age of the child. Perhaps families expected the NHS to have shorter waiting times in general or felt frustration towards other services for not noticing signs of Autism in their child earlier. Therefore, it is not conclusive

that the dissatisfaction of the assessment of Autism is due to long waiting lists or their children getting older.

The findings above were consistent with those from Sansosti, Lavik and Sansosti (2012) who found that longer waiting times affected the satisfaction of the diagnostic process for Autism. Sixteen families explored their experiences through questionnaires. Longer waiting times were associated with greater dissatisfaction and the manner of contact with professionals also affected satisfaction. Families reported that they research different interventions for children with Autism and most indicated that they used strategies which were evidence-based. The sample included 16 families from a variety of social, economic and ethnic backgrounds, meaning that the results of the study may be applicable to different groups of individuals. However, the study focused on parents with children that had been diagnosed, so the results may not be generalisable to families at different stages of the diagnostic process.

Research conducted using questionnaires has given some insight into the factors that can affect parents during the diagnostic period and conveys that this is often a difficult time for parents. However, these studies cannot provide an in-depth understanding of the parents' experiences during the diagnostic process but suggests important factors that may lead to a negative experience for parents.

1.4. Experience of Parenting a child with Autism

Raising a child who is on the Autism Spectrum can be challenging for parents. Some of the problems lead to a high level of stress (Eisenhower, Baker & Blacher, 2005; Pisula, 2007) compared to parents of typically developing children. However, there are both positive and negative themes that emerge from

parenting a child with ASD, such as stress, social isolation, parents' wellbeing and marital relationships (Myers, Mackintosh & Goin-Kochel, 2005). Some of the positive aspects can include parents experiencing higher levels of life satisfaction and caring less about what other people think of their child's behaviour (Tunali & Power, 2002). Therefore, it is important to support parents with the more negative aspects of parenting children with ASD, so they can enjoy more of their experience.

Neely-Barnes, Haley, Roberts and Graff (2011) ran focus groups with parents of Autistic children. The 11 parents that participated in the study experienced blame from others for their child's behaviours in public and from extended family. However, they felt that as parents, they had a better understanding of their child than other members of their family and society and were able to identify positives in their child's Autism.

Makintosh, Myers and Goin-Kochel (2005) examined the social support that parents of children with ASD access using questionnaires. The sample included 498 parents, who reported sources that they gravitated towards for information about Autism and personal support. The parents in this study divulged that the main source of information about Autism was professionals, whilst sources of social support included other parents of children with ASD, neighbours, friends, spouses and family members. However, there was no indication as to how helpful these were to parents. Few implications can be drawn from the findings, due to the unknown effectiveness of these sources of information and support. It is one of the few studies that have contacted parents directly to gain opinions and information. Another interesting finding from the study was that parents from low income families access less support. A potential

reason for this could be the indirect financial implications. Many parenting

workshops are free of charge but costs related to travel, missing work, or

childcare could explain the lack of attendance. It raises an important implication;

that simply providing free workshops is not enough to provide low income

families with support. This could be where online support may appeal to these

families.

Fleischmann (2005) conducted an interesting study based around the

parallels between parents' narratives about coming to terms with their child being

diagnosed with ASD and the "Hero's Story". The Hero's Story consists of 6 stages;

Innocence, Call to learning, The test, Empowerment, Emergent and Celebration of

clarity. The sample included 33 self-published websites, where parents had voiced

their experiences of raising a child with ASD. The stages he found for the parents

were:

1) Innocence of the child in the first period of their life

2) Call to learning – from realisation to coping with the child's problem

3) Coping with the discovery of Autism

4) Empowerment – transitioning to the treatment of the child, learning,
   strategies of action, expectations of child and Autism

5) Emergence of personality changes in parents, coping perceptions of
   Autism, self-image and perceptions of the child

6) Celebration of clarity – helping others and overcoming helplessness

This study generated a lot of discussion around online themes of parents

of children with ASD. It provides a clear standardised adaptation process that

parents may go through following their child's diagnosis. However, the danger

with standardising the adaptation process could be that not all parents follow the

phases or may have different ones. If this is the case, then parents may be unsupported. Furthermore, the knowledge that they are not following the "normal" process may lead to greater feelings of isolation and despair. This could have a negative effect on the mental health of the parent, family, and potentially on the child with ASD. It is important to acknowledge that each parent's experience is unique and individual, but the study provided an interesting template for the process that parents may go through. It has some important implications for support, as different interventions could be put into place to help parents cope through different phases of the process.

Feeling isolated and alone emerged as a theme in Zeman, Swanke and Doktor (2011)'s study. They explored how mothers of children with Autism experience social relationships through the medium of the internet. These mothers mainly blogged about their experience of raising children with ASD. The researchers also investigated the aspect of social relationships that may be inhibiting and the perceived existence of these online relationships. The themes that emerged were vulnerability and strength. Even though the cyber mothers felt supported, they reported that there were moments when they experienced feeling isolated and despair.

The reason that they seemed to blog was to connect with others to gain encouragement and acceptance. However, there were some limitations in this study. The researchers assumed that the cyber mothers' blogs were an authentic and accurate representation of their perception of their experience. Social desirability may lead them to edit their experience in order to come across in a different way to other parents. In addition, it is possible that the study only includes a subgroup of parents. Cyber mothers may have a greater ability to

articulate their experience of raising a child with ASD. Since this is an incredibly emotional and stressful experience (Myers, Mackintosh & Goin-Kochel, 2005), it can be difficult to put this into words and perhaps these cyber mothers are more self-aware and maybe more educated.

A Romanian study investigated how the diagnosis affects the lives of mothers and families (Oprea & Stan, 2012). Twenty-two mothers completed open ended questionnaires about the impact of the diagnosis and the family, society's views of Autism, factors that increase support of mothers and the qualities of mothers of Autistic children. The responses to questionnaires were analysed and coded. They found the mothers experienced negative affect and shock towards the diagnosis. Some parents shared that diagnosis had a positive effect on the family and helped them to understand the child in a different way. They perceived society as critical and judgemental towards the child and mother. The mothers also expressed hope and perseverance to help their child. The sample was restricted to Romanian parents, which limits the generalisability of the study to parents of different cultures.

Research has been conducted on how parents make sense of their child's diagnosis. Using grounded theory, Huws, Jones and Ingledew (2001) investigated the functions of parents of children with Autism on an email group. They found that parents used the email group to help with coherence of events by telling their narrative. The participants also made sense of Autism by validating and reciprocating concerns, identifying representations and perceptions of Autism, anticipating cures, and searching for religious explanations.

Huws et al. (2001) suggested that the benefits of using the internet for social support was that it was available to parents 24/7 and it allowed

psychological constructs about understanding of Autism to be distributed socially. However, the authors also showed awareness of potential limitations of online support. For example, the negative correlation between the time spent on the internet and social and psychological wellbeing. They were also aware that the discussions in the group were of like-minded people, that is parents of children with Autism, seeking social support outside of family and friends, and perhaps this could lead to an exaggeration of opinions and perceptions. This would mean that themes emerged due to this dynamic, rather than being a true function of the email group. Furthermore, the researchers lacked any demographic information about the participants, including any evidence that these parents did have children diagnosed with Autism. This brings into question the validity of the study, as it is not certain that the researchers investigated the functions of an online group of parents of children with ASD.

1.5. Diagnosis Process of Autism

Literature suggested that the experience of diagnosis is negative for parents. In a survey, Howlin and Moore (1997) found that 87% of parents were unsatisfied with the diagnostic process and only half of the sample were satisfied with the help they had received. The study was conducted on parents in the UK and due to the method of data collection, the researchers were able to gain data from a large sample from lots of areas in the UK. It could be argued that the experience of Autism diagnosis could be generalised to other UK parents. However, using surveys was also a limiting factor. Since questions were written, the researchers were unable to ask and gather more information about why the parents felt unsatisfied with their experience. This limits the recommendations of the research as specific aspects of the diagnostic process cannot be improved.

For example, parents could be unsatisfied with the process due to the long wait, because of the quality of the assessment or due to not receiving a diagnosis. However, the study does give an overview of parents' experiences of the diagnosis process in the UK.

Other research has suggested that the experience of parents of the diagnostic process can be positive (Braiden, Bothwell & Duffy, 2010). They interviewed 11 parents who had received a diagnosis for their child recently (in the last 18 months). A semi-structured interview was conducted, and data was analysed using thematic analysis. The themes identified were; Initial Concerns, The Diagnostic Process and Delivery of Diagnosis. Eight participants indicated they were happy with the process of diagnosis although they also noted feeling unsure about the process, overwhelmed by paperwork, concern that professionals were making a snap judgement and having difficulty in the interviews remembering information about the child's early years. The limitations highlighted included caution about generalising the results. The study used a small sample from Belfast. From the number of parents invited to take part, only 17% responded. The researchers also used retrospective data in the study, which limits the accuracy of the data since memory can be subject to biases.

The diagnostic process for parents of pre-schoolers with suspected Autism has shown that they start to identify concerns before the child's second birthday (Andersson, Miniscalo & Gilberg, 2014). Andersson et al. described the diagnosis process as satisfying and were happy with their experience. However, it is important to recognise that the sample's children were presenting with more than mild Autism and that this may have reduced the stress about the diagnostic

process because the difficulties were easily associated with Autism (Siklos & Kerns, 2007).

An IPA study has highlighted the experience of the diagnosis process for parents with Autistic daughters (Rabbitte, Prendeville & Kinsella, 2017). Boys are diagnosed 10 times more frequently than girls due to females having a different presentation of Autism. It is also more common for girls to camouflage the deficits associated with Autism (Dworzynski, Ronald, Bolton & Happé, 2012) and that they are able to mimic social behaviours (Gould & Ashton-Smith, 2011). The analysis elicited 4 superordinate themes; Noticing the signs (misdiagnosis, reflecting on signs in hindsight), An emotional journey (advocating, going for shock to relief), Moving forward (support for the child, understanding the child, the child understanding the diagnosis, other's perceptions of the child) and Looking to the future (fear of the unknown, hope). The research sheds light on the lived experience of going through the diagnostic process with their daughters. The sample used had varying time since diagnosis; that is some had daughters that had been diagnosed 5 years prior whereas others had received their diagnosis recently. A limitation of the study could be that the researchers are assuming that the needs of families with Autistic children do not change over time and are comparable.

Midence and O'Neill (1999) conducted a pilot study on how parents experience the diagnosis of Autism. They interviewed 4 parents and used Grounded Theory to analyse the data. The themes elicited were Behaviour development, Confusion, Incorrect diagnosis, Autism, Support and Acceptance/adaptation. They discussed the feelings that they experienced before, during and after their child was diagnosed with Autism. They also

identified shifts in their expectations of the child, so they were more realistic and accommodating of the impact of Autism on their child's abilities. The researcher recommended that the study should be replicated with a bigger sample to improve the generalisability of the findings. Another finding was that parents experienced relief when their child was diagnosed. It is possible that this may distort their recollection of the more negative aspects of their experience. The parents may have reflected on the pre-diagnosis time as a means to an end and may report it as less negative. It could challenge the research question, in that perhaps the study measures the experience of having an Autistic child and their reflection on life before the diagnosis. To improve the study, it may be important to interview parents whilst they are in the different stages of diagnosis to truly capture their experiences.

Obtaining a diagnosis is associated with many perceived benefits by parents, such as access to appropriate interventions and knowledge (Watson, Hayes & Radford-Paz, 2011). They reviewed existing literature that explored the experience of parents seeking a diagnosis for a developmental disability. They found that generally the experience of receiving a diagnosis was negative and stressful for parents and the family. They identified that research is needed to elicit true experiences of families and the meaning that they attribute to a diagnosis. Whilst the review does not specifically address Autism diagnosis, it could be important to acknowledge that families could be having similar challenges and that findings could be applied to different groups.

Gray (2002) conducted a longitudinal study of 26 families. At the beginning of these experiences, before diagnosis, parents are stressed, anxious and confused about their child's development as their child's difficulties became

more prominent. The focus of the interviews was on parents' and siblings' wellbeing and the families' social experiences. He found that over time, parents reported that their lives had become better. This was linked to being able to manage the child's Autism, having access to appropriate services and having greater coping abilities. However, this was not the case for all families and some continued to be under considerable stress. He later suggested that another factor that could increase stress is being well educated (Gray, 2006). He suggested that mothers with a better understanding of Autism and the implications of having this condition could make them more fearful of a diagnosis.

1.6. Having a child with Autism: Impact on parents

Parenting children with Autism has been shown to have an adverse effect on parents' mental health. They experience greater stress and have a higher rate of depression (Wolf, Noh, Fisman & Speechley, 1989). One potential factor that increases stress is the child exhibiting problem behaviours (Bromley, Hare, Davison & Emerson, 2004). In their interviews they identified factors that increase and decrease the stress of mothers of Autistic children. Whilst this sample of mothers had already received diagnoses for their children, it is possible that some of these factors may apply to parents pre-diagnosis. For example, the child's behaviours are likely to be present pre-diagnosis, creating stress for the parents.

Further research on the mental wellbeing of parents of Autistic children identifies stress and depression (Benson & Karlof, 2009). They found that stress proliferation mediates the effect of symptom severity on parent depression, in a sample of 90 parents. As in Bromley et al.'s (2004) study, problematic behaviours of the child increased parental stress. However, Benson and Karlof (2009) found

that anger acted as a mediator on stress proliferation and depressed mood. It could be argued that the development of depression may not be caused by having an Autistic child and perhaps these difficulties existed earlier. For example, depression may have existed before becoming a parent or perhaps during the wait for diagnosis. Unfortunately, the study did not gather pre-existing mental health information about parents so it is difficult to ascertain the impact of parenting Autistic children on mental health. The study collected data over a longer period of time, which indicates that stress is long term for parents and that these could lead to mental health difficulties.

As in the previous studies there is a strong foundation of research indicating high levels of stress in parents of Autistic children. Feinberg, Augstyn and Fitzgerald (2014) conducted a study sharing problem solving techniques to parents after their child had been diagnosed with Autism. They used a Randomised Control Trial (RCT) to evaluate the intervention and used pre and post questionnaires to measure depressive symptoms. However, the study had a small sample and did not complete any follow ups on the parents, so it cannot be certain about the positive effects of the intervention were long term. The study suggests that parents benefit from psychological interventions after diagnosis and that this only needs to be brief to have an impact on mental health. Perhaps, instead of waiting for mental health to deteriorate, there is a role for the intervention pre-diagnosis, which may be even briefer to be effective.

Regarding more general themes, Aziz (2014) looked at the needs of 58 Arabic families of children with Autism. He examined the cognitive, financial, and psychological and social needs of the family. He found that cognitive needs (e.g. gain information about Autism and associated behaviours, resources to educate

and train child) of the family was rated as the most important, followed by financial needs (e.g. financial support for health care, training and other support for the child) and lastly, psychological and social needs (e.g. support from other people like family and friends, services that support the whole family). However, in the demographic information, they did not specify how long ago the child was diagnosed. This could be important as the needs of the family may be different immediately after the diagnosis, compared to years after. Furthermore, cultural influences may play an important role in the support that the family need. For example, in Jeddah, where the study was conducted, it may be socially acceptable to send the child to a residential home or institute to manage the child's behaviours associated with Autism. This may mean that the parents have less face to face contact with their child, reducing stress and meaning social support is less important. However, this may put more financial strains on the family. Since institutes for children with Autism are not commonly used in the UK, it may mean that the needs of UK families are different.

Da Paz and Wallander (2017) also evaluated the effect of therapy on the stress of parents. Using RCTs, they implemented interventions of relaxation, expressive writing, mindfulness and Acceptance and Commitment Therapy. They found that the interventions reduced stress and depression in parents of Autistic children. The samples in the study were small, so it is not possible to know if these interventions would work for most parents. Being a parent of an Autistic child can be chaotic and unpredictable. Perhaps improvement in mental health was due to having time away from the child and having their own space. It would have been interesting to have another group of parents, who did not access psychological support, but had to complete an activity of their choice away from the home. This would suggest that focusing purely on the child can lead to more

stress, creating time to focus on themselves and increasing their time spent on self-care. The therapeutic approaches mentioned above also seem to focus solely on the parents rather than how the family functions as a unit to support each other.

This is supported by another study that found that after 8 sessions of problem-solving skills, the parents experienced a decrease in negative emotions and an increase in their skills (Nguyen, Fairclough & Noll, 2016). These parents had recently received a diagnosis of Autism for their child. I wonder whether this approach promotes labelling the child or Autism as a "problem" and that the parent is active in finding solutions to "fix" the problem. It could feel overwhelming for some parents if they are struggling with their own mental health. Therefore, the more vulnerable parents may drop out of interventions like these and so problem-solving sessions may only be helpful for some parents. In addition, perhaps the idea that their child can be fixed increases the hope for parents and places them with more control of their child. Therefore, they could be feeling more positive as a result of being told there are solutions to their problems.

Thomson (2015) examined blogs written by parents with a diagnosed autistic child. She investigated the themes in blogs when parents wrote about themselves, their children and the family relationships. Data from 8 parents were used for the first stage of analysis. Using thematic analysis, Thomson was able to identify 3 themes; coping, searching for an explanation, and a sense of belonging versus not belonging. The researcher then performed a deep analysis on the data of 2 participants. She was able to find that within the category of searching for an explanation, there were two sub-categories; relationship with ASC (Autism

Spectrum Condition; used interchangeably with ASD within this review) and relationship with society. The researcher was concerned about the role of self-censoring that may come into play and that they may create a bias within the blog. For example, parents may not admit to how difficult things are because they do not want to come across as weak or they may believe that the difficult behaviours associated with ASD are a result of their parenting, and may feel ashamed. However, this study raised a crucial point; the importance of the clinicians using this medium to support parents. The discussion groups allow parents to raise the issues that they perceive as important and clinicians could use this to supply the parents with the necessary resources to gain the skills to cope with the issues.

Moh and Magiati's (2012) research continued to build on the existing literature on the impact on parents when having an Autistic child. They examined a number of factors that were associated with stress. The researchers recruited 102 parents, mostly Chinese, with Autistic children. The parents were asked to complete a survey which asked them the age of the child when emerging difficulties were recognised as Autism and the number of professionals consulted. They were given 14 types of information post-diagnosis and parents were asked to rate how helpful these had been. The researchers used another questionnaire (Family/Professional Collaboration Scale; DeChillo, Koren & Schultze, 1994) to explore their experiences of working with professionals. The Autism Treatment Evaluation Checklist (Rimland & Edelson, 2000) measured Autism severity and functioning of the child. The parents also gave a retrospective rating of the stress they had experienced during the diagnostic process. They found that parental stress was higher when there were more professionals consulted and lower perceived collaboration. A possible explanation could be that parents feel more

isolated and alone when there is less collaboration. The limitation of this study

was that it only provides correlations and it is not possible to understand why

these factors increase stress for parents. It gives some indication that parents

experience a high level of stress during the diagnostic process but this is a

retrospective insight and therefore, may be distorted by biases. Furthermore, the

questionnaires were provided in English for a sample of participants whose first

language was Mandarin. This may have limited their understanding of the

questions and led to incorrect perceptions and inaccurate answers. To improve

the study, the questionnaires would need to be translated accurately and perhaps

sent to participants who are currently waiting for a diagnosis.

