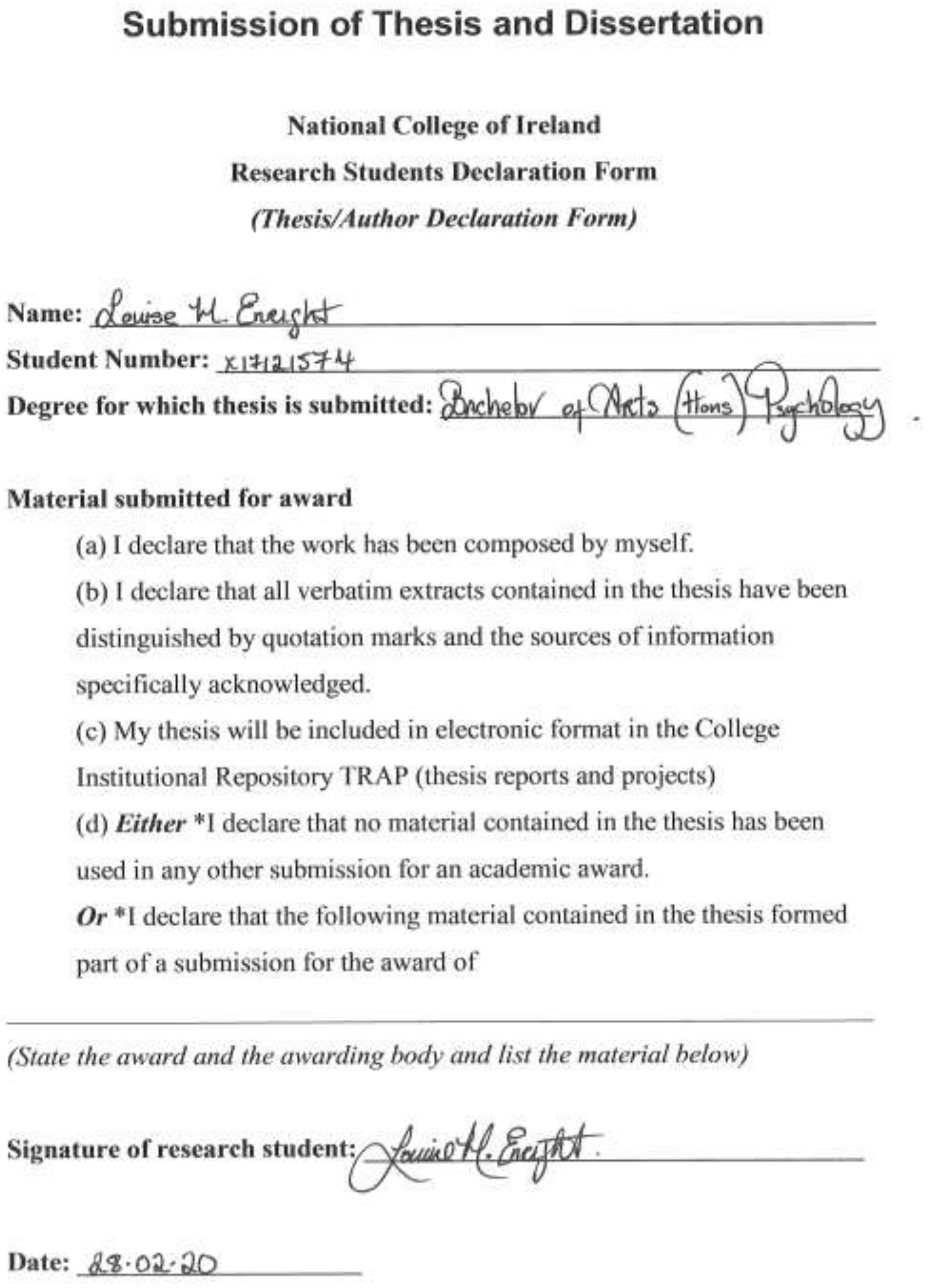
Louise M. Enright
17121574

National College of Ireland
BA (Hons) Psychology

Supervisor: Dr. Caoimhe Hannigan
Year of Submission: 2020



Submission of Thesis and Dissertation

National College of Ireland
Research Students Declaration Form
(Thesis/Author Declaration Form)

Name: Louise M. Enright
Student Number: x17121574
Degree for which thesis is submitted: Bachelor of Arts (Hons) Psychology .

Material submitted for award

(a) I declare that the work has been composed by myself.