Swanke, Zeman and Doktor (2009) looked to identify the expectations,

perception and feelings of mothers, of children with ASD, that blog. They

classified themes using content analysis of blogs. Three themes were identified;

organisational reactions, maternal activism and maternal discontent. Their

discontent seemed to be directed at professionals in educational, health and

social settings. This could be important for clinicians to acknowledge, and could

take place through an online forum. It may enable professionals in the health

service to understand areas where parents feel unsupported and address this

directly and swiftly. Furthermore, this could facilitate more communication

between parents and clinicians, which may improve both the service and the

relationship between these two groups of people.

1.7. Pre-diagnosis experience of parents

A meta-synthesis of qualitative research by De Pape and Lindsay (2015)

explored the experience of parents of Autistic children. From the 31 papers

analysed in the study, they found that there were 6 major themes; Pre-diagnosis,

Diagnosis, Family Life Adjustment, Navigating The System, Parental Empowerment and Moving Forward. The Pre-diagnosis theme referred to parents knowing that there was something wrong with their child and looking for answers to this. This focused on their child meeting developmental stages. They searched for answers by contacting health professionals like the family doctor. At times, their concerns were dismissed (Hutton & Caron, 2005). Whilst this study gives a wide overview of the experiences of parents, it is possible that the details have been lost. In addition to this, there were some methodological limitations. The researchers excluded papers where children had co-morbid conditions. However, it could be argued that this is not representative of the population, since 70% of children with Autism meet the criteria for another disorder (Simonoff, Pickles, Charman, Chandler, Loucas & Baird, 2008). The study also included research from other countries, such as India, Saudi Arabia and Israel. Whilst the researchers acknowledged that cultural beliefs influence parents' expectations, they were still included in the study. Therefore, it limits the generalisability because it is not possible to be certain that the experience in Western cultures can be compared to Non-Western cultures. Finally, the age of participants' children ranged from 2 to 31 years old. It would be important to acknowledge that some of the parents' expectations may change dependent on the developmental stage of the child. For example, concern about the child living independently may be more salient for parents whose child is over 18.

Mulcahy and Savage (2015) investigated parents of pre-school children who had concerns about their child's development. Parents compared their child to other children, similar to the present study. The themes were elicited using IPA and the sample included parents who did not have a diagnosis of a developmental disorder. However, whilst it is a strength that the research contributes to the pre-

diagnosis experience of parents, and may include the experience of parents with children on the Autism spectrum, it cannot be certain.

Chao, Chang, Chin, Li and Chen (2018) investigated the experience of obtaining a diagnosis for a child. Their sample included 15 parents from Taiwan. The aim of their study was to understand the experience of these parents as they went through the diagnostic process. Parents participated in semi-structured interviews for an hour. After the data had been transcribed and analysed, using a descriptive phenomenological approach, they were translated from Mandarin to English by a bilingual expert. The translations were also discussed with the researchers. They found that parents underwent 5 coping behaviours:

1. Uncertainty and difficulty understanding the child's behaviour in the pre-diagnosis phase.

2. Obligation to obtain professional services during diagnostic phase.

3. Anxiety regarding a second opinion in the diagnostic phase.

4. Acceptance and fortitude during the post-diagnosis phase.

5. Further adjustment during the post-diagnosis phase.

Although the study claims that these were experiences of parents, there was only one male participant in the study. To be able to generalise the results, it would be important to have a sample that had a similar number of male and female participants to prevent underrepresentation that could highlight gender differences. In addition, the sample of parents were Taiwanese, so it would reduce the generalisability of these findings to different cultures. The parents in the study also had easy access to medical care. It is possible that having supportive systems around them may mean that their experience is less negative than the experiences of other parents.

Ryan and Salisbury (2012) conducted some qualitative research on pre-diagnosis experience of parents with Autistic children. They used semi-structured interviews to explore with 24 parents, using thematic analysis to identify themes of the experiences. They identified concerns that fell into 3 themes; No concerns pre-diagnosis, Passive concerns and Active concerns.

No concerns explored the surprise that parents felt when someone suggested that the child displayed unusual behaviours and parents misattributing Autistic traits. Passive concerns represented parents who were concerned about their child's development but had not raised these with professionals. Sometimes, this was linked to fears that professionals may not listen, not being able to articulate their concerns or not being aware that something was wrong until comparing the child's development with a sibling. Active concerns applied to parents that were concerned and asked professionals for advice. This included reporting developmental delays in achieving milestones. Some of these parents felt that the health professional did not engage with their concerns, in particular, their lack of acknowledgement or action. The researchers stated that this increased the parents' feelings of being alone and isolation. However, positive relationships with professionals were also reported.

The paper made some interesting recommendations for health professionals, particular in listening to parents' concern and sensitively exploring the difficulties further. The data collected from the study is retrospective. It also only includes parents of children who were diagnosed and therefore excludes parents whose concerns may not be appropriate.

Ducey (2009) aimed to describe the experience of parents before and during the diagnosis of Autism for their child. She recruited 4 mothers and

conducted in-depth interviews. Whilst an interview schedule was followed, it was kept semi-structured to allow the mothers to discuss ideas that they perceived as most relevant to her own experience. Meaning was derived from the data using phenomenological data analysis. The researcher found 6 main themes; confusion, reassurance and denial, realisation, searching for answers, perceptions of the diagnosis and the importance of a support network. The final 2 themes applied to the mothers' experiences after diagnosis. However, using the van Kaam approach to analyse the data means that the researcher focused on the descriptive phenomenology. This could limit the findings of the study to how other factors, such as gender or culture, can influence the experience of parents. Whilst the study provides an exploratory, "pure" description of the experience, it may miss out on a richer, more interpretative understanding of the experience.

1.8. Summary

The current study aims to continue to add to about parent's experience of waiting for an assessment of Autism for their child.

The literature examined shows that parents can experience both positive and negatives when raising a child with possible Autism and that different factors can mediate this. There is also evidence to suggest that some parents have positive experiences of the waiting process, although there appears to be more literature supporting the negative aspects of this process. The period between being referred for an assessment and the child being assessed appears to be a confusing and stressful time for parents.

The main limitation of the existing research on this topic is that the data collected is mostly retrospective. This limits the accuracy of the data because

retrospective data can be subject to different biases. For example, parents may

remember the waiting period as less negative as a way of protecting themselves

from the distress that they experienced at the time. People also have the ability

to reflect on experiences, and this could distort the memory or the intensity of

feelings that they had been experiencing originally. To be able to report this

experience as accurately and truthfully as possible, interviewing participants

during different stages of the diagnostic process appears to be the most

appropriate approach.

Fully understanding the impact of waiting for children's assessments of

Autism would be important for Counselling Psychology in supporting practitioners

to understand these parents more effectively and be able to support the parents,

children and families at different stages of the diagnosis.

2. Rationale for the present research

The literature within the field indicates that parents of children with Autism

Spectrum Disorders (ASD) are more stressed (Eisenhower, Baker & Blacher, 2005;

Pisula, 2007). They are less satisfied with the process of receiving an assessment

of their child due to the length of waiting times and lack of information for the

family and child (Siklos & Kerns, 2005).

However, the research to date has explored parental experience of

waiting for a child's diagnosis uses retrospective data that reflects on different

stages of diagnosis (Ducey, 2009; Ryan & Salisbury, 2012; Chao, Chang, Chin, Li &

Chen, 2018; De Pape & Lindsay, 2015). I was interested in adopting a more

exploratory approach in investigating how parents think, feel and make sense of

their lives, while waiting for their child's assessment. This helped to develop the research question; how do parents experience waiting for their child's assessment of Autism?

I am also interested in how these experiences manifest in parents' behaviour, in particular, how they cope, to add to the research in this area. It will help to identify short fallings in support provided for parents during this time and if/how they meet the needs and expectations of parents. Since Child and Adolescent Mental Health Services are under constant financial pressure, it is possible that waiting times for assessments may increase and may continue to be a problem in the future. Supporting families during this waiting period may become essential to the family's mental health. The aim of this research is to gain in-depth knowledge of parents' experiences of waiting for their child's assessment of Autism, with the hope that this insight may allow for recommendations of improvements and development of support.

Within the media, research by the former Health Secretary, Norman Lamb (2018), has described the current waiting times as a crisis. The target suggested by NICE guidelines is to see individuals for an Autism Assessment within 3 months of referral. The research uncovered 22/27 Care Commissioning Groups do not meet these targets. I feel that the current study is in line with Lamb's crisis plan, in providing an understanding of the impact of waiting times on parents who can wait up to 5 years for their child's assessment of Autism.

2.1. Research aim

The present study intends to explore the experiences of parents during the period of waiting for their child's assessment of Autism. This led to the research question; how do parents make sense of waiting for their child's assessment of Autism?

CHAPTER 2: METHODOLOGY

1. Introduction to the methodology

The chapter outlines the methodology. Firstly, the rationale and aim of the study is discussed. In the second section, the epistemological position which supports the approach of the research. The importance of reflexivity within the methodology is also focused on in this chapter. In the final section, I outline sampling methods, ethical considerations and procedures for data collection and analysis.

2. Theoretical Position

2.1. Ontology

Ontology refers to the nature of the world and questions what is possible to know. It examines the existence of knowledge and how it relates to reality (Willig, 2008).

The focus of this research is how parents experience a particular period of their life, when they are waiting for their child's assessment. It aims to explore the individual reality of the participants and the significance of their thoughts, feelings and behaviours in making sense of their experience. The research does not imply whether these are right or wrong but simply how individuals experience and make sense of the process of waiting. A relativist ontology subscribes to these values and in addition, allows the acknowledgement that the concept of "Autism" is socially constructed (i.e. that it is influenced by the child's perceived difficulties in different settings and whether they fit a certain pattern).

2.2. Phenomenology

Phenomenology is an approach to research that focuses on an observable event. It focuses on conscious experience and objects within this experience (OED, 2001). A phenomenological approach was required for this study as it investigates the direct experience of parents waiting for their child's assessment of Autism. This approach emphasises that understanding the significance of this experience does not require imposing an external framework on the data. Although this can happen using both quantitative and qualitative methodologies, Husserl (1962) described a process of bracketing biases, to minimise researcher bias.

Husserl (1962) explained phenomenology as descriptive, where no assumptions are made about the data and analysis takes place through reflection (Moran, 2000). However, this has been critiqued as it creates issues surrounding accessing hidden meaning (Grbich, 1999).

The phenomenology of this study resonates more with Heidegger's (1962) hermeneutic phenomenology. This differs to Husserl's approach by placing the focus on understanding of being. Heidegger's book, *Being and Time*, considered how being-in-the-world exists over time. He suggested that it cannot be possible to separate existence from historical existence and that perhaps our one existence is stretched from birth to death. However, he also suggests access to existence is through tradition and previous experiences. When applying this idea to philosophy itself and he suggests that considering the history of philosophy becomes integral to itself. He treats time as the horizon in which our questioning occurs. Consciousness of time enables us to gain distance to pursue

the reflection and analysis, and the interpretation of existence must be a historical analysis.

Gadamer (1975) emphasised language as the medium of existence, i.e. that nothing can exist without it. Therefore, he summarised that the conversation, the reader and the articulator were required to establish meaning. However, controversy still exists. At a later date, Gadamer (according to Coltman, 1998) critiqued Heidegger's theory, questioning whether multiple subjective accounts could lead to one true objective experience.

In the current study, the focus is placed on the passing of time and the experience of waiting for their child's assessment of Autism. Therefore, Heidegger's theory about the importance of time and how this can affect the experience of existence is helpful. From the study, the data has captured the lived experience, whilst respecting the impact of the past as part of the existence of the mothers. I believe that in the current study, the past existence of the mothers impacts on their present existence, including how they make sense of the waiting period, before their child's assessment of Autism. The focus of my study is not to find one objective truth and I believe it would be impossible to combine different experiences from different people to form a truth.

2.3. Epistemology

The hermeneutic circle describes the process of interpretation that operates on a number of levels. This idea revolves around being able to identify parts of a whole. This could be a single word in a sentence, a single extract in a text, an interview in a research project or an episode in a complete life (Smith, Flowers & Larkin, 2009). The hermeneutic circle emphasises that meaning

becomes clear within context, but this is also dependant on the context having meaning. Interpretative Phenomenological Analysis, like other qualitative methods describes a linear procedure to data analysis (Smith et al., 2009), but the influence of the hermeneutic circle differentiates it from other approaches. It is useful in explaining the analytic process in IPA in describing the back and forth movement through all the levels. It creates an interesting relationship with the data that is dynamic and flexible. It elicits meaning from the text by identifying features that are consistent across different levels.

Epistemology addresses how and what we can know (Willlig, 2008). It involves the philosophical stance on where knowledge comes from and the validity and reliability of our knowledge. It drives research by specifying the knowledge wished to acquire and which perspectives to utilise to achieve this.

My epistemological position in this research is critical realist. The aim of the study is to gain an insight into parents' experience of waiting for their child's assessment of Autism. A critical realist position suggests that the data reflects the real world. Further interpretation is required to understand the underlying constructs that emerge from the data (Willig, 2013). However, a critical realist position also acknowledges that a single reality is influenced by social representations, which lead to a "transitive dimension of knowledge" (Wilson & McCormack, 2006). Therefore, a critical realist approach was appropriate for this research.

3. Personal Reflexivity

Since using the hermeneutic circle of giving meaning encompasses the researcher in making sense of the story, I have felt it important to acknowledge

my impact on the data. I considered Landridge's (2007) questions, which encourage personal reflexivity in research. As I began the study, I considered why I had chosen this topic and what I hoped to achieve from it personally.

I was required to conduct a novel empirical piece of research as part of my portfolio for my Doctorate in Counselling Psychology. I have always been interested in working with people with Autism and have done so for the past 5 years. I encountered this within the charity sector and within the NHS. A placement with the Autism Assessment Team in CAMHS gave an insight into the tremendous pressure the service and clinicians were under. It encouraged me to think about the support that children and young people had while they were waiting. The reality was that much of the responsibility was falling to parents. The advice for parents was to engage with local services that provided psychoeducation and strategies, but I wondered whether this was enough for parents facing such an uncertainty and lengthy time, whilst coping with difficult behaviours from the child and often coping alone. For me, through the three years of training, I find myself in conflict between a relational model of understanding others and a medical model of diagnosis and meeting criteria. As a Counselling Psychologist, I prefer to work without assumptions, or as closely to this as is realistic. My own personal belief is that seeing the world in a different way can be pathologized as an illness, disorder or a problem. These are the connotations that I believe are associated with "Autism". However, parents that I spoke to, began to understand that a diagnosis of Autism has other meanings. As I continue to work therapeutically with young people and their families with possible Autism and co-morbid mental health conditions, I understand that a diagnosis can also provide a framework for them understanding and supporting their child.

The researcher's assumptions and beliefs can impact on the quality of qualitative research (Brantlinger, Jimenez, Klingner, Pugach & Richardson, 2005). I felt that this was a population that had not been heard in research and had not had the opportunity to voice their opinion. It is possible that I expected participants to be struggling so this could have put a negative slant on the interpretation. Whilst I was aware of this, I was careful as to how I constructed the interview questions, so not to prime the participants' view of their experiences with a negative bias. I also spent time in therapy exploring these feelings around wanting to help this population. This has encouraged me to think about bracketing (Smith et al., 2009). I have felt that during this research, my own opinions and beliefs about diagnosis has changed. Before, I felt that I held a simplistic view whereas now I feel that diagnosis is more complex, with more advantages and disadvantages than I had considered before. I felt that this demonstrates Landridge's (2007) argument that reflexivity becomes especially important when investigating a phenomenon in vulnerable populations where the researcher themselves has not experienced it first-hand.

I considered how participants may view me, perhaps as an outsider, as someone who is not a parent and without having waited for an Autism Assessment. I was aware that they may view me as a professional with certain expertise and possibly a source of knowledge. Or perhaps, as an employee of the NHS, the organisation that is subjecting them to the process of years of waiting. However, on the other hand, I feel my experiences allowed me to empathise with the participants and be able to hold different accounts and experiences as equally valuable, as I am not comparing them to my own experiences.

I considered my age and gender might influence the research. At the age of 24, I considered whether participants may see me as inexperienced and find it uncomfortable talking to someone younger. However, I also wonder whether being younger, and therefore unlikely to have children, made participants feel more comfortable because I did not have as much expertise as them about children and parenting. They may have felt that I was less likely to judge them.

All of the participants recruited were women and I wonder whether the reason for this could be that men felt uncomfortable discussing this topic with a woman. I also considered my cultural background as a factor affecting the research and my role as the researcher. Coming from a mixed-race background, English and South American, participants may notice my ethnicity from my features and skin colour. I wondered whether participants from a similar background would be impacted on by my culture; that they may feel more comfortable and relate more easily or they feel embarrassed and ashamed in disclosing their personal experiences.

4. Methodological Rationale

Interpretative Phenomenological Analysis (IPA) is a qualitative approach that is constantly developing. It consists of a series of stages which are outlined later in the chapter. It involves an in-depth examination of a subjective lived experience. In order to develop an understanding as close to the personal experience, Heidegger's (1927) hermeneutic circle links the whole experiences and detailed parts. Smith et al. (2009) shared this idea when developing IPA where they believe that the understanding of a single word is determined by the context of the whole sentence. Moving between part and whole allows the researcher to develop an understanding of the meaning of the data (Smith et al., 2009).

IPA was selected as the methodology for the research. It is based on the idea that people self-reflect (Smith, Flowers & Osborn, 1997), and IPA can be used to explore this through the participant's experience and perceptions (Reid, Flowers & Larkin, 2005). This was considered amongst quantitative and other qualitative methods. The following outlines the methodological rationale for using IPA, considering the research question and theoretical positions.

Previous research has used questionnaires to explore parents' experiences of waiting for their child's assessment of Autism (Howlin & Moore, 1997; Siklos & Kerns, 2005; Moh & Magiati, 2012) and they identified how parents cope. It gave a basic understanding of parental experience of waiting for an assessment but a deeper understanding was needed to further the knowledge in this area. Therefore, a qualitative approach was felt to be more appropriate to add novel knowledge to this topic.

When thinking about qualitative methods, grounded theory and thematic analysis were also considered to answer the research question.

Grounded theory promotes a set of systematic procedures that use the data in qualitative research to generate theories about a phenomenon (Strauss & Corbin, 1990). They suggested that grounded theory consists of a series of stages. Firstly, the text is coded using open coding, axial coding and selective coding. The purpose of this is to gain different insights into the data and by comparing similarities and differences, themes emerge (Petty, Thomson & Stew, 2012). Whilst this method examines the data carefully, it was felt that the purpose of the research was not to generalise findings and theorize the experience. This was partly due to the huge variation of the needs of children with Autism and therefore, it would make parental experiences very different. Grounded theory is associated with social pressures and promotes a more descriptive understanding of experiences (Willig, 2013), which would not answer the research question in this study.

Thematic analysis was also considered. Thematic analysis is a qualitative method that organises data into themes. These emerge from the data and patterns are found. The analysis takes place over one level and provides a clear summary of the data (Braun & Clarke, 2006). It was the epistemology that determined that this would not be the most appropriate approach. The possibility that social representations may play a role in parents' experiences made me consider that a deeper level of analysis would be required. In addition to this, previous research has identified themes on parental experience. Therefore, to contribute to further knowledge and understanding to this topic, it seems

appropriate to adopt a different perspective and methodology, to explore these on different levels.

IPA was the chosen methodology for the research. It allowed the further and deeper exploration into the lived experience of parents, and addresses the research question, due to the double hermeneutic approach. It combines both empathic and questioning hermeneutics (Smith & Osborn, 2003). The methodology was also compatible with the theoretical stance. The aim of the research was not to compare and the emphasis of IPA is on an analysis, which goes beyond descriptive and is interpretative. Smith and Osborn (2003) recommended that IPA was a useful method in research topics that are novel because it acts as a framework, rather than imposing theoretical pretext (Brocki & Wearden, 2006).

5. Sampling

Participants were parents of children and young people waiting for an assessment of Autism. The inclusion criteria for participants were parents over the age of 18 with a child on the waiting list for an assessment of Autism. There was no cut off on age. The study welcomed both mothers and fathers to participate. I was aware that it was typically mothers that had been more prominent in previous research, perhaps because they are the main carer of the child. I was interested to speak to men about their experience, as this is underrepresented within the current literature. Parents were excluded if they had more than one child on the waiting list. This was because it may be confusing for the parents to talk about the experience, without getting details mixed up. Non English speaking parents were also excluded because I did not have access to a

translator. Exclusion criteria were applied after recruitment by telephone screening.

Snowball sampling was also used as the participant appeared to link with other parents going through the waiting process.

6. Recruitment

Participants were recruited through a local charity who supported parents with Autistic children before and after diagnosis. Pre-diagnostic workshops were attended and flyers (see Appendix 1) about the research were distributed at the break. The workshop was aimed at parents who had just begun the waiting process and were provided with psycho-education about Autism and the diagnosis process. The recruitment process took approximately 8 months. Three participants were recruited through the workshop and a further three participants were recruited through snowballing. If parents were interested in participating, they were asked to provide a contact number and a convenient time to be contacted. Parents were contacted later and screening questions were asked, relating to the exclusion criteria.

7. Data Collection

7.1. Procedure

Participants were recruited from workshops run by the a local charity. The participants were contacted by phone and were asked screening questions. If parents were not excluded, they were invited to take part in an interview lasting approximately 90 minutes.

At the start of the interview, I introduced myself to the participants and explained that I was interested in their experience of waiting for their child's assessment of Autism. I acknowledged to the participants that this may seem vague, but that I did not want to express any further ideas because the aim of the research was to gain an insight into their experience. However, we would be able to discuss the research further after the interview. I outlined the structure of the interview, that it would be semi-structured. I explained that this meant that I had a few questions, but the interview would be flexible. Informed consent was gained and the interview was recorded and later transcribed for analysis. Participants were debriefed at the end of the interview. I gave an explanation about my interest in the topic and how this had developed. Participants were given the opportunity to ask any questions about the research. I kept a reflective diary throughout the process of the research. I used this to consider my thoughts after the interview and process some of my own feelings that had been prompted during the interview.

7.2. Semi-structured interviews – Constructing the schedule

The interview schedule was constructed from examining questionnaires and interview schedules used in previous studies, for example, Keenan's (2007) Family Autism Needs Questionnaire and Ducey's (2009) schedule. Questions were adapted to be more open and sought to elicit more insight and detail. This was achieved by avoiding any leading questions and a selection of prompts were generated for each question. Questions were kept broad to encourage participants to control the direction of the interview. Questions were developed to reflect my own curiosity of their experience, for example, "Can you tell me…"

or "I wonder what it was like for you when…". Questions using "why" were avoided, since these can imply that there is a right and wrong answer or make participants feel judged (Legard, Keegan and Ward, 2003). This was important to avoid because if participants felt there was a correct response, they may change their answer to something that they think I wanted to hear or that makes them "right". Since the aim of the research was to elicit parents' experiences, the effect of a poorly worded question could lead to the quality of the study being compromised.

1) Can you tell me what has brought you here today? (Prompt: tell me more)

2) Could you describe for me what autism means to you? (Prompts: tell me more, how does it relate to your child)

3) I wonder what it is like for you to wait for an assessment (Prompts: tell me more, has it met your expectations)

4) Could you describe your expectations of services and support after your child's assessment? (Prompts: what are they, what is it about them, how would it impact you/your child)

The first question looked to identify any agenda that participants may have. It also presents an opportunity for the researcher to address any misunderstanding that the research is linked to their child's assessment. Furthermore, it gave more insight into the significance of the waiting experience to them.

Question two looked to elicit participants' understanding of Autism. I hoped from this, it would expose any stereotypes or prejudices that the participants held about Autistic people. It also looked to see if parents were linking their child's difficulties to those associated with Autism. This question

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explored the significance of Autism to the participant. This was used at the beginning of the interview because it allowed the participant to steer the conversation into their chosen direction and provided me with the opportunity to ask additional questions.

The third question helped focus the interview to answer the research question. It was designed to allow participants to talk about their thoughts, feelings, coping and other behaviours. It also allowed participants to bring other aspects of their life that have been impacted whilst waiting for a diagnosis.

The final question attempted to explore how participants would meet their needs and their child's needs after the assessment. In this question, it was also possible that it would elicit more information about the participants' understanding of Autism and the significance of a diagnosis. It could also explore why participants place this significance on diagnosis.

7.3. Conducting interviews

Interviews were arranged over the phone. It was important for participants to feel at ease. This was achieved by organising for the participants to be interviewed somewhere they were familiar with. This reduced the stress for participants before the interviews. Since attending interviews can be anxiety provoking to participants, I attempted to reduce other possible causes for additional anxiety.

The interview was conducted on a 1:1 basis and lasted approximately 90 minutes. Participants were informed of this and informed consent was requested. I explained confidentiality, that is, their data would be anonymised. I explained that the interview would aim to finish after 60 minutes, with 20 minutes at the

end to debrief and answer any questions. I explained that it would be likely that I would say very little through the interview. The reason for this was because I wanted to make sense of their experience. After this, the interview recording began.

At the end of the interview, I debriefed the participants verbally and gave this to them on a debrief sheet (Appendix 2). Participants were informed that they would have one week to withdraw their data from the study, as after this time, the data would be transcribed, and analysis would begin. I asked if they had any questions.

7.4. Pilot study

A pilot study was conducted to examine whether the interview questions were clear and the study ran smoothly. The pilot was conducted with a parent who had recently been through the process of waiting for their child's assessment of epilepsy. Although this was different to the participants in the real study, the emphasis was on the experience of waiting and therefore, it was deemed appropriate.

7.5. Transcription

Participants were required to give consent for interviews to be recorded and transcribed. Smith et al. (2012) outlined guidelines to transcription that I followed. Transcripts showed words spoken by the participant and the researcher and line numbers were used to help identify turns in the conversation. This was also useful during the analysis process when choosing quotes. Square brackets were used in the quotes to provide context. Ellipses' were used to represent long pauses and laughter was also identified as "*laughs*".

Audio recordings of the interview were converted to transcripts. Since content was crucial for analysis, the transcriptions did not include significant detail about any non-verbal utterances (O'Connell & Kowal, 1995). However, laughing, pauses and sighs were included when they gave context to the language, for example, in expressing sarcasm and irony.

Recordings were transcribed by hand and line numbers were given. This helped to engage with the data and line numbers would make the later stages of analysis easier, especially in identifying themes and providing examples. Transcripts were stored on the computer in encrypted folders.

8. Analytic Process

Qualitative research acknowledges the role of the researcher, in particular, the impact on interpretation of the data (Willig, 2012). Interpretative Phenomenological Analysis (IPA) allows for a detailed analysis, focusing on the lived experience of individuals (Reid, Flowers & Larkin, 2005). This follows the principles of phenomenological analysis where the participant's account is significant and important.

Interviews were recorded and transcribed, and analysis took place at a later date. The purpose of this was to allow total immersion and concentration to be on participants during the interview and I was able to empathise and pursue different areas of their experience without an agenda. This was important in building rapport with the participants (Osborn & Smith, 2008). The analysis of the data followed the 6 steps of IPA.

The first stage of analysis involved reading and re-reading the transcripts of the interviews (Smith, Jarman & Osbourne, 1999). After I had transcribed the

interviews, I read through the transcripts while also listening to the interview. The purpose of this was to become immersed in the data. Active engagement with the data allowed me to bind together parts of the narrative to understand the participant's experience. I also reflected on the rapport built through the interview and the effect this has on the detail of the data. I listened to the interview and read the transcript simultaneously so that I could form my understanding of the text, using both the words that the mothers used and the non-verbal cues, such as pauses.

Initial noting is the second phase of the analysis. This explores the language and semantic content used in the interview. In the phase, I identified specific ways by which the participant talks about, understands and thinks about their experience. Smith et al. (2009) identify 3 different levels of analysis; descriptive comments, linguistic comments and conceptual comments. Descriptive comments focus on face value and looks to identify the objects that structure the thoughts and experiences of the individual. Linguistic comments focus on the specific language that the participant uses in describing their experience and conceptual comments engage in a more interrogative and interpretative analysis, although these are still closely tied to the text. For each page of the transcript, I read through 3 times, focusing on the different types of comments and using different colours of pen to highlight the type of comment (Appendix 5). I feel that this helped me to focus on the type of data I was eliciting and how this was grounded in the text.

The analysis then moves to the next stages; developing emergent themes. This is where the I organised the exploratory notes into themes. The aim of this phase is to produce phrases that can be grounded in the data but with enough

abstraction to be conceptual. This part of the analysis brings together the participants' words with the researcher's interpretation. I was able to complete this by highlighting similar initial notes in the same colour if I felt that they were similar. This helped me to group them visually and to create a name for the theme that represented the group.

The researcher then looks to identify connections between themes. The emergent themes were mapped out to explore how they fit together. There are several suggested methods for this (Smith et al., 2009). One of the methods is abstraction, where the researcher seeks to cluster emergent themes together and forming a sub-ordinate theme. This allowed for the data to be summarised concisely without losing the richness of the data. I used post-it notes to arrange the themes into clusters and from this I was able to name the super-ordinate theme (Appendix 6).

Smith et al. (2009) also highlight the importance of maintaining each interview/participant as individual and separate. Since the themes emerge from the data, I felt that it was important not to bring a bias from one participant to another in the themes found. I managed this by reflecting in my research journal to debrief my findings and thoughts about one participant before beginning the analysis of the next participant. In my journal, I wrote the feelings that the mother had elicited from me during the analysis of her interview and sometimes looked back on the notes that I had made on the participant following the interview. This allowed me to examine if my feelings had changed during the analysis, and think about the reasons for this. I often left one or two days after finishing one interview analysis before beginning the next one to ensure I reduced my bias.

The final step of IPA, according to Smith et al. (2009) is looking for patterns across cases. At this part of the analysis, I moved further away from the original raw data and more towards a theoretical understanding of the experience of the participants. For this, I created tables to identify the super-ordinate themes and themes that I had elicited from the participants. As before, I grouped them to create new master themes that represented the data in the study. In naming the master themes, I focused on titles that represented the lived experience in a clear and direct statement.

This analytic strategy gave a clear guideline on how to analyse the data confidently. However, this strategy also allows flexibility to change and adapt it towards the data since it is not fixed, and different stages of analysis can be added where the researcher feels this is necessary. I was able to incorporate my own style into the analysis. At times, I felt overwhelmed by the amount of data from the interviews. Colour coding and using post-it notes helped me to clearly visualise the emerging themes and to condense them into more concise major themes.

9. Ethical Considerations

Ethical Approval was granted by City University of London Ethics Committee (See Appendix 4). The British Psychological Society (2018) ethical principles were followed, as discussed below.

9.1. Informed consent

The research aims were clearly explained, along with a description of the data collection procedure. Informed consent was gained from participants before the interviews commenced. They were required to confirm that they had read

and understood participant information sheet (Appendix 3). Consent forms were

stored in a locked cabinet.

9.2. Right to Withdraw

Participants were reminded that they could stop the interview at any time

and did not need to give a reason to withdraw from the study. Since the topic

was emotional for some parents, they were also informed that they could take a

break from the interview at any time, if they felt that this was required.

Participants were informed that after the interview, they would have one week to

withdraw their data from the research. This information regarding data

withdrawal and plans for dissemination were given verbally and also on their

debrief sheet (see Appendix 2).

9.3. Confidentiality

Before the interview began, it was explained to parents that the interview

would be confidential and their data would be de-identified. The data from the

interviews would only be used for the purpose of the research.   It was also

explained that if safeguarding concerns arise, the interview would be stopped and

the data would not be used. From this, safeguarding procedures would be followed

and confidentiality would be broken in this case. Participants were informed that

interviews would be transcribed and pseudonyms would be used to replace any

identifiable information. Participants were advised that supervisors would see the

transcripts after anonymisation.

9.4. Transparency and Debrief

The brief and debrief documents were transparent as no deception was involved in the study. When debriefing the parent, they were asked if they have any questions about the research. In addition, the parent was provided with a debrief sheet (Appendix 2). The emotional impact of the questions on the participants were considered (BPS, 2018). Signposting parents to other services was included in the debrief sheet for further support regarding their child and themselves. Contact details for the researcher and the university were given in the debrief sheet for any further questions or concerns parents have about the research.

9.5. Risk to Researcher

Interviews were held in a public community building. It is possible that some parents may have been waiting for their child's assessment for over 18 months. For many parents, this can be frustrating and they may have been hostile towards the researcher. To minimise the confusion over the purpose of the study, parents were informed that it was an academic study not funded by CAMHS but focusing on parents' experiences rather than support for their child. As a precaution, I took appropriate steps to ensure personal safety. Another person was either in the building or close by. There was a procedure in place to ensure that I was safe.

10. Dissemination

At the point of recruitment, participants were informed that the research may be published and that their data would be anonymised. They were reminded

of this again at the start of the interview. Furthermore, the research would be presented to other parents at conferences held by the local charities that support parents during the process of an Autism diagnosis. This was important in normalising the experience of parents to other parents but also, the research highlighted resources and strategies that would help parents during the wait for their child's assessment of Autism. Participants were also informed that the research may be presented to other organisations that supported families and parents, for example, CAMHS. I hoped that this insight into parental experience would assist in service development for the support of families and parents.

11.   Safe Keeping of Records

Participants were informed that recordings of the interviews would be stored securely. Transcriptions and consent forms were kept in a locked cabinet. Recordings were transferred to the computer immediately and audio recordings deleted from the dictaphone. Further security measures are outlined below:

- Personal data was not stored on portable devices.

- The computer that the data was stored on had updated firewalls and virus checking to protect from any threats.

- The computer was password protected. No other person had knowledge or access to the password.

- Regular password protected back-ups were taken of the computer, so if any problems occurred with the computer the data would not be lost.

- The data will be retained for five years as advised by the BPS (2018) guidelines. Following this, all information will be destroyed.

12.   Validity and Evaluation

When thinking about quality of qualitative research, Yardley (2000) suggested sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance as criteria. Sensitivity to context was addressed by recording and transcribing interviews. By recording the interviews, I was able to stay in the participant's frame of reference during the interview and was able to fully explore their experience. Reading and rereading helped to be sensitive to the context during analysis by immersing myself in the data. Commitment and rigour was attempted by engaging fully with previous research when selecting an appropriate research question and with the participant during the interview. The study was rigorous by choosing the appropriate methodology and analysis to address the research question. The research also demonstrated transparency and coherence. I was very clear with participants during recruitment, informed consent and debrief as to what I was interested in studying. In addition, the interview schedule was clear in how it was constructed and the rationale for the questions. Finally, the impact of the research was explored prior to the research and during it. I deliberately engaged with organisations for recruitment that I felt would be influenced by the research by the type of support that they provide. In the dissemination of the research, I investigated services, such as charities and CAMHS, and offered to share my findings through presentations to consider how it would change the support they offered to parents.

Guidelines proposed by Elliot, Fischer and Rennie (1999) focus on "owning one's perspective, situating the sample, grounding in examples, providing credible

checks, coherence accomplishing general versus specific research tasks and resonating with readers" (Elliot et al., 1999, p 220).

One way is improving validity in triangulation. Triangulation is the consideration of multiple perspectives to converge the data (Breitmayer, Ayres and Knafl, 2007). This was completed with emerging themes through supervision and peer reviews. This include an examination of major themes and whatever they could be justified and grounded in the text. From this, I hoped to demonstrate transparency in how the themes had been derive and credibility in the data I collected.

With regards to how this fits with my epistemological philosophy, I feel that it represents the conflict with triangulation. It can be argued that triangulation relies on a positivist stance, whereby this is one, singular truth (Angen, 2000).

13.   Methodological Reflexivity

With reflexivity being a crucial component of this research, I have used this section to explore my relationship with the data.

My initial research proposal focused on parents' experiences of waiting through an online forum. However, the literature review identified studies where data had been collected and analysed through forums without any direct contact with the parents. Since my experience of talking to parents waiting for an assessment, I was aware that they were often frustrated that they were unable to speak with someone face to face. I decided that I wanted to interview parents, partly to validate them as important and worth meeting. This led me to develop my research further with a clearer idea about data collection and eventually to

the research question. I identified their experience of waiting as a lived

experience and began to build my ideas. I intentionally left the research question

open to parents' experience of waiting for their child's assessment of Autism. I

did not want to limit the findings of the study and I hoped to represent the voice

of the participants by allowing them to express openly in the interview without

too many restrictions.

To support this, I included open questions in the interview schedule and

provided myself with a list of prompts and probes to build a greater

understanding of participants' responses. I thought carefully about the order of

questions and the importance of building rapport before asking sensitive

questions. I started the interview by introducing Autism as a general topic and

what the participants wanted to gain from taking part in the study. I had made a

conscious decision to share my own ideas and opinions about the topic at the end,

so not to bias the participants' accounts. This felt awkward and incongruent to

me. I felt that starting with more factual information allowed the trust to develop

in the relationship with the participants before asking more personal and emotive

questions.