(b) I declare that all verbatim extracts contained in the thesis have been distinguished by quotation marks and the sources of information specifically acknowledged.

(c) My thesis will be included in electronic format in the College Institutional Repository TRAP (thesis reports and projects)

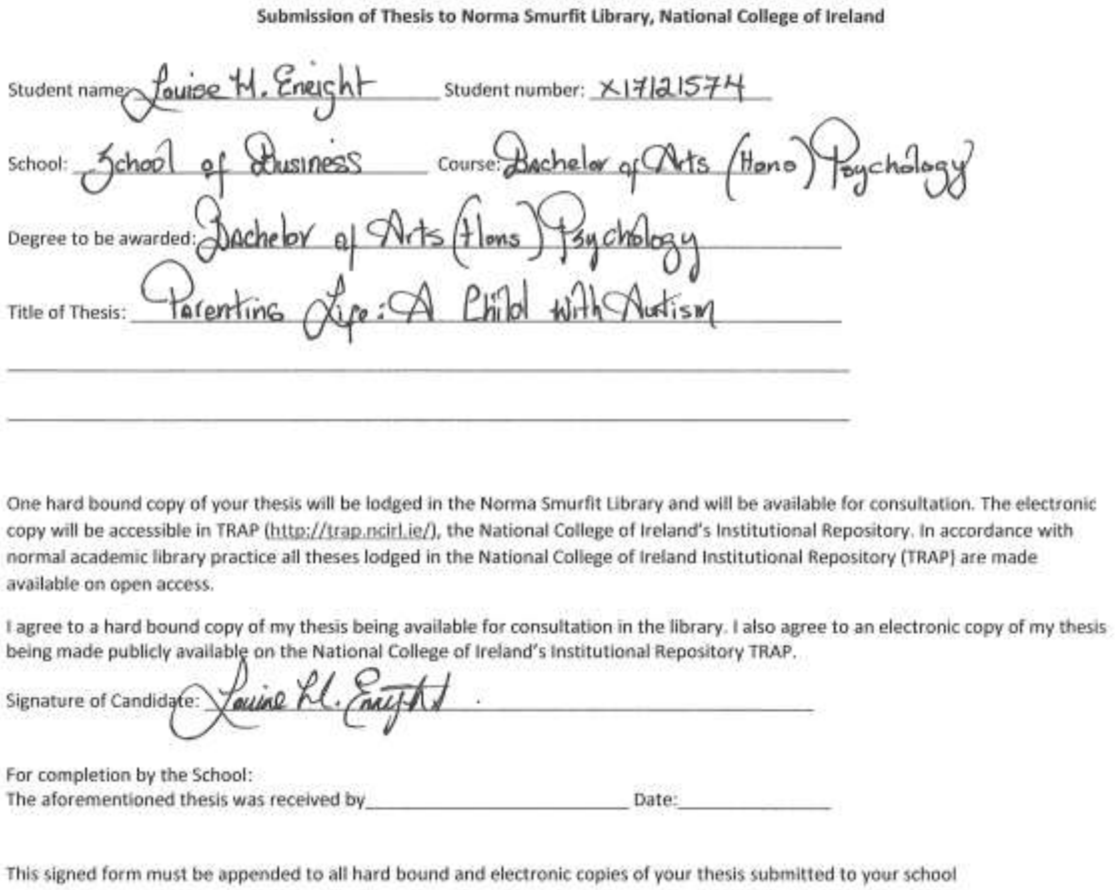
(d) ***Either*** *I declare that no material contained in the thesis has been used in any other submission for an academic award.

Or *I declare that the following material contained in the thesis formed part of a submission for the award of

(State the award and the awarding body and list the material below)

Signature of research student: Louise M. Enright.

Date: 28·02·20



Submission of Thesis to Norma Smurfit Library, National College of Ireland

Student name: Louise M. Enright Student number: X17121574

School: School of Business Course: Bachelor of Arts (Hons) Psychology

Degree to be awarded: Bachelor of Arts (Hons) Psychology

Title of Thesis: Parenting Life: A Child with Autism

One hard bound copy of your thesis will be lodged in the Norma Smurfit Library and will be available for consultation. The electronic copy will be accessible in TRAP (http://trap.ncirl.ie/), the National College of Ireland's Institutional Repository. In accordance with normal academic library practice all theses lodged in the National College of Ireland Institutional Repository (TRAP) are made available on open access.