I started collecting data in September 2017 and this process took

approximately 8 months. I kept a reflective diary where I wrote my own thoughts

and feelings. I wrote about how I felt with my participants before, during and

after the interviews and ideas I had about the research during the interview. This

helped me to reflect on myself in the role of the researcher, but also how it was

affecting me as a practitioner and a person. I often found that while I was

interviewing, I was focused on the task. It was during the transcribing process and

analysis that the data began to have a greater emotional impact on me. I found

that it affected my mood, making me feel sad and helpless. I was aware that there was some transference from the participants to me through reading the data. For example, I sometimes worried that others reading the research would think that I was overexaggerating how negative this experience was for the parents. Feeling like others would suspect lying became one of the subthemes for the participants. Acknowledging this pattern through my reflective diary helped me to focus on my own wellbeing and looking after myself when engaging with the data.

I think that the biggest challenge that I faced during the interviews was feeling that I wanted to help. In some ways, I felt that this was linked to the researcher-practitioner conflict. In these moments, I tried to remain quiet. I noticed that when I did this, participants often continued to speak. I would often encourage participants to answer my questions until they expressed that they did not have anything left to say. When I talked about these feelings with my supervisor, we acknowledged the similarities between how I was feeling and how participants felt about their experience of waiting; powerless.

14.   Participant Information

Pseudonyms were used for the participants and their children. Other identifiable information was omitted from the transcripts.

Gemma was a woman in her late 30s. Her daughter, Hannah, was on the waiting list for an Autism assessment and also had a diagnosis of ADHD. Hannah was 6 years old. Gemma was a working parent and lived with her husband and two daughters. She had been waiting for an assessment for two and a half years.

Rebecca was a single mum in her early 40s. Her son, Tom, had been on the Autism assessment waiting list for two years. He was 9 years old. Rebecca lived with her son and her older daughter. She also worked.

Amy was in her late 30s. Her daughter, Anna, was 10 years old and they had been waiting for an assessment for two and a half years. Amy worked and lived with her husband and daughter.

Louise was in her early 40s and was a stay-at-home mum to four children. Her daughter, Emily, was 10 years old and had been waiting for an assessment for two years. She lived with her husband and four children.

Olivia was in her 50s and worked part time. Her son, Lee, was 10 years old and had been waiting for an assessment for two and a half years. She lived with her husband and her son and had another son and daughter who were grown up and lived outside the family home.

Zoe was in her 50s and was self-employed. Her son, Henry, was 17 years old and they had waited 6 months for an assessment. She lived with Henry and her husband and had an older daughter at university.

CHAPTER 3: ANALYSIS

1. Introduction to analysis

The research focused on how parents make sense of their experience of waiting for their child's diagnosis of Autism. Previous literature explored aspects of this experience using quantitative methods that provided some understanding, but I felt that qualitive methods would gain more insight into this experience. Interpretative Phenomenological Analysis (IPA) was the most appropriate method of analysis to answer the research question. This was because IPA incorporated the assumption that people can self-reflect (Smith, Flowers & Osborn, 1997), which seemed crucial in understanding how parents make sense of their experience and allowed for a deeper exploration. The double hermeneutic approach used in IPA combined empathic and questioning hermeneutics (Smith & Osborn, 2003). The methodology was compatible with the theoretical stance. Smith and Osborn (2003) recommended that IPA was a useful method in research topics that are novel because it acted as a framework rather than imposing theoretical pretext (Brocki & Wearden, 2006).

IPA includes interpretation that is influenced by myself and my experiences. This means that data is explored reflexively. I have tried to be tentative in my interpretations to reduce the chance of misunderstanding the participants. I have kept a reflective diary to explore the pre-conceptions that I bring to the research.

2. Table of master themes and sub-ordinate themes

This chapter explores the interviews of parents' experiences of waiting for their child's diagnosis of Autism. Master themes and sub-themes are shown in the table below.

Master Themes	Sub-ordinate themes
Developing an understanding of the child	Comparing child to others
	Differentiating between Autism and the child
	Having a shared understanding of the child
The suffering parent	Identifying as a bad parent
	Struggling with own mental wellbeing
	Feeling like other's suspect me of lying
Focusing on the future	Feeling uncertain
	Feeling hope
	Feeling stuck

Table 1: Master themes and sub-ordinate themes of the study.

In this chapter, the master and sub-ordinate themes are presented, including quotations from the transcribed interviews. Participants are referred to by their number to protect confidentiality and the names of their child are pseudonyms. Names of any professionals or places are omitted from the transcripts. Quotations are labelled with participant name and line number from the original transcript. E.g. *Participant Pseudonym, L14-15*.

3. MASTER THEME 1: DEVELOPING AN UNDERSTANDING OF THE CHILD

All of the mothers in the study related a difference in understanding their child, whether this was through sharing their confusion about their child's behaviour, applying Autism to understand the child or comparing the child to others. The participants identified difficulties in understanding their child, although there were moments of clarity and a change over time.

3.1. Comparing the child to others

Participants made sense of their children by comparing them to others. Some mothers compared their child to others who had Autism and identified similarities and differences with this group. They also compared them to neurotypical people, identifying common behaviours with them.

Gemma compares her child to Autistic children in the first quote. She uses it to minimise the child's speech and language issues by comparing her to non-verbal children. She conveys that her child is "not that bad". She is not convinced that her child has Autism and that she is struggling to accept it. Perhaps she is showing that she is grateful that her child's symptoms are not worse.

Since Autism exists on a spectrum, Gemma shows her knowledge and awareness that her child's symptoms are "not that bad". Gemma may be trying to think more positively about the child, but she is down playing her experience as "not that bad". If Gemma feels that her experience could be worse, perhaps she feels that her suffering is not justified.

"Hannah has some verbal communication issues but it's not that bad. Some

children with Autism are non-verbal" (Gemma, L425-426)

"But actually, this is another point which I do struggle with, and this is the guilt

coming in, is I've only got 2 children, both of which have additional needs. I have

additional needs, obviously, other people in the family do. I don't actually know

what normal is, so I have no base line to know, is what I do normal? Do all parents

have to do this? Am I doing more? Am I doing less? Do you know what I

mean? It's quite hard to base opinion on something if you don't have a

*datum. Do you know what I mean? Because our family's like *waves hands in air**

*yeah and I presume people are here *lowers hand* but maybe I'm, maybe*

everybody has to do scenario-based training with their children, I don't

know. Again, there's no it…you just don't know. ….. you just don't know what

children are meant to be like. I never grew up with children, you know some

people grow up with thousands of cousins and things and you kind of get an idea

of what children are like. I don't have anything to say oh children are like that, I

don't know, but just because professionals tell me that's not the case but do you

know what I mean, it just it would also be nice to know what is normal standard,

neurologically normal, whatever" (Gemma, L625-640)

Gemma attempts to compare her child to a neurotypical child, but she

struggled with an example. She claims that her family have additional needs, so

she was not certain about "normal" parts of her child's presentation. She is trying

to compare her child to establish differences and similarities, perhaps to alleviate

the uncertainty of whether her child is Autistic. Gemma is second guessing herself

when she wonders whether her parenting is different to others. She is doubting

whether her child requires more support or whether this is a normal level of

support for a child. By doubting herself, it could affect her confidence in coping with her child or her perceptions of her parenting by comparing herself to other parents.

Rebecca makes sense of her child's behaviour by comparing him to an Autistic child, "Daniel".

"I don't want Tom to be….there was a young boy in the school called Daniel and he was in my daughter's year, so he's nearly 14 now, he um he was picked on he was hated by the school staff um and I mean hated by the…he was not very likeable boy, um, I suppose if you had to make him work. However, this is a boy that when he came to school he was so excited to give out all of his sweetie cones to everybody, this was his last year in primary, so he was old enough, he was so excited to give the sweetie cones, when he gave my daughter, she put it down on the table, but someone swiped it, and she was like, oh someone's taken it, he went home and saved part of his birthday cake and brought it in for her the next day. He was such a caring loving misunderstood boy. And it's awful and he went through the whole of that school without…the teachers hated him, you know, I've seen them roll their eyes at him before and I'm thinking that must be heart-breaking for his mum. And I can see my son being the Daniel of this year."
(Rebecca, L220-230)

She explores how others perceive an Autistic child in a negative way, and she fears and predicts that this will happen to her son. The reference to Daniel's mum gives insight into how she believes she would respond in the future. She uses "heart-breaking" as a way of emphasising the strong bond with her son and the physical pain experienced by a mother of seeing her son ostracised. She recounts the positive attributes of Daniel and particularly focuses on how others

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misunderstand him, such as the staff at school. She uses strong language like "hated" and "roll their eyes" but Rebecca identifies with Daniel's mother. She worries that her son may also experience this treatment from school staff and she feels that it is breaking her heart. It is interesting that she does not explore explicitly how she feels about this and perhaps distances herself from this emotion by talking about it through Daniel's mother because the pain feels too intense for Rebecca to tolerate.

"My daughter went through the whole of the school absolutely beautifully, she's wonderfully average, no ups, no downs, beautifully average, sailed through the school and I just praised it. As soon as my son started, he's had awful times from the beginning, he's in the beginning of his fifth year and um he's just had an awful time the whole way through it, um people take advantage of the fact…at the beginning when my son started, his speech wasn't very good, they would take advantage of that" (Rebecca, L25-29)

She compares her son with her daughter, who is not Autistic. She values being "average" and highlights the difference of school life in the children. She uses comparison with other children to explore her son's similarities with Autistic children and differences with neurotypical children. She explores how her perception of the school has changed with the experiences of her two children. She talks about the time being awful compared to her daughter who "sailed through". Holding two different experiences of the school is confusing for Rebecca and reflects that she struggles to combine them into one understanding of the school. For example, she attributes the struggles of her son to him being new to the school but acknowledges that there has been no improvement over time. This makes her feel powerless and at a loss to know what to do.

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Louise compared her child's behaviours to those of her other children, who did not have neurodevelopmental conditions:

"But the parenting skills thing, was everything I already knew, I was already doing with all my other kids, but had learned through, I think we got to a crisis point, where Emily was being very aggressive, swearing, shouting, be violent with me, being violent with the other children, but it was because she could not have the same, let's say, reward and you can't discipline her in exactly the same way as the other kids. There was like a vacuum, she constantly tried to manipulate situations which, all children try and do that any way, that's just survival, normal, learning, but I think because she was struggling to cope, and I wasn't listening in the way she needed me to, she wasn't really telling me what was going on." (Louise, L112-120).

She drew on how she needed to be different for her daughter with regards to her parenting and that strategies that worked with her other children were not appropriate for her daughter, whilst waiting for her assessment. Although Louise was able to identify what did not work for her child, she did not seem sure about which strategies would work. Perhaps it reflects that the mother is going through a process of elimination. She also talks about the impact of having to treat Emily differently and I wonder whether she feels guilty that she is unable to treat all her children the same.

I felt that what Louise highlighted here is that not all undesirable behaviours of the child were due to Autism or the personality of the child. She normalises her daughter being manipulative by acknowledging that all children can behave like this, regardless of personality or diagnoses. She acknowledges the reasons that children can behave like this but feels that Emily was behaving

like this to cope. It feels as though Louise takes some responsibility for this but the limitations of Emily's ability to communicates is also responsible. Louise looks to understand her child's behaviour, her own behaviour and how she and Emily communicate with each other. Perhaps Louise feels inadequate as a parent because her child is struggling to communicate with her.

"My best friend who I used to work with, her son was Autistic, but he was lower scale. Oh, he was bad. All the windows had to be locked. I mean he's 19 now, but all the windows were locked to stop him jumping out. She used to come in with black and blue arms. She used to worry about what was going to happen, she was only tiny. That was before anything about Louis, and you see now I can understand where she is coming from" (*Olivia, L479-483*).

Olivia talks about her friend's Autistic son to compare him with Lee. She relates to her friend's concern about managing her child's behaviours. Olivia expresses worry about managing Lee's more physical behaviours as he grows bigger and stronger. She feels scared that her friend's experience is an insight into her future of raising Lee.

"Some children present obviously, something that is not the norm, whatever you think the norm is, and I guess the norm in our society is measured by how people cope with school. It's interesting in Henry's year, there were clearly two other children much more noticeable than my son. Actually three, now I think about it because him and another have some similar traits, don't quite fit in but they don't cause any problems and academic mostly achieve and never going to be picked out." (Zoe, L9-11)

Zoe compared her child to others in his class at school, in particular, those with Autistic traits or additional needs. She draws on her understanding of the

other child to normalise her child's experiences. She acknowledges that Autism

can present in a subtle way and can be missed in schools when the child does not

cause problems in the classroom. She uses this to normalise her son's

presentation and experience in education.   There is a sense of hopelessness when

she says, "never going to be picked out" and frustration that her child has been

overlooked by the education system because his behaviour is not problematic in a

classroom environment. She is also frustrated that the school felt he was

achieving academically but Zoe does not feel that he is reaching his full potential.

This reflects how Zoe's expectations of her son are not the same as those held by

the school.

Since her child was not referred for assessment until age 17, she uses

others experiences to normalise the more subtle Autism that is more difficult to

recognise, particularly within the education setting.

3.2.   Differentiating Autism and the child

During the period in which they were waiting for a diagnosis, the mothers

indicated in the interview that they had begun to try to apply their reading and

research about Autism to the child, to make sense of their behaviours. Whilst it

felt that this allowed them to understand their child in a different way, it also

caused some conflict in establishing how much of their child's personality and

behaviour was due to Autism, leaving them wondering which parts were

attributable to their child. It felt as though a conflict existed here, causing more

confusion and uncertainty for the mothers.

Amy illustrated this when reflecting on her child not having siblings:

"There's also times where she is very immature, she can speak like a toddler when she's in a bad mood and can be very babyish. Other times she can come out with things and your like "what are you are a grown up?" But I am unsure if that's because she's an only child and only surrounded by adults or if that is part of her autism." (Amy, L275-276)

Amy reflects on her child's behaviours, fluctuating between behaving like an adult and behaving like a toddler. She conveys her uncertainty about her new understanding of the child around the child's preference of interacting with adults rather than children of her own age. She attempts to establish the cause of her daughter's behaviour. She draws on her daughter's preference in socialising with adults and attributes this to her daughter's upbringing where she is an only child. Amy aims to ascertain her own responsibility and guilt for her daughter's Autism. She is drawing on the nature versus nurture debate; whether Autism is determined by biological and genetic factors that we have no control over or due to environmental factors in early life. Amy is looking for something to blame for her child's behaviour, even if that is her own parenting, to gain some clarity and understanding about Autism and her daughter. She is desperate and willing to self-sacrifice in order to obtain answers.

Louise also picked up on the difficulties around this:

"I know because I have friends who had said it to me, oh Emily is just taking you for a ride. Don't you think that Emily is taking you for a ride? And the problem is, it's that! Because it happens with every other child! It definitely is that! And you have to be like an absolute machine to understand the difference between the two every time." (Louise, L1053-1054)

Louise shares her confusion about Autism and the child and identifies this as a problem. She shows that she makes a conscious effort to makes sense of Emily's behaviour in the context of Autism. She adds another level to the uncertainty and difficulty of differentiating when she says, "every time". This was a constant preoccupation for Louise. When observing her child's behaviour, she is thinking about this differentiation between Autism and the child's personality. It was important for Louise to do this because it distinguished Autistic behaviours from child's behaviours and provides an understanding of Autism and the child. This would allow Louise to keep the two concepts of Emily and Autism separate. Perhaps her hesitance to merge her understanding of Emily with Autism is that she has not been diagnosed or it is easier to understand the concepts as separate rather than combined.

Zoe put this differently:

"Because he's him. And this sort of thing, high functioning you're thinking…. he can mostly cope with life. There are some things that will always catch him and he's just got to know what they are. Anything like that I can help him out but some of the stuff I can't" (Zoe, L545)

She had been talking about her doubts about receiving a diagnosis and not being sure if he would meet the criteria. In a way, this felt more integrated, perhaps with the Autism being part of the child. For her, it felt that Autism and his personality were difficult to separate, perhaps because her son was 17 and they had been living with his difficulties for a longer time. She appears to take a more problem-solving attitude towards his difficulties. Whilst it feels like the conflict exists, and she feels uncertain about whether he will be diagnosed, she

does not appear to consciously try to differentiate Henry from Autism and accepts the uncertainty.

3.3. Having a shared understanding of the child

For many children and young people with Autism, they are able to mask their symptoms. By this, I mean that they make a conscious attempt to hold in behaviours that are socially undesirable. This creates a tension within them. It is common for children on the spectrum to mask symptoms at school, leading to more extreme behaviour when they return home. This can create inconsistent accounts of the child. Some of the mothers explored how this was for them and the impact of the shared understanding on their children.

"But we have a lot of trouble getting her to school, and because we have no diagnosis I don't feel the school truly believe what we go through just to get her to school. Because as soon as she goes through the gates she puts that smile on her face, tears are dry and she's fine. But as soon as she's out of school, it can happen as soon as we leave school, she'll just burst out with all of these emotions." (Amy, L36-38)

Amy illustrates how her experience of the child and in particular, she focuses on the difference in the child's presentation between home and school. She describes her daughter at home as "bursting out" which suggests how Emily's behaviour can be powerful and unpredictable. I interpreted this as the child being very uncontained and that this may feel overwhelming for the mother. This experience makes Amy feel isolated and alone in managing her child's behaviours. Amy feels that her experience is unique, specific to her and feels unsupported.

Louise shared her perspective of this:

"But I feel when you're put under the microscope, and also, kind of made to feel like, initially, every time I said anything about Emily, felt like it wasn't a problem, because actually she presents at school very quiet, very compliant, very well behaved, so it sounded as though the issue was at home" (Louise, L190-194)

Louise uses her language in a graphic way to describe her experiences. Different and conflicting accounts of Emily makes her feel that she is under scrutiny from others and that other people are suspicious of her account. She is under pressure and this creates doubt that her account of Emily is correct.

The impact of the inconsistent accounts for this mother was that for some time, she and others felt like the child's behavioural difficulties were due to factors at home. She emphasises the child's behaviour using the word "very" to more clearly convey the difference between the child's behaviour at school and home. She understood the reasons that others felt there were problems with home rather than the child but this left her feeling like she had to justify herself to others.

"I mean I remember having conversations with my mother when he was in Year 5 and it was really frustrating, his school report. He's clever but almost that teacher, there were 2 or 3 teachers at primary school, and on reflection, understanding things much more, they didn't know what the hell to do with him. But they had to put him in a box somehow, but he was almost [marked] down and I remember one teacher talking to me and thinking I have no idea what you're talking about" (Zoe, L147-148)

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"I think for us that we've been very fortunate that when um things deteriorated

the school were very good at pushing forwards to get us this help. Now I'm aware

of other people that this happened to in the same school, so I have one teacher

that I'm very thankful for, who really started to push it" (Zoe, L138-139)

Zoe explores the impact of having a joint understanding of the child with

school. She talks about his experiences of primary and secondary schools. She

reflects on how primary school did not have the same understanding of her child,

leaving them confused and unsure how to best support the child. At parents

evening Zoe felt frustrated that her child was being marked down because he did

not fit in a box. She describes feeling confused by the teacher's account. Zoe felt

helpless in this, that she could not support her child to achieve or advocate for

him because his intellect was not compatible with the education system.

The difference of having a shared understanding later at secondary school

was that they were able to support the child and family with the assessment of

Autism and through the crisis point. Zoe feels grateful when others saw the needs

of Henry and began to advocate for him. It shared the responsibility and Zoe felt

less pressurised as a parent. She experienced having a shared understanding as

more supportive to Henry, herself and the family.

"It's the schools. They've got a plan ready for him because they knew he was

Autistic, but they couldn't do anything until he was diagnosed." (*Olivia, L202-203*)

Olivia describes having a shared understanding of Lee with the school, in

that they believe he is Autistic and in need of more support at school. She goes

on to explain how this situation is frustrating for her because currently Lee cannot

access the support that he needs. Olivia feels upset and powerless in the

situation, adding to her distress. It adds an urgency to the assessment because

Lee needs to have a diagnosis to access support at school and relieve the suffering for Lee and Olivia.

For the mothers in this study, the experience of developing an understanding of their child is expressed through comparing the child to others, differentiating between the child and Autism and having a shared understanding of the child. It feels as though the mothers are constantly trying to navigate between different positions in the conflicts that they face, whether it is establishing "normal" child behaviours, identifying the traits of Autism or the different presentations of their child in different settings. It gives an insight into how difficult and exhausting it may be for a parent to understand their child's Autism and the confusion of holding so many different ideas that are in conflict.

4. MASTER THEME 2: THE SUFFERING PARENT

All of the mothers in the study talked about their own struggles whilst waiting for their child's diagnosis. They considered their identity as a parent, their difficulties with their own wellbeing and suffering and the impact of this on their parenting.

4.1. Identifying as a bad parent

Throughout the interviews, mothers were critical of themselves and their parenting. Significantly, many used the word "bad" to describe themselves or their parenting. Whilst the mothers engaged with self-education about Autism and interventions, this seemed to increase the feeling of responsibility to support their child. Any time that the child failed or behaved in a challenging way, it reinforced their identity as a bad mum.

*"Even now, I often will be like am I imagining it, you know, am I a bad parent, am I just causing a fuss and then I'll let someone know and go, no don't be ridiculous, you know, etc, and I'm like, ok *sighs*"* (Gemma, L519-521)

Having no certainty about the diagnosis, Gemma doubted whether her child did have Autism or if the behaviour was a result of her parenting. She feared to be seen by others as causing a fuss by requesting an Autism assessment for Hannah. She was not certain whether Hannah's behaviour was more linked to her parenting. These doubts make her feel ridiculous and she was critical of herself for experiencing them. She manages these doubts by talking about it with others, which reassures her. She appears to value this support and can reflect on her doubts by sharing them with others.

"It is really frustrating because I feel that because she's hiding it all, that it is all my fault. I felt that it's all my fault. It just feels like me and that I'm a bad mum" (Amy, L42-43)

"So we have the relief that there is a diagnosis but you still have those doubts in your head that it's your fault and you're a bad mum, stop making excuses" (Amy, 72-74)

Amy also labelled herself as a bad parent and felt that the child's behaviour was due to her, rather than the child. Whilst talking about managing her child's difficult behaviours, she became tearful. She felt alone and isolated as she shared that "it just feels like it's me" and she was struggling to cope more than others around her. I felt moved by her words and a sense of sadness for her.

Amy mentioned this on a number of occasions through the interview indicating that she feels guilt and desperation. Amy uses the uncertainty about

the cause of Autism to take responsibility for her daughter's behaviour. Amy anticipates that a diagnosis will take some of the responsibility away, but she explains that she will always doubt the cause and be partly to blame. This suggests a more permanent state of mind, rather than one linked to the process that she is going through. The invalidation from others and the suggestion early on that parenting was the problem not the child, have expedited this. She suggests that the diagnosis is an excuse for her parenting.

"But the guilt thing, feeling like you're a bad parent. I think everyone has that anyway don't they, so everything I'm saying is like what any parent feels" (Louise, L188-190)

"but I do feel that she will make mistakes that would, in a sense, I don't know, I feel that I have to pre-empt her mistakes before they happen so that they're not too detrimental for her. For example, like friendship, there's a lot of situations that she doesn't tell me that she finds confusing" (Louise, L501-505)

Louise linked the feeling of guilt to being a bad parent. She goes on to normalise this but she minimises her experience. Louise is vulnerable and says that she feels like a bad parent and it is a weakness. Louise feels she needs to be strong during this difficult period, so she justifies her feelings by claiming that all parents identify as bad.

Louise talks about the problems that Emily has with social relationships. Louise feels that Emily is confused by them and suggests a suffering that has a big impact on her. Louise wishes to protect Emily from this suffering and identifies pre-empting difficulties to do this. However, a huge amount of responsibility is placed on the parent to anticipate every difficulty the child faces. For Louise to be able to achieve this, she is hypervigilant, increasing her anxiety about Emily. Pre-

empting all of Emily's "mistakes" is an ideal. Louise is setting herself up to fail so she feels punished, suffers and fails, when Emily also feels this.

"That's the flag we should have really picked [up on]" (Zoe, L331)

This is also reflected by Zoe and feeling responsible for the assessment of her child being delayed until he was 17. She shares this responsibility with her husband, indicating that responsibility for their child is something that can be experienced by both parents. Zoe feels guilty about this and disappointed in herself for missing the signs. From the interview, Zoe had described herself and her husband as well educated and she sees this as a failing on their parenting and intellect.

4.2. Struggling with own mental wellbeing

The participants talked about the impact that waiting had on their own wellbeing. Through the interviews, the mothers became upset and tearful when talking about their experiences.

"it does come with a high level of anxiety for the parent um and worry because obviously you hope with diagnosis comes support, um even if you have to drag it out by your teeth" (Gemma, L190-192)

"I'm awful, because I have ADHD myself, so I struggle with managing all of that plus we both work full time, and our other daughter has additional needs as well. So that's, it's tough" (Gemma, L62-63)

Gemma explored her own diagnoses of ADHD and anxiety as part of her mental health, and the impact on her ability to support her child. For example, to manage self-education and remain consistent with interventions. She needs

support for her condition, to be able to support her child. Gemma feels guilty that she is struggling to meet her own needs and therefore her child's because she recognises the impact of her own difficulties on the child.

In addition to this, she felt that waiting for the assessment had increased her anxiety. She describes the hope of support for the future. This implies that she feels that she is not receiving enough support. However, Gemma does not expect the access to support to be easy. She imagines that she will have to "drag it out by your teeth", which implies that accessing support will be a long, painful process. She feels anxious about how she will be able to do this.

Rebecca explored the deterioration in her own mental health, which was linked with her child's developmental stages and particularly challenging moment during the waiting process. She felt depressed and was not having her basic needs met.

"he was walking at 1, um so 2-4 I pulled my hair out. Don't get me wrong, there were good times as well, um but looking back now, I was depressed as well he got me there. I didn't take anything for depression, but I think I was depressed then" (Rebecca, L418-420)

"You feel like you're going mad" (Rebecca, L427)

"And sometimes people say, oh I've had a really bad night with my child, I'm absolutely shattered, I mean me I can go 3 hours of sleep, I can do it all week, yeah, all week long 3 hours of sleep fine. Because I'm so used to it now" (Rebecca, L502-504).

er mental health and wellbeing was low priority, secondary to her child's. Sacrificing her needs was a way of validating her parenting, because she spoke

proudly of herself for functioning on so little sleep on a regular basis. This was linked to the feeling of guilt that a lot of parents describe. If she is exhausting herself for the sake of the child, then there is nothing more that she can do to support him. Rebecca feels that she needs to be suffering to know that she is doing her best for her child. Rebecca is using exhaustion to manage difficult feelings like guilt. If Rebecca feels guilty that her child is suffering, she may manage this by suffering too. This process helps Rebecca to manage her guilt about disliking her child or his behaviours.

Amy described her anxiety about waiting for the assessment.

"It seems like they are detectives looking to expose me as a fraud rather than identify an issue in my child. Because what I say doesn't even matter, this is so scary and sick when I think about it, I can't sit and relax or I will just have panic attacks about it. I have to distract myself. I've found throwing myself into work has helped as a distraction." (Amy, L197-198)

Amy manages her anxiety by working and distraction, as a temporary solution. She describes an anxious state where she is constantly on alert. Her only way of coping with the anxiety is to avoid thinking about it. In terms of her own wellbeing, she describes a vigilant state where she cannot relax and a fear that she will have a panic attack. The impact of stress on her mental health could be detrimental during 2 years of waiting for her daughter's assessment and how she sees the process of waiting as a threat to herself. Amy's anxiety focuses on her daughter's assessment, in particular, she believes that they are looking to critique her as a parent rather than diagnosing her child. She describes thoughts of being found out, which suggests she is experiencing paranoid thoughts. She relates this to feelings of fear and nausea.

When becoming tearful during the interview, Louise explained:

"I don't know why I feel so upset" (Louise, L847)

"I beat myself up anyway, regardless anyway. I think it's my character. But I think that a lot of parents are like that anyway. A lot of things are their fault. I always see the negative rather than seeing the positives." (Louise, L374-377)

Louise is confused about how she was feeling, perhaps this was more of a reflection of being overwhelmed than upset. There were times in the interview where she shared that she knew she was doing the best that she could, but also she recognised how critical she was of herself. She used graphic language, "*I beat myself up*" to describe this. She used this phrase to convey the pain that she experiences when she feels that she is not good enough. She mentions that she does this "regardless", which implies that she feels any reason would be enough. She feels that she deserves to suffer. She attempts to minimise and normalise this behaviour by stating that all parents feel like this.

Zoe used similar language to explore her and her husband:

"But you know the other thing my husband said is I can't understand, why is he like this when we're a comfortable family, he's had lots of opportunities, you know we sit down, we interact, you know so we go beating ourselves up on that, we've done wrong." (Zoe, L399-400)

She relates this to times when she and her husband have felt they are the cause for the issues that their son is experiencing. She draws on their interaction as a family and their socioeconomic status to search for their reasons that Henry is Autistic. They feel a sense of injustice that Henry may have Autism, with no explicit reason. Although Zoe acknowledges that they gave Henry a good

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upbringing, they continue to blame themselves and punish by "beating ourselves up" under the assumption that they are to blame.

"It has been hard at times, yes when he keeps on about something, sometimes it can be a nightmare, when he kicks off and I think how much more of this can I take, then after I said it, I say how dare you say that. You know you can't say that. We've had some ups and downs. I think for some time we didn't know how to handle him. We know a wee bit more about it now. But it's hard when he kicks off, half of him wants to fight me." (*Olivia, L402-406*)

Here, Olivia talks about the emotional impact of the waiting process on her. She struggles to cope with Lee's behaviour and conveys how difficult it has been for her when she says, "how much more of this can I take". Olivia describes how she criticises herself for saying that she cannot cope. She exaggerates this by saying it twice, perhaps to try and punish herself. Olivia is telling herself off for having these thoughts. She repeats the word "hard" through this quote and the significance of this is in conveying how difficult this experience is for her.

"but for parents and grandparents it's hell. I mean, it's made me ill. With the worry, but there's a lot of things going on apart from Lee." (*Olivia, L578-579*).

Olivia describes the waiting process as "hell" and considers the impact of the worry. The anxiety of the situation has had an impact on her own health. She also considers the role that other stresses impact on her. Olivia implies that the worry caused by the waiting process impacts on her ability to manage other stresses in her life.

4.3.   Feeling like others suspect me of lying

For the mothers in the research, there appeared to be an underlying concern that others would think that they were lying about their child. Many felt that others would think they were exaggerating the child's behaviours or outright creating a false account of their child.

Gemma expressed this by reporting her actions:

*"I get stressed because I spend my life having to video, and I do it in secret, the girls have kind of sussed it out now, so it's a bit difficult, um I've run out of space on my computer, I'm going to have to go through them all because I haven't got time, you know when I'm doing them I just go, kind of dump them because I have to evidence my girls, because it's the only way that I can prove what I'm talking about and actually it's awful. I sat down the other day and thought I haven't taken a photo or video for years, they're all evidence because every time it's like *gasps* got to catch that, and that's awful"* (Gemma, L561-567)

She kept video recordings of her daughter's behaviour to show professionals, including CAMHS and school, since she can mask her behaviours in these settings. She thought that the professionals would be suspicious of her theories of the child and she needed hard evidence to support her case. She describes the extent that she feels that she must do this; to the point where she uses up all of her computer memory. She describes "evidencing" her daughter as "awful", particularly her instinctive reaction to record her daughter when she sees a suggestive behaviour. It has become almost an obsession to Gemma to capture these. This is likely to impact on Gemma's relationship with her daughter where the only thing she feels worth in capturing is her daughter's potential Autistic traits. She is starting to view her daughter as a set of symptoms rather than as a

child, which makes her feel awful, but continues out of her fear of other accusing her of lying.

"I always think, oh people will think that I'm embellishing, and stuff like that, I'm really not embellishing" (Rebecca, L32-33).

Rebecca talks about her belief that others will think that she is lying about her child's behaviour. She expressed in anger, fear that others think that she is lying and feeling relieved when validated by others. This affects Rebecca's behaviour, particularly when raising concerns about her son. She does not feel confident and afraid that others will not take her opinions seriously. It makes her hesitant to share her understanding of the child with others and so other professionals working with the child are unable to support him because they do not have a full picture of the child. This could lead to a deterioration of behaviour of the child both at school and home, and more suffering for the child and parent. Not advocating for her child may lead Rebecca to feel guilty that she is not doing enough for her child and lead to her feeling isolated.

From Amy's quote, she feels isolated and alone. Being without an official diagnosis but advocating for her child made her feel like "a fraud and a liar". Amy is in the transitional state of not knowing if her child is Autistic and knows the support that her child needs but does not feel that she has the validation and authority to campaign for it.

"It's been a really hard week, trying to get her to school, and then she magically becomes that happy go-lucky girl that goes through the school gates, must make the school just think I'm lying. Not having that diagnosis makes me feel like a fraud and a liar" (Amy, L47)

"she presents at school very quiet, very compliant, very well behaved, so it sounded as though the issue was at home, it also sounded like, me, that I was exaggerating things, so there would be situations like she would go to school and she would try and avoid going to the toilet for the whole of the day, because she had a fear of going to the toilet in public places. And she would just not tell anyone that" (Louise, L192-198)

Louise felt that there was a risk that others did not believe her and that she was exaggerating the difficult behaviours of the child. There is a focus on how others perceive the parent and she is not easy to believe when others see the child present in a different way.

Louise's quote gives an example where she feels that she is the only person who can know what is going on for her daughter. Louise believes that the school are more willing to invalidate her concerns as a parent than to try to understand difficult behaviours that are not being presented at school. This illustrates Louise's expectations of the school to be able to understand more about her daughter's behaviour.

5. MASTER THEME 3: FOCUSING ON THE FUTURE

5.1. Feeling uncertain

Some participants expressed uncertainty whilst waiting for an assessment. Some expressed uncertainty of whether their child will receive a diagnosis and what life might be like with or without a diagnosis. Others focused their uncertainty on the child's future.

"…there's always a part of you thinking well that might not be us, oh… but that might not be us. Or ok, I'll save that, do you know what I mean? Because you have, it such a grey, it's such a land of unknown" (Gemma, L394-396)

Gemma describes her uncertainty as a "land of unknown". She is describing another world that is unfamiliar, something that she perceives as big, almost like a country. This waiting is foreign to her, something that she does not understand. It is grey, which suggests that it is bleak and unclear. Gemma describes her uncertainty when she says "it might not be us". She talked about the workshops she had attended prior to the quote from the interview. She talked about not attending some so she has something to "save". She feels that she needs to do this because of her uncertainty of support after the diagnosis. If she saves one of the workshops, then she gains some control over what her future may look like.

Other participants focused their uncertainty about the future around the diagnosis:

"With the assessment it made me very anxious as everything has built up to the assessment, and what happens if she doesn't get diagnosed? Does that confirm me as a bad mum and then that's it?" (Amy, L178-179)

Amy wonders about what her life might look like without the child's diagnosis of Autism. There is a fear that life may continue as it is. Since she expressed how difficult and hard her life has been while waiting for a diagnosis, it seems impossible to imagine a continuation of this. She places importance on the diagnosis because she believes will change her life. Amy also draws on her identity. Mixed in with the fear of no diagnosis is a worry that she will be confirmed as a "bad mum". From the interview, Amy believes that she was a bad

parent, so she uses confirmed rather that labelled or accused. Amy sees that this

would be a permanent status when she says "then that's it", which feels final and

conclusive.

"Going to the assessment, I think would he be?" (Zoe, L544) "Well what do we do

then [if he is not diagnosed]?" (Zoe, L600)

Zoe also shares her uncertainty about the future through diagnosis too.

She wonders about whether Henry will be diagnosed. Through the interview, Zoe

seems to identify Henry's difficulties and describes how they found, or how they

were finding a solution. However, in these quotes, Zoe's ability to problem solve

does not appear. Instead, she expresses uncertainty about how to support Henry

without a diagnosis of Autism. There is a sense of a lack of control, which perhaps

Zoe usually manages through using problem solving to cope.

Louise focused on what support might be like in the future:

"I don't really know what support is out there" (Louise, L682-683)

There was an ambivalence to find out what this support might be and a

fear that there may not be as much support for the child as the parent hopes for.

She focuses on the support in the future as something more concrete that could

change her life rather than a more existential and abstract concept of "the

future".

"Yes that's another worry I've got. He's going to get older and he's quite strong at

the moment and he's only eleven. I think, how am I going to cope when he's

older." (Olivia, L413-414)

Olivia views the uncertainty of the future with worry. In particular, she is

worried about Lee's behaviour and how to manage it as he gets older. Her main

concern is that he will become stronger and she will not be able to restrain him. It is possible that having the choice of restraining Lee may give her a sense of control and that as he grows up, she will have less control over his behaviours. Perhaps restraint is her last resort and that a future without a last resort seems scary and uncertain to her. This links to the unpredictability of behaviours of Autism and perhaps Olivia is also considering this.

5.2. Feeling hope

In contrast to the previous themes, there was also hope expressed about the future. The mothers directed their hope towards accessing more support that would be appropriate for their child, through receiving a diagnosis of Autism. Others focused on their life becoming better in the future and the child succeeding in their own right.

"*Because you do need intervention, they do need to learn skills, I'm 36 and I think I've only just got my ADHD under control this year, you know which is crazy but it's been a long journey for me but I haven't had the support and I just hope that by getting that early support that they'll have a happier life, I hope, we'll see, yeah yeah so that would be good, diagnosis is definitely required.*" (*Gemma, L193-197*)

Gemma expresses hope for the future in using interventions early on. She uses her experience of having ADHD and the difficulties that she has had in accessing support to improve her life. Gemma recognises the value to support from her own experience. This places an urgency on Hannah's Autism assessment, to enable Hannah to access the support as soon as possible. She explores this with regards to her child's life being happier. She sees her child

accessing support as the key to being happier and the idea that the sooner the diagnosis, the sooner the happiness. It places an urgency on the diagnosis.