I agree to a hard bound copy of my thesis being available for consultation in the library. I also agree to an electronic copy of my thesis being made publicly available on the National College of Ireland's Institutional Repository TRAP.

Signature of Candidate: Louise M. Enright

For completion by the School:
The aforementioned thesis was received by____________ Date:________

This signed form must be appended to all hard bound and electronic copies of your thesis submitted to your school

Acknowledgements

Firstly, I would like to thank every parent who gave their time to participate in this study. Each and every one of you are wonderful people and thank you for so openly discussing your experiences with me. I am forever grateful; you are inspirational as parents and without you this would not have been possible.

To my sisters, Claire and Geraldine who have been supporting me throughout the last five years that I have been studying. Thanks for always being there to listen to me and guide me and believe in me.

To my mother Anne, whom I have neglected by not having any free time to visit, you knew of the meaning and significance that this meant to me and you never made me feel guilty.

To my friends Aoife and Sarah, thank you for listening and supporting me over the past few years.

To Maria, an inspirational mother and friend, thank you for everything.

To Prof. Ciaran Meegan for being there as a friend and always believing in me.

Finally, to my supervisor Dr. Caoimhe Hannigan. I am grateful for your belief in me and my ideas from the start. You are a wonderful academic, both as a lecturer and as my supervisor and this experience albeit demanding has been thoroughly enjoyable. Thank you.

Table of Contents

Abstract

In an Irish population there has been limited qualitative research inclusive of both parents of a child with autism. The aim of this study is to explore the subjective experience of parents within their parental roles, coping strategies, perceived supports, and various stress factors. The objective is to expose themes using a qualitative approach and ascertain if themes are different for mothers and fathers. A series of one to one semi-structured interviews were conducted with parents via open-ended questions. In total 8 participants were interviewed: 4 men and 4 women. A thematic analysis of the interviews were conducted, revealing five main themes: (a) self-blame and self-doubt; (b) adjusting expectations; (c) gender specifics; (d) coping and (e) navigating the autism journey. The findings have shown important implications for professionals working within the field of autism; that parents require both emotional and practical support. Parents did not differ greatly in terms of their experiences, however, the way in which they adapt and approach their experiences have impacted relationship outcomes for families. The implications of this are discussed.

Introduction

Autism Spectrum Disorder (ASD) is a neuro developmental disorder presenting in childhood and continuing through adulthood (American Psychiatric Association, 2013). It is characterised by problems with social interaction, a lack of understanding of other people’s emotions and difficulties with language and communication (Heinrich et al., 2018). Autism is a “spectrum” where symptoms can vary from mild to severe presenting in different ways (Booth, 2016). The Autism and Developmental Disabilities Monitoring Network shows that about one third of children diagnosed with ASD will also have an intellectual disability (Baio et al., 2014). In Ireland that 1 in 65 school children are diagnosed with ASD (Department of Health, 2018). A recent review found the main challenges for parents of children with ASD were: feelings of guilt, blame, poor self-efficacy and feelings of being judged by society (DePape & Lindsay, 2015). Many studies have focused on reporting levels of stress that mothers experience (Baker-Ericzen et al., 2005; Peters-Scheffer et al., 2012; Tomanik et al., 2004), however, Flippin and Crais (2011) posited that fathers were underrepresented in ASD literature and this research aims to address this gap. This qualitative study aims to explore parent’s subjective experiences of their parenting lives, stresses, coping strategies and perceived supports whilst committing to inclusivity of fathers. The following literature review will discuss, with reference to relevant research, the broad range of challenges faced by parents that have a child with ASD, how gender roles may differ in parenting and the effects that this can have on families. It will also cover coping strategies that parents adopt and discuss which strategies that parents found most useful in helping them to cope along with discussing support systems available.

Challenges Faced by Parents

Families of children with ASD experience an array of increased challenges, these can stem from behaviours that children with ASD display as well as social deficits, language difficulties and communication problems, sleeping difficulties and agitation (Estes et al., 2009; Gray, 2003 Keenan et al., 2016 Sim et al., 2018). Research suggests that the behaviour the child exhibits is an important predictor of elevated stress in parents and that parents who have a child with a developmental disorder report higher stress levels than parents of children without a developmental disorder (Argumedes et al., 2018; Baker-Ericzen et al., 2005; Benson, 2010; Dabrowska & Pisula, 2010; Lecavalier et al., 2006). In recent years there has been an increase in societal awareness of ASD (Dillenburger et al., 2015), however, parents still experience criticism from the public regarding their children's behaviour and this can increase stress levels for parents (Farrugia, 2009; Schwartz, 2001). Parents reported experiencing looks and comments of disgust at their child's behaviour (Farrugia, 2009) and parents blamed cultural ignorance for society's perception of them as inadequate parents (Byrne et al., 2018). Other parents perceived the level of judgment displayed by society towards them to be as a result of ASD being invisible unlike disabilities such as Downs Syndrome (Neely-Barnes et al., 2011). The literature reveals that the related stress is caused not only by the child and the behaviour but also from society and it's expectations on how a child should behave.