"But he's good on the computer. He's brilliant, he teaches the other kids. Aye, they get him to teach the other kids. How to use the computers. He's fantastic on the computer. So hopefully that's where he will excel when he leaves school." (Olivia, L268-270)

Olivia describes hope for the child's future. In particular, she focuses on the child's strengths and sees how this may assist him in his career in the future. Olivia suggests that he will not be able to succeed until after he finishes school and I wonder whether she feels the current educational setting is holding him back in some way. Since he is only 11, she feels frustrated and overwhelmed about supporting him through the next 7 years of education, until he can fully thrive.

Amy focused on support available:

"At least I can say to them, look the diagnosis is on paper, this shows that there is a thing and it does exist. Then I could hopefully get more help from professionals without having to fight for it as much. This is especially important for secondary schools, because we want to start looking for the correct school now because she's in year 5, meaning we are going to have to make a quick decision, in a years' time." (Amy, L89-91)

Amy feels like there is a hope that her concerns will be validated and that she can prove to others that her daughter has Autism. Her hope is also founded in the support that may be available for her child. She sees the diagnosis of the child as the key to professionals and their formulation. Amy also hopes that there

will be less of a battle for support for her daughter in the future and possibly life will get easier. She applies her hope for the future by thinking about the most appropriate school for her daughter. Like Gemma, Amy suggests an urgency for diagnosis.

Olivia's hope for the future focuses on support that the family will receive around Lee's Autistic behaviours. Olivia perceives the diagnosis as something that will take some of her worries away. The label of Autism means treatment for behaviours that may hinder Lee is some way, such as his health.

"Yes but eating habits! Chocolate sandwiches, crisps, McDonald's, Chocolate rolls, and that's it. He drinks juice as though it's going out of fashion. And I'm terrified about his teeth, there's something worrying me about his teeth. But then again, I'm hopeful we'll get some help with that." (*Olivia, L192-194*)

Louise suggests that anything different would be an improvement on the current situation. This shows that her perception of her experience at this moment is that it can't get much worse. She also talks about her hope from each moment where there is a change in her daughter's behaviour in feeling that things could get better. Whilst this illustrates the hope that she has in her daughter to be capable of change, there is also a sadness. Louise is constantly raising her hopes that things are improving before they return to normal. She recognises that there has been a general improvement. Louise feels a sense of disappointment but is trying hard not to direct this at Emily by attributing it as "just one of those things".

"Even though, I know what I know, I think because, it's at the back of your mind, you're still hoping that maybe, you know, maybe it could be different if. You don't want to push her any way.

I always hope that this is the moment when she breaks through and it's not so bad. But it is getting better but I think it's just one of those things." (Louise, L396-400)

"And because there's no reason why he can't be successful. I think he will be more successful when he figures out which pathway he wants to be on. So where he can shine." (Zoe, L286)

Zoe chooses to focus on the achievements of the child in the future and remains positive that the future is bright for her son. She identifies that her son is not focused on a particular route at the moment but hopes that when he decides he will succeed. Zoe is relaxed and confident about her son's future. In this quote Zoe is acknowledging that her son may not be successful in everything but feels there is a place where he can "shine".

5.3. Feeling stuck

The participants that were interviewed in the study reflected on how waiting for an assessment of Autism for their child had impacted on their lives. They described being stuck in this transitional state between diagnosis and no diagnosis. This impacted on their everyday lives where they almost seem suspended, unable to make changes and wasting time.

"I think it's very difficult because you kind of feel like you're on pause until you have a diagnosis or not and the other things is, like with the OT assessment, once you've had an assessment I hope they will be able to give you better information about what issues your child has so at that point it would be easier to link in with specific services rather than generic waiting lists, it could be any of these, this is roughly what Autism means but may not relate to you, it may do. And that's just

wasted time on a parent, that's wasted funding of paying for someone to stand up

there and talk to you about something that you may or not relate to you."

(Gemma, L391-402)

Gemma described being on pause until having the certainty of the diagnosis. In particular, she identified the support that that is on hold. She uses the example of having an Occupational Therapy assessment for her child, which gave her a greater understanding of her daughter's specific needs. She also identifies feeling that her time is being wasted while she is on pause because she can only access a generic understanding of Autism, rather than a specific understanding of her child. Gemma is frustrated that funding is being wasted on support that she does not feel is beneficial. This also illustrates the hope that Gemma has of clinicians, to be able to have a definite, clear understanding of her child. It places the clinicians in an Autism assessment in a very powerful position. Gemma's faith in gaining this from an Autism assessment is misplaced and will inevitably feel disappointed when clinicians are unable to give a full comprehensive understanding after a 2 hour assessment.

Amy described help and life as "on hold" until they received the diagnosis or no diagnosis. This is an example of parents not just wanting the diagnosis but wanting the certainty of knowing whether their child is Autistic or not. She identifies support as being on hold for her child and there is a sense of frustration. Amy feels powerless to help her daughter.

"I kind of feel like our whole life is on hold at the moment, waiting for it. Even

though I have read getting the diagnosis through isn't actually this big thing and

that it doesn't help that much but I do feel like it is on hold to get all the help we

need, because at the moment she has a teaching assistant, but that is for the
whole classroom and not specific to her" (Amy, L102-105)

"But, it still feels like I have been waiting so long that nothing has changed. In the
big scheme of this, no one sees anything whereas, I feel that we have come
through a massive journey as a family and worked so hard just to get to an even
keel" (Louise, L879-882)

"So that's been the lowest part of waiting just having situations like that where
you aren't able to get much more help for it rather than the overarching help
which does generally help, but also, it's almost like you're still feeling culpable for
something which is not actually within your control. I also think waiting for
something that may not come is another thing like I can see that may be the
diagnostic criteria and the extremely high functioning, how much does her
possible ASD impair her life. I can say, quite high, her behavioural issues are quite
damaging and I don't know, you know, how that will progress." (Louise, L624-632)

Reflecting on being stuck, Louise shared how nothing had changed in their
life since they had been added to the waiting list for the Autism Assessment.
Being in this transitional phase seemed to indicate that things feel stagnant. She
describes her lowest point of waiting, the most difficult part to cope with, is only
being able to access generic help for Emily and feeling that things are out of her
control, leaving her feeling powerless. She also illustrates how everything is
pinned on this one uncertain assessment, when she says "waiting for something
that may not come". This feels hopeless and that Louise is simply waiting for
something to happen.

"even though we did a lot of research ourselves, you're in no man's land for the last five years because you can't go here, you can't go there, you're just stuck. And there's this brick wall that you just can't get through. Frustrating, and you think Oh God, it's just awful. The wait." (Olivia, L168-170)

Olivia describes the experience of waiting as being unable to move. She expresses how restricted she has felt in being able to access the support that Lee needs. Olivia describes being stuck as being "in no man's land". The image from this language suggests that she experiences the waiting as a battle. Since the term is associated with war and conflict, she uses it to emphasise the lack of movement and changes that she feels while waiting. She is stuck between having a diagnosis and knowing her child has Autism and not having a diagnosis and being unsure if her child is Autistic. Her choice of "you" instead of "I" reflects the pain associated in an environment that she likens to a war zone by using the language to distance herself from the feeling of "stuckness".

She describes a brick wall, perhaps that she sees the waiting process as an obstacle to her moving forward, which feels impossibly hard. She describes it as "awful" and "frustrating". She feels powerless or weaker than the obstacles that she is against, which stop her from helping Lee.

6. Summary

The findings of the analysis indicate that there are 3 master themes and 9 sub-ordinate themes. The mothers make sense of their experience of waiting for their child's Autism assessment by developing an understanding of their child, identifying as a bad parent and focusing on the future. Within this, there are many negative themes that focus on the conflicts that they experience and the

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desperation that they feel towards an Autism diagnosis. Overall, it conveys

waiting for an Autism assessment as a negative experience for mothers that leads

to a deterioration in their mental wellbeing and their confidence in their

parenting. Whilst they maintain hope for the future, it is laced with desperation

that their lives cannot get any worse and a focus on the need to move forward.

CHAPTER 4: DISCUSSION

1. Introduction to discussion

The study's aim was to explore mothers' experiences of waiting for their child's assessment of autism. The research used IPA to investigate this and 6 mothers were interviewed. The purpose of the study was explorative, so there were very few questions on the interview schedule. I was interested in how parents experienced waiting for the diagnosis of their child. The mothers in this study experienced the following themes; developing an understanding of their child, the struggling parent and focusing on the future. The chapter presents the master themes and sub-ordinate themes identified in the analysis in the current study, paying particular attention to any clinical and research implications of the findings.

2. Overview of themes

2.1. Developing an understanding of the child

The research in this area suggests that parents seek to understand their child (Neely-Barnes et al., 2011). For participants in my study, there was the presence of comparing their own child to others of all the participants, with an exception of Amy. Some spoke about having a clear understanding of their child but also experiencing moments of bewilderment and confusion. The salient idea in this area was that the mothers wanted and drove for a better understanding of their child. There were many benefits that they associated with understanding but I felt that the main hope was that their lives would improve, as they could predict and feel more confident in helping their own child with difficulties.

2.1.1. Comparing child to others

Perhaps one way for the mothers to better understand their child is by comparing them to others. It appears that comparing their child to Autistic children helped them to identify and label some more typical behaviours and led to greater understanding of their child in the context of Autism. It also seemed as though parents compared them to neurotypical children, perhaps to understanding their child in the context of being a child. That is, that parents identify behaviours that are typical of children.

I think for most parents, there was a feeling that there was something wrong with their child without knowing what it was specifically. This leads to a sense of confusion about who their child is, how to raise and support them.

Whilst the research on Autistic children and their parents has not highlighted comparison, Mulcahy and Savage (2015) identified it as a theme in their study. Therefore, the current study builds on the literature presented by Mulcahy and Savage (2015) by applying the theme of "comparing the child to others" to parents of children pre-diagnosis of an Autism assessment.

From the study, parents compare their child to siblings, the child's classmates and friends' children. It appeared to be an important part of the processing about who the child is, by drawing similarities and differences with others. A label can change how an individual identifies their relationships with themselves and others (Erikson, 1968). I wondered whether just the prospect of their child being faced with a label has changed how they relate to their child. The mothers are trying to make an effort to understand their child with a possible new identity before they have received a diagnosis. Gemma gives an example of

this, as found in the analysis section; there were feelings of frustration that others were not seeing the full picture of the child and therefore, there was inadequate support, leading to a deterioration in the child's behaviour, suggesting a greater sense of struggling for the child.

The current study seems to have findings that are compatible with previous research. The mothers looked to understanding their child better by comparing them to children who were Autistic and Neurologically Typical. They did this by seeking similarities and differences that they held with their own child. This study contributes knowledge that this process also exists when parents are waiting for a diagnosis of Autism.

2.1.2. Differentiating between Autism and the child

Through the interviews, parents talked about their understanding of Autism. Many talked about researching Autism online and speaking to parents of Autistic children. Some talked about their own knowledge of Autism prior to the referral for an Autism assessment, but most started acquiring it around the time their child was referred. The mothers in the study began to apply their information and knowledge of Autism to their child. However, this also seemed to create conflict at times, that is, whether their behaviour was due to the child as an individual entity with their own free will and agenda, or whether their behaviour was linked to Autism. An alternative explanation could be that due to the varying presentations of Autism, with no one typical presentation, there are a lot of discrepancies between children with Autism, making Autism more difficult to understand as a separate concept. Perhaps there was another function of externalising Autism and their child. The negative behaviours associated with Autism may feel more removed from the child. This would allow parents to

continue to love and support their child, without feeling guilty about disliking the behaviours exhibited by the child. This could be protective towards the parent and child attachment and alleviate the guilt of not liking their child.

Externalising a problem is a technique used in systemic therapy. The purpose of using the technique is to distance the responsibility and shame away from an individual (Good therapy, 2016). White and Epston (1990) highlighted the benefits of this; it decreases conflict, reduces the sense of failure, opens up cooperation to manage the problem, including generating new possibilities and creates a lighter, more effective, less stressed approach.   The mothers appear to be doing this when talking about Autism and their child. Using this theory, the mothers' experiences could be explained as externalising Autism and attributing the negative aspects of their child's behaviour to the Autism. This may protect the child from the dislike, embarrassment or shame that the behaviours elicit in the mothers. However, this may be interfering with the process of incorporating Autism into the child's identity, and therefore, limit their understanding of the child and their needs. It may be helpful to do this when an individual is Autistic because there is so much variation in the presentation of Autism.

An alternative explanation for this could be that the mothers have not had an assessment for their child and are uncertain about whether their child is Autistic. Until their child is diagnosed, perhaps it feels safer for them to distance Autism from their child. This may be part of their grieving for the loss of their child (Gray, 2003), that the mothers are in denial that their child is Autistic. They distance Autism and their child because they have not accepted this yet.

Several studies highlight the process of incorporating and separating Autism from the child's identity (Molloy & Vasil, 2004; Robinson, York,

Rothenberg & Bissell, 2014; Craig, 2015). This research fits into the ideas

suggested by previous research, especially Punshon, Skirrow and Murphy (2009)

identity formation, which suggests that Autism becomes integrated into identity

after diagnosis, which may explain why the parents in this study saw Autism as

external to their child. Whilst this study focused on people's experience of their

own diagnosis, they highlighted that it takes time for Autism to be integrated.

Their participants described a process where they internalised what people said

about them, which was usually negative, and the framework of understanding,

provided by a diagnosis, promoted a sense of belonging. The authors likened the

experience to that of "coming out" by members of the Lesbian Gay Bisexual and

Transgender community; that identity formation was a process of change rather

than a single revelation (Cass, 1979).

Interestingly, in this study, Zoe was the only participant that did not

attempt to separate her son and Autism. She expressed that Henry's personality

and Autistic traits were who he was and that she did not split her child's identity

into separate concepts. Rather, for her, these concepts were merged and were

not possible to separate. This suggests that there is a small number of parents

who may not experience this conflict. Zoe's son was 17, compared to the age of

other mothers' children (age 7-11). Perhaps this was because Zoe had the

opportunity to spend more time processing the possibility of her son having

Autism.

2.1.3. Having a shared understanding of the child

For the mothers in this study, there seemed to be an importance on their

understanding of their child being shared with others. Mostly, this appears to be

with the child's school in order to support the child, CAMHS to be diagnosed, and

sometimes with extended family and friends. Many parents in the study did not experience a shared understanding, which elicited feelings of isolation and loneliness. The existing research suggests that parents perceive positive collaboration as decreasing uncertainty and as a result they feel less stressed (Moh & Magiatti, 2012). Existing research has also found that when parents and professionals collaborate the quality of information increases and is more helpful (Osbourne & Reed, 2008; Brogan & Knussem, 2003). They also suggest that this could lead to parents feeling empowered to help their child. Perhaps another reason that this reduces stress in parents is because it shares the responsibility of the child's development and progress amongst a larger group of people. This applies a more systemic approach in supporting a child with Autism.

An additional complexity in Autism is that children are capable of masking symptoms. This refers to the ability to hold in Autistic behaviours, sometimes motivated by wanting to fit in or only express behaviours that are socially desirable. This can create accounts of the child, which are very different and dependant on the setting that they are in.

2.2. The struggling parent

Throughout the interviews, I felt that the mothers identified waiting as a mostly negative experience. There were moments where they described stress, desperation and hopelessness. There was a sense of sadness that ran through their stories, suggesting that they were suffering.

The mothers in this study expressed suffering through their sense of self, their own mental wellbeing, through their beliefs of how others perceived them and their perceived responsibilities whilst waiting for a diagnosis.

2.2.1. Identifying as a bad parent

Existing research with parents who have children with additional needs suggests that they often feel that they are failing to parent their child. Taslaq's (2016) paper identified parents blaming themselves and trying to sacrifice some things to bargain with fate. In this study, one mother in particular, Rebecca, appeared to sacrifice her own needs by exhausting herself to feel like a good enough parent. Most of the mothers expressed a responsibility towards their child and perhaps this indicates a need to have some control over their lives. However, there is little research that explores the impact of this, for example, parenting confidence while waiting for a diagnosis. This current research plays a role in introducing a new idea about how parents perceive their own identity whilst waiting for their child's assessment. In future research, it may be helpful to explore where the experience of identifying as a "bad parent" comes from and the influences in the environment that can exacerbate this perception.

However, this research does not address how this may affect the parents or the professionals supporting the child. The mothers in the current study experience their sense of self as bad parents. There was a sense that they were responsible for the way that their child behaves, with some mothers feeling that they had done something wrong in the early childhood parenting that may have caused their child to have Autism. This could be associated with feeling ashamed and guilty. One parent, Amy, felt that even a diagnosis of the child would not change this. Instead she felt that this was a permanent state of her identity and she framed the potential diagnosis of her daughter as an excuse of her parenting. This could suggest that identifying as a bad parent, starts before diagnosis and continues for an indefinite time after this has happened. I believe that this would

have an impact on a parent's self-esteem, belief of their competence and their emotional wellbeing.

Goffman's (1964) paradigm states that parents are stigmatized as a result of being associated with a stigmatized group; that is their child. This affects their biographical identity and how they negotiate the social world. Gray (1993) added that parents of Autistic children can also be subjected to enacted stigma, whereby members of the public glanced, stared at their child or gave unsought advice on parenting. This led to parents reducing their activity in public to avoid being positioned as the "bad parent with naughty children" stigma (Farrugia, 2009). Perhaps the mothers in this study experienced similar stigma in public, leading to the internalisation of being a "bad mother". Farrugia (2009) concludes that the medical construction of an Autism diagnosis allows parents to resist stigmas by placing them in a discursive setting, such as the "world of Autism" where their identities are not spoiled by stigmas. Since the mothers in the study did not have a diagnosis for their child, they may experience their identity as bad parents because they are unable to resist the stigmas associated with being a parent of a child with Autistic traits.

Through the interviews, the mothers expressed responsibility. This included them being responsible for their child's behaviour, their child's distress and for them having Autism. Whilst all of the mothers that were interviewed had self-educated about Autism and they had a better understanding of their child, many interpreted this as them being solely responsible for the successes and failures of the child. Since all of the children were without diagnosis and mostly struggling, the mothers focused on examples that demonstrated the distress that

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the child and parent were experiencing. There were feelings of guilt and isolation associated with this experience.

Mothers in the study identified as bad parents and this made me consider how they came to this conclusion, and how they differ from good or ideal parents. Belsky, Conger and Capaldi (2009) suggest that parenting styles can transmit over generations, therefore expectations about parenting are based on the individual's own experience of child rearing from their parents. Perhaps the mothers in the current study had a positive upbringing where there were clear boundaries and discipline. Since these were not effective for managing their own children's behaviour, they labelled themselves as bad parents. With hindsight, it would have been interesting to explore this in the interviews and understand the mothers' expectations of parenting.

Transgenerational parenting styles may also be linked to maladaptive schemata. Milosi, Szabo and Simon (2017) considered that adverse childhood experiences with parents' caregivers could lead to the development of maladaptive schemata, which could then manifest into their perceived competence as a parent. Since the mothers in this study considered themselves to be bad parents, they may share similar schemata which have affected how they view their own parenting.

The mothers also came from different cultural backgrounds. One participant was Asian, two were working class and another two participants had postgraduate qualifications. Research suggests that culture affects child rearing practice (Bornstein, 2012) and that parents have different expectations of their children.

Whilst parents of different cultures have different expectations of the child, they also exhibit different behaviours towards the child. Keller, Voelker and Yovsi (2005) compare German mothers to Western African mothers. They observed mother-infant interactions and found that German mothers focused more on face to face communication and exclusive attention and Western African mothers addressed body contact and body stimulation. When considering the behaviours of Autistic children, it is possible that the behaviour of both groups of mothers are challenging to Autistic children. Autistic children can struggle to make eye contact with others, which may cause problems when communicating with German mothers. They can also be sensitive to sensory stimuli, such as hugs and touching, which they find overwhelming and is more characteristic of Western African mothers.

Five out of six participants expressed that they were bad parents, regardless of the difference in their expectations of the child. This shows that the mothers in the study may have had different ideas about parenting based on their culture, but all felt that they were failing as parents during the waiting period.

2.2.2. Struggling with own mental wellbeing

Following on closely to this was the parents' mental wellbeing. Many of the mothers in the study disclosed the emotional impact of waiting for their child's assessment. Mostly, it was the worry that parents struggled with, but depression and stress were also mentioned. The mothers believed that the combination of parenting a child with additional needs and the stress of waiting for an assessment of their child's diagnosis impacted on them significantly. Previous studies have documented stress of parents with an Autistic child.

Most of the existing research indicates that parents with Autistic children experience more parental stress (Estes, Munson, Dawson, Koehler, Zhou & Abbott, 2009) and increased stress can make an individual more vulnerable to mental health issues. For parents waiting for their child's assessment of Autism, there can be the experience of depression. In particular, mothers are at a higher risk than fathers of developing depression (Hastings, Kovshoff, Ward, degli Espinosa, Brown & Remington, 2005). One explanation of this could be that mothers have a more prominent role in caring for the child and fathers adapt coping strategies (Hasting et al., 2005). However, as gender roles are changing in society and more men are becoming the primary carers for their children, it is possible that this may change.

It would also be important to consider the impact of having additional stresses besides the stress of parenting an Autistic child. This study adds new literature to this topic in understanding how it feels to experience additional stress when parents have an Autistic child.

This could provide more information in the dynamic that can influence the parent-child relationship before the child is diagnosed with Autism. Although the current study does not seek to do this, it would be interesting to investigate the impact of stress on family relationships.

2.2.3. Feeling like others suspect me of lying

The mothers in the current study expressed concerns in their interviews that others perceive them as liars. This came partly when the child used masking at school, as it generates a different account of the child, leaving the parent seeing a very different side at home. The other part came from the extreme behaviours of the child. For example, some mothers felt that others would not

believe how distressed their child would become in some situations. This left

them doubting themselves and feeling unsure about sharing their understanding

of the child with others.

The existing research shows that parents often experience professionals

as dismissing or minimising their concerns (Caronna, Augustyn & Zuckerman,

2007; Schall, 2000). Ryan and Salisbury (2012) conducted a thematic analysis of

parents' experiences pre-diagnosis and found that parents who felt their concerns

were not believed by professionals left them feeling isolated and alone. However,

this data was collected retrospectively, meaning that the experience could have

been distorted by time. It may also have allowed them to reflect on how different

things felt then, whereas parents in the current study were having the experience

of continuously feeling like they would not be believed. Braiden, Bothwell and

Duffy (2010) also had a sample of parents that experienced this, but unfortunately

were subject to the same limitation.

The current study adds to the existing literature of how parents feel when

they are judged by others. It may be leading to more isolation of the parents and

possibly creating a taboo about how parents are feeling. This may impact on

parents' ability to process their experience of waiting if they are not able to talk

about it and may result in an unconscious supressing of the associated feelings.

This could be understood in different ways using different psychological theories;

for example, it could be evidence in psychodynamic therapy as a defence

mechanism or in narrative therapy as preventing thickening of alternative stories.

From a narrative perspective, the dominant story could focus on instances

when parents feel that they have not been taken seriously or their concerns have

been dismissed by others. This could be reinforced by the cultural context of

parenting, for example, parents should be able to manage their child's behaviours. This may come from the mothers' own experience of being raised by their parents and how this contributes to their own expectations of their parenting (White, 1993).

It also may limit the usefulness of peer support for parents if they are concerned about being judged. It could increase social anxieties in this particular group and possibly lead to deterioration in their mental wellbeing.

2.3. Focusing of the future

The final master theme from the analysis was the focus that the mothers had on the future. This related to thoughts and feelings that the parents had about the future and what it may look like. This was separated into three themes; feeling uncertain, hopeful and stuck. In line with being in their transitional state, the mothers were not sure how things would progress, with particular emphasis of what life may look like, with or without an Autism diagnosis. Many felt that life may get better after the assessment, whilst knowing that the diagnosis of Autism would not resolve all of their problems. There was also a feeling of not moving and being static while they were waiting for the assessment of Autism for their child. The research in this area supports focusing on the future as a key experience. The existing literature suggests that parents have hopes and worries for the future (Fong et al., 1993; Mount & Dillon, 2014; Craig, 2015).

2.3.1. Feeling uncertain

The mothers expressed uncertainty about their own and their child's future. Some focused on the diagnosis and that they were unsure if their child would receive it. When discussing not receiving a diagnosis in the interviews, they

expressed even greater uncertainty about how they would feel, think and act, if their child was not diagnosed. For others, they focused on the support that may be available after the diagnosis. This was around the child's needs and whether they would have access to specialist services to help them to manage difficult behaviours. There were feelings of desperation and fear associated with not knowing what might happen in their future.

Some mothers expressed uncertainty about their child. Mulcahy and Savage (2015) found uncertainty was a superordinate theme in parents with concerns about their child's development, in particular, how their child might function in the future and what their abilities might be. Furthermore, the literature also supports the uncertainty of parents about their child receiving a diagnosis (Midence & O'Neill, 1999). Braiden et al.'s (2010) research also highlighted that parents can feel uncertain about the diagnostic process. The current research supports previous findings that parents waiting for an assessment of Autism for their child experience uncertainty.

2.3.2. Feeling hope

Whilst there were many themes in this research that indicated negative experiences and processes whilst waiting, many of the mothers also expressed hope for the future. In particular, there was hope for their child's future with regards to career or functioning. However, for others like Louise, hope was expressed because she felt she had reached crisis point and that her life could not become any worse. There continued to be a sense of desperation and sadness within this hope.

Taslaq's (2016) research on Palestinian parents waiting for a diagnosis identified hope as a theme. In her paper, she describes parents holding hope for

their future and their children. This could support hope as an experience that is

consistent across cultures for parents who are waiting for a diagnosis of Autism

for their child. Hope has been identified with Romanian parents (Oprea & Stan,

2012) with regards to their child. Furthermore, evidence suggests that mothers

that experience high levels of hope experience lower levels of worrying (Ogston,

Mackintosh & Myers, 2011).

Even with the combination of the samples, it would be important to

exercise caution about generalising, as the sample is still very small. In addition,

there could be another reason that this similarity exists in these cultures. Perhaps

the research only attracts samples of parents who want to improve the literature

and understanding to enable life to be better for others and may naturally be

more hopeful than other parents.

This study supports the existing research. However, I believe that the

experience of hope for parents in this study was not simple and not necessarily

positive. Perhaps the hope that anything would change represents how difficult

and awful this current experience is for them. The experience of waiting for the

assessment is so all consuming for the parents, that there is little evidence of

positive emotions. Perhaps, this reflects how big the impact of waiting is having

on their life. Not only does it affect their present life, but also their perceptions of

the future.

2.3.3. Feeling stuck

Finally, the mothers expressed a sense of being stuck whilst waiting for an

assessment for their child. Being stuck has been identified in previous studies.

Donald (2015) identified a mixture of experiences in the participants that she

interviewed. She explained that some parents felt stuck when perceiving Autism

as a life-long condition, acknowledging that their child would always experience difficulties. It felt that, in the current study, the mothers were stuck in their uncertainty about the understanding of their child and what steps to take to benefit their child. In some ways, it illustrates how the focus can change from the child, to this undefined period of waiting where there are no changes and only the anticipation of the outcome of assessment. This current study contributes to the existing research. Whilst Donald (2015) indicated a minority of participants experienced feeling stuck, this study suggests that the experience applies to more parents than previously thought and can apply to a number of concepts including diagnosis.

In this study, the mothers expressed an inability for life to continue or move on whilst waiting for an Autism assessment. This led to a feeling of urgency for a diagnosis. Perhaps it also reflects who is affected by waiting. If parents feel stuck and unable to move forward with their lives, how might this feel for the child and other children within the family unit? It directs a sense of frustration in not being able to receive a diagnosis in a timely way. Perhaps it adds expectation and frustration towards the NHS, particularly in their failure to relieve suffering. For the mothers in the current study, this could have added to their isolation and loneliness experiences and increase the level of stress within the family.

3. Limitations of the research

3.1. Limitations of the research method

IPA is a subjective qualitative methodological approach. I have attempted to conduct the analysis of the data in this study by being transparent in my

interpretation of the data and have tried to promote the voices of the participants.

The research method did not include sufficient attention to the discourse and language in the interviews. This was due to the focus of the research being on the lived experience and sought to gain an insight into this. However, it could be argued that insight into the experience is entwined with the language used to communicate this with the interviewer. Therefore, it would be important to consider that different insights may have been found if the study had considered the role of language more explicitly.

Finally, it could be argued that this approach favours information that is more easily linked with cognition. IPA focuses on the meaning that participants attribute to an experience and how they make sense of this.

3.2. Limitations of the sample

It would be important to consider the selection bias amongst the participants. The experience of other parents that did not participate may have been different from the mothers who did chose to participate.

As the sample consisted only of women, this research cannot contribute any further understanding of the experience of fathers to the current literature. Future studies could explore this, as it remains an undeveloped area of research.

The women in the study all had school age children on the waiting list, suggesting that perhaps their child had not begun to present with Autistic behaviours until later life. This could be due to the children having better coping

strategies and difficulties did not start earlier. The themes found in this study may not apply to mothers with a pre-school child on the waiting list.

I have also considered the recruitment of the participants as a possible bias on the sample. They were recruited through an organisation that supports parents of Autistic children, before and after diagnosis. Mothers were also recruited through other participants, who were friends. It is possible that the sample may have been engaged with support services and support networks because they were more vulnerable or struggling to cope, compared to parents who did not seek any support. It may be possible that the mothers in the study experienced waiting for an assessment as more negative and having a bigger impact on their lives. The themes from this research may not be applicable to mothers who are coping through the assessment wait as they may not experience it so negatively.

All the mothers in the study were recruited from the UK and therefore, the cultural perception of diagnosis may impact on their experience. For example, in Western cultures, there is a preference for labels and diagnoses. Perhaps if this study had been replicated in Non-Western cultures, particularly those who do not recognise Autism formally, the focus may be more on the needs of the child rather than a label they receive from a health professional.

3.3. Researcher limitations

This was the first qualitative study that I have conducted, and I consider myself to be a novice qualitative researcher. Through the study, I believe that this is reflected in some of my decisions. During the process of completing this

research, I have gained essential learning that I believe will be valuable for future research projects.

The dual role of practitioner and researcher was a challenge during the research. I felt that it was important to be able to embrace a researcher persona, which allowed me to bracket common interactions; for example, sharing my own experiences and opinions, using my clinical judgement and steering conversations to examine appraisals from different and more positive perspectives (Smith, Flowers & Larkin, 2009). I was mindful of my practices as a therapist and tried to remain focused on the task. I was aware of the power that I held as the interviewer. I used my reflexive journal to consider this and it helped me to process my own thoughts and feelings. I believe that this helped me to separate my experience from the participants. However, I was aware of the impossibility of bracketing everything, so I acknowledge that my own perceptions have inevitably impacted on the research.

When I started interviewing, particularly in the first interviews, I believe that I was very focused on the researcher persona I was trying to embrace and conduct the research "by the book". I feel that after, I reflected on the data I had collected and the richness of the experience. I began to feel more certain and confident in my role as a researcher. I also recognised that I was concentrating too much on my role and the interview schedule. It had led me to miss out on probing discussions and perhaps uncovering new information about the participant's experience.

Power in the relationship between the participant and myself was considered. This was promoted as viewing the mother as the expert and having a semi-structured interview to allow them to speak freely. Whilst I was unable to

share too much information about myself at the beginning of the interview, I was transparent and explained that I did not wish to influence them. I think part of this was due to the anxiety of being a novice researcher and perhaps I did not need to convey this so explicitly as it assumed that I have the power to withhold, whereas I was expecting them to share. However, I think explaining that I would share after the interview helped them to trust and understand that I was only delaying the information. One participant did seem surprised that I did work for CAMHS and said that she may have not shared her view about the service if she had known. I also explained that it was likely that I would not say much during the interview because I hoped to capture their experience.

4. Strengths of the research and relevance to Counselling Psychology

The study contributes new and novel findings to the existing research. IPA focuses on the lived experiences in the present, rather than establishing the reasons that the experience occurs.

The current adds to the understanding of mothers who are specifically waiting for an Autism assessment for their child. Whilst there are waiting times associated with other neurodevelopmental disorders such as ADHD and learning disabilities, the themes found in this study are likely to be specific and exclusive to parents waiting for Autism assessments only.

Parents of children with potential ADHD may be more focused on the diagnosis to access treatment in the form of medication. For parents with Autistic children, there is no treatment or cure and the mothers in the study expressed an understanding that the diagnosis would not provide a solution of all the problems. However, due to the treatment options available for ADHD, parents may experience this differently.

For parents with children with a potential learning disability, there may be less guilt than those of Autistic children. The reason for this would be that the cause of learning disabilities is bio-medical and this takes the responsibility away from parents. Also, learning disabilities are often present from birth or after trauma to the brain and unlikely to be caused by parenting. Perhaps there is less stigma attached to parents of children with learning disabilities because of these reasons, so the feedback from the environment around the parents is also less negative. This would mean that parents of children with learning disabilities may

not experience concern that others think that they are lying, feel less guilt and not see the difficulties of the child as a result of their parenting.

Using a hermeneutic philosophy helped to gather a rich collection of data that allowed myself and the participant to explore their experience. The research method enabled the finding of themes at a time when mothers were experiencing waiting rather than retrospectively. This allowed a more accurate representation of their experience than in existing research. IPA accounts for the influence of the researcher on the study and promotes the openness of reflections. This study does not suggest that any replication would elicit the same themes but respects that each person has their own interpretation of the world, grounded in their perception of their experiences.

The study also makes a contribution to Counselling Psychology. In 1994, the British Psychological Society recognised Counselling Psychology as a distinct and unique profession (Corrie & Callahan, 2000). Counselling Psychologists have the flexibility of working in different settings including the NHS, where the dominant language of communicating an individual's difficulties is through diagnostic classification. This can lead to conflict for Counselling Psychologists in embracing a medical model instead of the humanistic approach of our training (Larsson, Brooks & Loewenthal, 2012).

Within the profession, Counselling Psychologists argue that they do not work from assumptions that are associated with a diagnosis. From this study, the themes suggest that diagnosis for mothers is important and that the anticipation of waiting for an assessment is a difficult process. It highlights that deterioration can occur for mother and perhaps contributes to the literature that negotiates the positive and negative aspects of diagnosis within Counselling Psychology. The

study could provide an increased awareness of how the wider system is affected with the absence of a diagnosis. This may lead to a better understanding of parents, their motivation for their child's diagnosis and assist in building a stronger therapeutic relationship with families. It may help Counselling Psychologists to re-evaluate their stance between the medical model and the relational model when working with families with a potentially Autistic child, by incorporating the phenomenological experience of the family. It may also reduce the anxiety and resistance based on losing the identity of a Counselling Psychologist (Larsson et al. 2012).

5. Clinical implications

Whilst completing the study, I reflected on how it influenced me both personally and professionally in my reflexive diary. In particular, I considered the impact of the knowledge elicited from the study on the populations I would work with as a Counselling Psychologist. I had spent some of my training working with young people, children and their families and felt that my passion and way of working was associated with a systemic approach. I view the young people and their difficulties as an interaction within different systems such as, school, work and home. Socially constructed meaning is affected by context and context connects us with different stories, influencing how we make sense of our interaction with the world (Pearce, 1994). Cronen and Pearce's (1991) Coordinated Management of Meaning (CMM) model promotes using a collection of ideas to understand how young people communicate and allows us to build a more complex understanding about them. This helps to identify their difficulties and needs more accurately.

Since starting the research, I have noticed a difference in outcomes of therapy with young people, which is dependent on their parents' own mental wellbeing and understanding of their child. For example, parents with mental health conditions may be more focused on their own needs than their children's needs. This study is relevant to working with parents who are waiting for their child's assessment, in helping them to manage their own stress and wellbeing, provides implications when working with a child and perhaps working systemically with families that are going through this.

One of the aspects of this research that surprised me was the extent to which the mothers in the study were suffering. There was a significant amount of anxiety expressed about their children, anxiety about what others were thinking of them and a sense of guilt that they were not doing enough to help their child. Their response to this seemed to be behavioural; reading about Autism, trying new interventions or recording their child's behaviour. However, their reaction when talking about their experiences was emotional. Perhaps having a therapeutic space would be helpful to reflect and process the emotions that they are experiencing. It would also be important to consider the role of therapy to validate concerns or worries that they hold within the experience. From this, they could be empowered to continue to support their child and seek appropriate support from others.

Another benefit of providing therapy for this population could be to help draw on their strengths and resilience. Research (Polkki, Ervast & Huupponen, 2005) found that having a resilient parent helps children to cope with adversity and build their own resilience.

In thinking about suitable therapeutic approaches for this population, it would be important to consider the role of self-criticism and doubt during the process of waiting. Therefore, Compassion Focused Therapy (Gilbert, 2009) may be appropriate. In addition, it may be helpful for parents to consider circular hypotheses around anxiety and how this may impact on their children. For example, the stress caused by waiting may lead parents to be short-tempered and shout at the child. The child may react negatively, having a meltdown because they feel overwhelmed by the sensory experience of shouting. This could lead to the parent feeling unsure about how to manage the child's behaviour and this could cause the child to continue to express their distress. The parent could feel even more stressed and place a greater urgency on the assessment and diagnosis, to access support for the child, leading them to feel even more stressed about the diagnosis waiting times. This could be useful in acknowledging unhelpful patterns within the family that lead to dysfunctional behaviours and unmanageable dynamics.