Parents of children with ASD are also confronted by a myriad of other challenges including navigating support systems (Keenan et al., 2010), managing personal expectations (Dale et al., 2006), dealing with educational systems (Connolly & Gersch, 2016) and financial difficulties (Saunders et al., 2015). Furthermore, with many ASD children remaining in the home as adults, this may add to stress for parents as their role as caregiver may continue through their child's lifespan (Myers et al., 2009. Looking at their child's future prospects is a natural consideration for any parent, however parents of a child with ASD have additional factors to consider including: fears about their child's ability to cope in the world, fears about the future, hopes that their child has the ability to form relationships and find employment (Fong et al., 1993; Gray, 2003). It is evident from the literature that parents with a child with ASD face challenges that are directly associated with the child and their developmental disorder; however, the wider community that families engage with can also add to parental stress, if their experiences of services are unsatisfactory.

Gender Roles

An area of consideration are the differences individual parents experience in relation to their own stress and coping within the family of a child with ASD. Little research has been conducted in relation to fathers. In studies where both parents were included generally fathers were a much smaller grouping. Research suggests that mothers reported more mental health problems and that father related stress was predicted by the depression levels scores of their partners (Hastings et al., 2005, *a*). Mothers traditionally participated more in the care of their children with ASD and this may contribute to greater mental health problems for them (Benson et al., 2008). While some studies show that parents support one another and can grow together (Aylaz et al., 2012) other studies saw tension and conflict arising from mothers' perceptions of their spouse/partner not contributing enough (Gray, 2003). The once traditional family is changing and fathers roles are evolving and so further investigation is required in this area. Parents are also engaging in shared parenting and a move away from the traditional roles should be recognised.

Parents of children with ASD are at an increased risk of poor partner relationships and relationship conflict (Dardas & Ahmad, 2014; Goetz et al., 2019; Kuo et al., 2011). Reasons reported were hidden costs of therapies which cause financial strain, these include occupational therapy (OT), speech and language therapy (SLT) and applied behavioural analysis (ABA) (Higgins et al., 2005; Saunders et al., 2014). Some parents noted that the child's ASD was also impacting on their relationship because of the fears and anxieties surrounding the future of the child (Gray, 2003) and the lifelong care that might be required. Indirect factors were also noted; lack of free time, lack of spontaneity and quality time spent together (Dardas & Ahmad, 2014; Kuo et al., 2011). Lack of self-efficacy and perceived parental incompetence may be further intensified by these factors (Weiss et al., 2015). Gender differences were also noted in terms of how parents deal with the situation, where mothers express their emotions and rely on family and friends for support, fathers tend to go it alone, and suppress their emotions (Gray, 2003). This area requires further research as to the exact differences experienced and examining the effects, if any, of differences experienced. More awareness may be required by professionals about the challenges that parents' face and the possibility that provisions such as counselling and ASD interventions involving parents may alleviate some of the pressures that they encounter.

Coping Strategies

The term coping is the concept of managing a stressful situation (Mahmood et al., 2015). Having a child with ASD can lead to increased parental stress (Hastings et al., 2005*a*). Coping strategies that parents apply can be behavioural e.g., becoming informed or being open about your child's ASD or cognitive e.g., positive thinking or taking one day at a time (Hastings et al., 2005*a*). Maladaptive strategies also exist e.g., avoidance of friends and family, blocking it out or avoiding discussions about your child's ASD (Wachtel & Carter, 2008). The severity of the developmental deficits may affect the type of coping strategies used by parents (Higgins et al., 2005). Dale et al. (2006) found that cognitive coping styles such as adapting one's expectations and living in the present added to an increased ability to cope. Research suggests that applying adaptive and task orientated coping (solving the problem) cause less stress than avoidance orientated (avoiding stressful events) or emotion-orientated coping (self-blame/rumination) (Dabrowska & Pisula, 2010; Hastings et al., 2005a; Kiami & Goodgold, 2017; Lai et al., 2017). While the coping strategies of mothers is well documented, those of fathers requires future investigation.