A narrative approach (White & Epston, 1990) may also be useful for parents to make sense of their experiences, perhaps also in understanding the development of their identity into a "bad parent". It could be helpful to think about the external events that have contributed towards the development but also identify the strengths in their parenting to explore how they are "good parents".

This research also has clinical applications to working with young people and children who are going through this process. For example, it gives a potential insight into some of the stress that could be experienced within the family home. This may help with the formulation of other mental health conditions that the

young person or child may be experiencing. Furthermore, the study emphasises the importance of collaborative working between parents and professionals to allow parents to understand the needs of their child. It may be appropriate for parents and professionals to share information, with the young person's permission, to empower parents to support their children.

6. Recommendations for future research

A dominant experience from the research was that the participants felt they were struggling in their role as a parent. They attributed this to being a bad parent, having difficulties managing their own mental health and being seen by others as a liar. Future research could explore the progression of their confidence as a parent, perhaps whether after diagnosis this changes in the short term or the long term. An IPA or Grounded Theory study could consider how mothers perceive their own parenting and the impact of different experiences on this. For example, the role of having a written and concrete diagnosis on their confidence in parenting of difficult and challenging behaviours. It could also investigate the impact of retrospective factors, for example, the impact of being told by professionals to attend parenting courses. Recommendations could be made about how professionals treat and communicate with parents pre-diagnosis. It could also give parents hope if confidence increases after diagnosis or create a rationale for increasing interventions to help parents feel more confident in parenting an Autistic child.

Further investigation could draw on the impact on parents when their child masks Autistic traits. In the current study, the mothers felt worried about not being believed due to their child masking and creating inconsistent accounts of their behaviour. However, masking can also be a positive coping strategy for

children and young people on the Autism Spectrum in helping to build friendships and perhaps helping them to feel that they can fit in. It felt like there was a conflict at times between allowing the child to be themselves but struggling when the child displayed socially inappropriate behaviours. This research may be helpful in understand parents' anxiety while waiting for a diagnosis, especially when working with this population therapeutically. It may help to reduce social anxiety and others labelling them as "liars" and help parents to advocate for their child more confidently.

7. Summary and final reflections

My perception when I started this project was that waiting for an Autism diagnosis was a tense and uncertain period of a parent's life, where they also experience additional stress from parenting a child with additional needs. On a personal level, I hoped to find some stories about resilience, coping and hope, perhaps to compensate for the depressing and negative stories with an Autistic child. The research, at times, was difficult due to the sense of hopelessness and struggling in the literature and the emotional impact that this had on me.

My interviews with my participants really drew my attention to how easy it was for the mothers to become lost in the struggling of their child. However, I was inspired by the love that these mothers had for their child and how it was used to motivate them each day to keep going. In this journey, some mothers had begun to find outlets for their child's behaviour and showed a real understanding of their child in the context of Autism. Other expressed the sense of feeling lost and finding it difficult to shift from the negativity.

The participants also inspired me to have the confidence in telling their story. Most expressed their fear of being seen as a liar and I felt privileged that they were able to trust me. I feel that this has given me the courage and motivation for this research.

Whilst acknowledging the uncertainty, anxiety and frustration of waiting for an assessment and help for their child, the mothers showed me, someone without children, that regardless of how awful it feels, there is hope for a better life for their child and themselves.

Throughout the analysis, I attempted to portray the good and bad experience accurately by staying close to the words of the participants.

During the interviews, I felt close to the mothers that participated. I reflected on the reason I felt this, perhaps in how I share similarities in gender, sexuality and living with someone with Autistic traits, despite not being a parent myself. Therefore, perhaps it would be a mistake to consider the issues in this study as a solely as a result of waiting for an assessment of Autism. Some of the ideas I could relate to, like being under pressure, and some that were more novel to me, such as understanding your own child.

I felt a great deal of responsibility for the mothers and their experiences. Throughout the period of the study, I often talked to my own mother about Autism diagnosis and the years of waiting, leading up to it. I felt a strong sense of desperation of their experiences when I thought about the cuts to the NHS and the reality that waiting times are likely to increase. I felt their frustration at schools and other services that could not support the child until after diagnosis. As I contemplated the strong feelings I held about my participants and their experiences, I felt that the role I wanted to take on for them was an advocate;

that others understood this was a difficult period but not appreciating how difficult it was. I think that this became apparent to me through the analysis that my participants and I shared a lot of similar feelings.

Having completed the research and reflecting on the process of this study, I have considered the questions/lines of enquiry that I did not pursue. The stress of waiting and having a child that the mother did not completely understand must have had an impact on their relationship. I did not explore what their perception of their relationship was or how they felt in the relationship. Perhaps the relationship had changed through waiting for the Autism assessment. I wondered why these ideas had not occurred to me earlier. Perhaps it demonstrates how it can be easy to be pulled into fixed ideas, for example, the impact of waiting on an individual and not on the wider systems and their interactions, meaning that it is harder to access ideas that are further away.

Conducting the research has given a small insight into the experience of mothers waiting for a child's Autism assessment. As a single, childless woman working with mothers of potentially Autistic children, I was able to see the challenges they face on a daily basis but also the resilience to keep going for the sake of their child and that a mother's love knows no bounds.

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APPENDICES
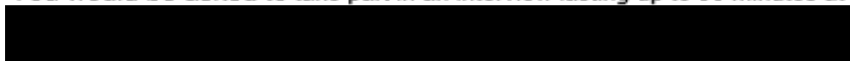
Appendix 1 Flyer for recruitment

**Department of Psychology
City University London**

PARTICIPANTS NEEDED FOR RESEARCH IN EXPLORING PARENTS' EXPERIENCE OF WAITING FOR THEIR CHILD'S ASSESSMENT OF AUTISM

You would be asked to take part in an interview lasting up to 90 minutes at

For more information about this study, or to take part,
please contact:
Emma Munro – Trainee Counselling Psychologist

Supervisor – Julianna Challoner

Psychology Department
at

Email

This study has been reviewed by, and received ethics clearance
through the Research Ethics Committee, City University London [PSYETH
(P/L) 16/17 158].

If you would like to complain about any aspect of the study, please contact the Secretary to
the University's Senate Research Ethics Committee on 020 7040 3040 or via email:

Appendix 2 Debrief form

Exploring Parents' experiences of waiting for their child's assessment of Autism.

DEBRIEF INFORMATION

Thank you for taking part in this study. Now that it's finished we'd like to tell you a bit more about it.

The research attempted to examine how parents experience waiting for their child's assessment of Autism Spectrum Disorders.

Previous research has suggested that parents with children on the Autism spectrum find waiting for an assessment challenging and stressful. Since the child's behaviours exist before diagnosis, the study looks to explore how parents experience this on a day to day basis, with the additional stress of waiting for an assessment. Whilst parents are usually unsatisfied with the process of waiting for an assessment, the research seeks to find out the types of support that parents access and their experience of them.

The analysis of the interviews investigated how parents think, feel and behave during this time, and how waiting impacts these. This could range from practical coping strategies to readjusting expectations of their child and their future.

The interviews aimed to gain the perspective of parents of this and whether parents accessed support that was useful and adequate. The research looked to identify the benefits, limitations and any potential improvements that can be made to feedback into this service. There is a possibility that the research will be published in academic journals and the data may be used in presentations to services that support parents and families with Autistic children.

If after the interview, you feel that you may need some support, you can contact Talking Therapies, who provide a confidential therapeutic service to adults http://www.talkingtherapies.berkshire.nhs.uk/.

Other services that provide support for parents and families include:

- Berkshire Autistic Society 01189 594 594
- National Autistic Society 0808 800 4104
- Raft Club (support for Reading based families through play activities) 01189 543 437

- Autism Support – Jenna Redmond (Autism Support worker for Reading based families) 07912 362 341
- Parenting Special Children – 07876 275 731
- ASD family help for Wokingham based families – 07707 660599
- Autism Spectrum Disorders Support Group for Slough families – 07528 372 811

Since ASD can be comorbid with ADHD, there are further resources if you have concerns about these below:

- The Hyperactive Children's Support Group 01243 539 966/ www.hacsg.org.uk
- ADDISS (National Attention Deficit Disorder Information and Support Service) – 020 8952 2800/ www.addiss.org.uk
- Parenting Special Children (ADHD and ASD) as above

We hope you found the study interesting. If you have any other questions please do not hesitate to contact us at the following:

Emma Munro
Trainee Counselling Psychologist
City University London

Ethics approval code: PSYETH (P/L) 16/17 158

Appendix 3 Participation information form

Title of study Exploring Parents' experiences of waiting for their child's assessment of Autism.

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The research aims to investigate how parents experience waiting for their child's assessment of Autism Spectrum Disorders. From the study, the researcher hope to gain parents' perspectives to potentially adapt the service to meet the needs of parents with a child on the waiting list for an Autism Assessment. The study will be conducted as part of the researcher's Doctorate in Counselling Psychology.

Why have I been invited?

The study looks to recruit parents who are waiting to have their child assessed for Autism Spectrum Disorders.

Do I have to take part?

Participation in the project is voluntary, and you can choose not to participate in the project. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw during the interview and without giving a reason. You will have one week after the interview to withdraw your data from the study.

The study is not linked with your child's assessment.

What will happen if I take part?
- *The data collection section of the project will be conducted until September 2017. The final write up of the project will be by September 2018.*
- *If you take part in the interview, you will spend approximately 90 minutes with the researcher.*
- *The interview will be semi-structured, that is that the researcher will ask some open questions but allow the conversation to follow your own concerns and interests.*
- *The researcher will be looking for themes in the interviews.*

What do I have to do?

Participation in the study will involve attending at interview with the researcher, on a one to one basis. The interview will last approximately 90 minutes.

What are the possible disadvantages and risks of taking part?

The topic of conversation in the interview will concern your perspective of waiting for your child's assessment. Sometimes life at home can be difficult for parents attempting to manage challenging behaviours of their child. It may become stressful to discuss this. The researcher will give breaks if the interview becomes overwhelming, and you will be able to stop the interview at any time.

What are the possible benefits of taking part?

These would be important discoveries for Counselling Psychology as it may lead to a more effective and accessible approach to supporting children and their families before and during the assessment phase of ASD. Furthermore, it will contribute to the understanding of waiting for assessments and the impact of this on the child, parents and family.

It will also help to develop the support that the service provides to parents during the time of waiting for the assessment.

What will happen when the research study stops?

The interviews with parents will be recorded and converted to transcript. Recordings will be stored on the computer in an encrypted folder and will be password protected. After the interviews have been transcribed, the recordings will be destroyed. Any identifiable information from the interview will be removed in the transcript. The transcription will also be stored in an encrypted folder.

The data will only be used for the purpose of the study and will not be used for any other purpose. The data will not be shared with any other organizations.

If the research is not completed, all data will be destroyed.

Will my taking part in the study be kept confidential?
- The researcher is the only person who will have access to data. The researcher's supervisor may be consulted regarding the data, after it has been anonymized.
- Audio recordings of the interview will only be kept until the transcriptions have been written. After this, the recordings will be destroyed.
- No personal information collected in the research will be shared in the future.
- Data will be archived. This will be kept in an encrypted folder, under password projection. All data will be anonymized.
- All information will remain confidential. However, confidentiality will be broken if the researcher has reason to believe there may be a safeguarding issue; that is the parent or children is at the risk of harm from themselves or others.
- The records will be stored with the City University database.

What will happen to the results of the research study?

The study will be submitted as part of the Doctorate in Counselling Psychology. It is possible that the project will be published in academic journals. All data will be

anonymized and maintained. If you wish to receive a copy of the paper, please contact the researcher at █████████████████████

What will happen if I don't want to carry on with the study?

As the participant, you are free to leave the study at any time without any consequence and explanation. You will be able to withdraw your data up to one week after the data is submitted to the researcher.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: *Exploring Parents' Experiences of Waiting for their Child's Assessment of Autism.*

You could also write to the Secretary at:
Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London
EC1V 0HB
Email: █████████████████████

City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Who has reviewed the study?
This study has been approved by City University London Research Ethics Committee, (PSYETH (P/L) 16/17 158)

Further information and contact details

Julianna Challoner – █████████████████████

Thank you for taking the time to read this information sheet.

Appendix 4 Ethical Approval for City University

Psychology Research Ethics Committee

School of Arts and Social Sciences

City University London

London EC1R 0JD

01 June 2017

Dear Emma Munro and Julianna Challenor

Reference: PSYETH (P/L) 16/17 158

Project title: Exploring Parents' Experiences of Waiting for their Child's Assessment of Autism

I am writing to confirm that the research proposal detailed above has been granted approval by the City University London Psychology Department Research Ethics Committee.

Period of approval

Approval is valid for a period of three years from the date of this letter. If data collection runs beyond this period you will need to apply for an extension using the Amendments Form.

Project amendments

You will also need to submit an Amendments Form if you want to make any of the following changes to your research:

> (a) Recruit a new category of participants
>
> (b) Change, or add to, the research method employed
>
> (c) Collect additional types of data
>
> (d) Change the researchers involved in the project

Adverse events

You will need to submit an Adverse Events Form, copied to the Secretary of the Senate Research Ethics Committee (███████████████████), in the event of any of the following:

> (a) Adverse events
>
> (b) Breaches of confidentiality
>
> (c) Safeguarding issues relating to children and vulnerable adults

(d) Incidents that affect the personal safety of a participant or researcher

Issues (a) and (b) should be reported as soon as possible and no later than 5 days after the event. Issues (c) and (d) should be reported immediately. Where appropriate the researcher should also report adverse events to other relevant institutions such as the police or social services.

Should you have any further queries then please do not hesitate to get in touch.

Kind regards

Hayley Glasford   Richard Cook

Course Officer   Chair

███████████████████   ████████████████

Appendix 5 Initial noting example

27 S: Definitely for the future, it wasn't really a big thing when she was little

28 because as toddlers the behaviours are pretty similar across all children

29 but as she gets older and the behaviour doesn't change, and do you know

30 about girls and masking.

31 E: Yes, they tend to be very good at masking and presenting themselves

32 S: Yes, so she can be really sociable, maintain eye contact, she can really

33 mask at school. But we have a lot of trouble getting her to school, and

34 because we have no diagnosis I don't feel the school truly believe what we

35 go through just to get her to school. Because as soon as she goes through

36 the gates she puts that smile on her face, tears are dry and she's fine. But as

37 soon as she's out of school, it can happen as soon as we leave school, she'll

38 just burst out with all of these emotions.

39 E: So what is that like for you, to have a child who when they come home is

40 very difficult to manage?

41 S: It is really frustrating because I feel that because she's hiding it all, that

42 it is all my fault. I felt that it's all my fault. It just feels like me and that I'm

43 a bad mum. (Cries)

44 S: It's been a really hard week, trying to get her to school, and then she

45 magically becomes that happy go-lucky girl that goes through the school

46 gates, must make the school just think I'm lying. Not having that diagnosis

47 makes me feel like a fraud and a liar. I'm sorry for crying.

48 E: It's a difficult process to go through as it's your child.

49 S: I don't really have anyone to talk to, apart from my husband, so
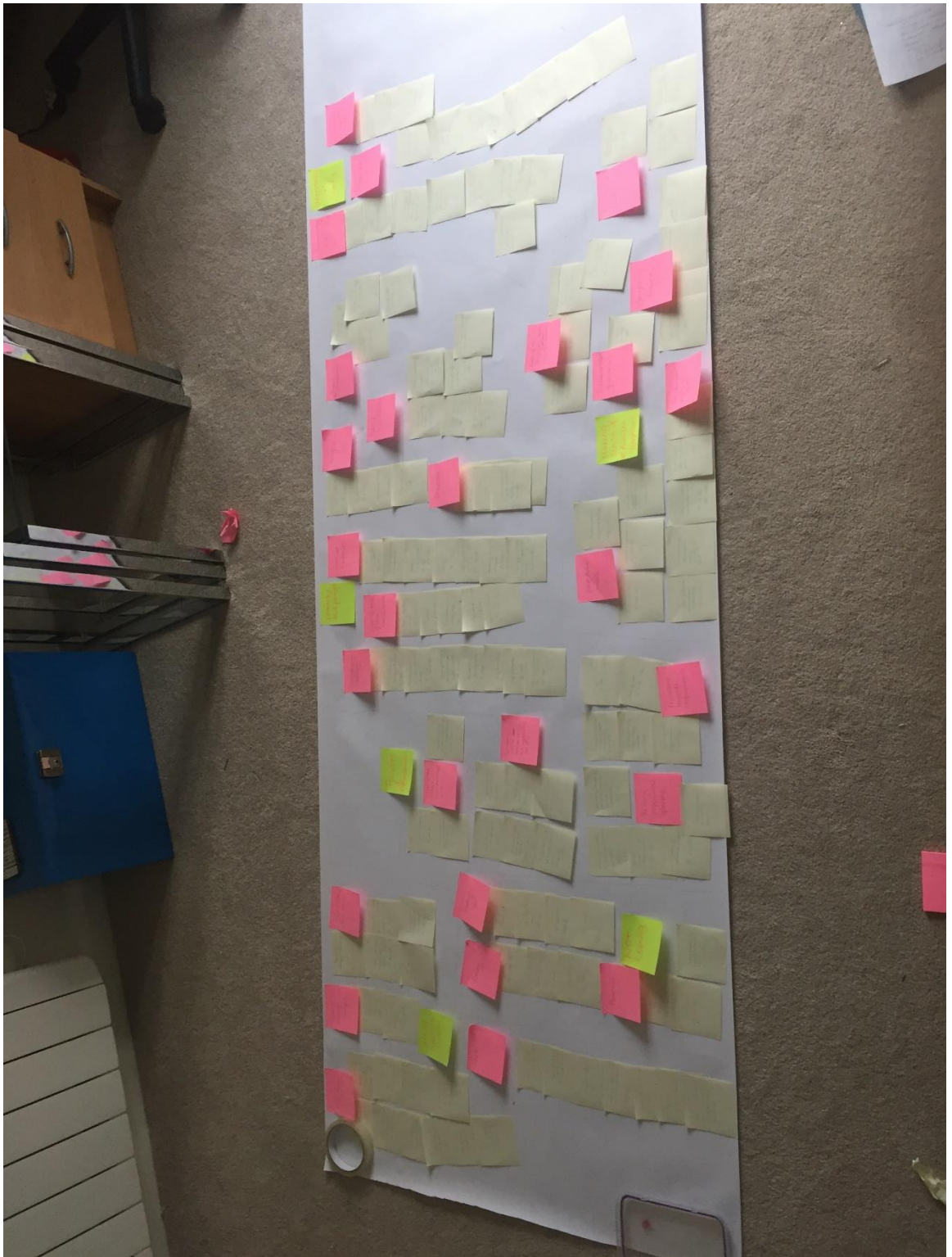
50 probably just talking about it.

51 E: Does it feel like it's just you and your husband most of the time?

52 S: Yes, we do go to a support group once a month for parents with autistic

53 girls. There are people there we can talk to, which we do but I wouldn't go

Appendix 6 Post-it notes