Despite the challenges parents report positive aspects of parenting a child with ASD (Kayfitz et al., 2010) e.g., personal development through examining their own belief systems and personal growth in the face of adversity (Gray, 2006; Myers et al., 2009). Other positives include applying a more active advocacy role to help their child, becoming more informed about their child's condition and taking appropriate steps to source the correct therapies and education (Altiere & von Kluge, 2009; Fong et al., 1993; Woodgate et al., 2008). Furthermore, parents found advocacy was sometimes insufficient and have found that engaging in a more direct manner when engaging with services and professionals gave them an increased sense of empowerment as parents (Fong et al., 1993). This identifies the importance of parents being informed and understanding what the effect of this has on them as individuals.

Supports

Parents of children with ASD perceive a lack of support in many areas including, post-diagnostic support e.g., SLT, ABA or OT, and on-going educational support. They reported being ignored by professionals and felt isolated as a result (Byrne et al., 2018; Legg & Tickle, 2019; Rubin, 2019). They found the challenges surrounding navigating the system very distressing, in particular, finding supports and competent professionals (Altiere & von Kluge, 2009; Fong et al., 1993). As a result of this and the challenges of long waiting lists, many parents independently source and pay for their own supports e.g., SLT, ABA and OT (Altiere & von Kluge, 2009). This can impact families financially and add further strain on family life. However, not all reports from parents were negative and some have described positive experiences (Hutton & Caron, 2005). Navigating the school system is another area where parents have felt unsupported and this was perceived by parents as a lack of knowledge or clear understanding from school staff on how to deal with a child with ASD (Divan et al., 2012; Fong et al., 1993; Lindsay et al., 2014; Woodgate et al., 2008). Parenting a child with a developmental disorder can be challenging and every effort from services to educate parents about supports can minimise the amount of research that they have to conduct independently. This highlights that there may be a lack of knowledge within the professional field that may require addressing in order for people working within the field to communicate with parents both empathically and professionally.

The importance of social supports for families of children with ASD has been widely researched and has been shown to be an important intervention when reducing stress, improving health and improved quality of life (Bromley et al., 2004; Johnson et al., 2011). Studies have found that higher levels of informal supports from family and friends and other parents were positively associated with reduced stress (Altiere & Kluge, 2009, Ekas et al., 2010). Research suggests that mothers often look to their partner or spouse as their primary support, however, fathers may be burdened by their own issues and may not be as capable as they would in normal circumstances (Boyd, 2002). This may cause some conflict for parents. Others find support through professional help, attending personal therapy (Shechtman & Gilat, 2005). The benefits of such supports enable parents to deal better with stress management, increase resilience, and improve parenting outcomes which impact positively on the child. This highlights the importance of a myriad of supports in reducing the difficult challenges of parenting a child with ASD.

Present Study

Existing research has indicated that parenting a child with ASD can lead to increased parental stress. However, research has not fully investigated, in a qualitative domain the sources, of these stresses. Specifically, the current research attempts to, in a qualitative approach, explore the cause of parental stress, the way in which parents deal with their stress and parents' perceived supports. It is evident from the literature that parents, of both genders, differ in terms of their views on perceived stress as well as their coping strategies. With this in mind this research aims to understand parents' perspectives and see if there are common themes across parents' subjective experiences. There is a clear gap in the literature, and in particular, in an Irish context, on paternal viewpoints. More information and understanding of both genders in relation to parenting a child with ASD, may inform us in preparing future interventions and programmes to guide parents of children with ASD. This study aims to explore parents' subjective experiences in relation to parenting a child with ASD, specifically parents' stress and coping strategies, parents' perceived supports with the objective of seeing whether there are common themes between mothers' and fathers' experiences.

Methodology

Study Design

The research methodology was qualitative in nature. Qualitative analysis suited the proposed study as it sought to establish the perspective of the participants and is based on a phenomenological position (Khan, 2014). This approach is best suited to this research using interviews to explore the thoughts and feelings of the participants (Sutton & Austin, 2015). Semi-structured interviews consisting of open-ended questions were used to explore the stresses, coping strategies and perceived supports of parents of children with ASD. The interview guide made every effort to prevent leading questions (see Appendix A).

Ethical Considerations

Ethical approval was granted for this study by the National College of Ireland. Permission was further sought from the administrators of the Autism Support Groups who assisted with recruitment. It was considered that because of the nature of the study that there was a possibility that parents may become distressed during or after the interview by discussing their experiences. This was clearly documented in the information sheet and in the event that parents required further assistance, voluntarily organisations details were provided (see Appendix B). This was also verbally presented at the beginning of each interview. Consideration was also given to the fact that interviews took place in various locations including in participants' homes and a third party was notified in such instances. Participants' names were not disclosed, however, location and estimated length of time for completion of the research was disclosed. Prior to conducting the study an informed consent was obtained from all participants which detailed confidentiality. Participants were provided with a detailed information sheet (see Appendix B). Prior to the interview the participants could ask questions and then signed the consent form (see Appendix C).

Sample/Participants

A purposive sampling stretegy was used to recruit participants for the study. This is one of the most commonly used sampling methods for qualitative research (Marschall, 1996). The researcher chose the participants based on specific perspectives in mind, i.e., wanting the perspective of both male and female participants. This type of sampling is known as non-probability sampling in which the likelihood of knowing the participants selected is unknown and individuals do not have equal chances of being selected (Luborsky & Rubinstein, 1995). Social media parental support groups created by parents for parents were used to recruit participants. Permission was sought from the administrator of the support group prior to the distribution of a recruitment poster (see Appendix D). Participants interested in the study made contact with the researcher by telephone or email. Once potential participants requested information this was provided to them,. Prior to interviews taking place, ongoing communication between researcher and participant to facilitate an appropriate time and place for interviews was conducted by email and phone.

All participants (*n*= 8) chosen for the study met the inclusion criteria which included having a child with ASD and that the child was under 18 years old. Participants comprised of four males and four females, of which one mother and father were married. Parents ranged in ages from 27 to 50 (M=40.5) and all participants were either married or in partnerships. One male and three female participants identified themselves as primary caregiver, the remaining four said they had joint responsibility with their partner. The age of diagnosis ranged from 3-6 years and children ranged from 5-16 years old. One child was attending a pre-school ASD unit, one child was attending a special education primary school, five children were attending mainstream schools with either a special needs assistance or an ASD unit and one child was attending a mainstream secondary school. Seven out of eight children presented with comorbidities and seven out of eight children were male.

Materials

The researcher's phone was used throughout all eight interviews to record the interviews using a voice recording application on an iPhone 6 and transcribed using a MacBook Pro laptop. An interview guide was devised that aimed to capture a broad framework of parents' perspectives on their stresses, coping styles and strategies and perceived supports. Prior to commencement interviewees were given a brief demographics questionnaire (see Appendix E).

Data Collection

A pilot study was conducted with one participant for the study, the participant was made aware of this prior to interview and agreed to participate. This was a mock interview that was conducted to ensure the open-ended questions created were suitable for the study and were clearly focused around the study's objectives and to ensure the device used the recordings operated efficiently. The pilot study allowed the researcher to check the timing of interviews and allowed time for modification of the questions if required which is an essential part of conducting qualitative research (Bloor &Wood, 2006). The data obtained from the pilot study was used in the main analysis as no changes to the procedure were required.

Data collection took place over a six week period. Eight semi-structured interviews were conducted as part of the data collection process and all participants were interviewed individually. Prior to the interview commencing participants were given a brief demographics questionnaire. The interviews began by asking parents to describe what a typical day was like for them, challenges that they might experience along with positive aspects that they experience; this led on to questions relating to stressful situations experienced, coping strategies used along with questions relating to perceived supports. The semi-structured interviews employed for the data collection allowed parents to express freely their experiences. Once the interview was complete the participants were thanked for their participation in the study and provided with debriefing sheets with relevant signposting towards supports and helplines if required (see Appendix F). The interviews lasted from 45-70 minutes. Interviews were audio-recorded in various locations; in the participants' home (five participants), in the researcher's home (two participants) and in a consultation room at National College of Ireland (one participant). The various locations were to best accommodate participants and their wishes. All interviews were recorded and transcribed verbatim.

Data Analysis

Data analysis was conducted using Braun and Clarke's (2006), six phases of thematic analysis. The method of inductive (data-driven) analysis was used whereby the researcher allowed for the themes to emerge from the data itself and themes were not selected based on a pre-existing framework/theory. The first step in Braun and Clarke's (2006) analysis is through familiarisation of the data. This occurred when the researcher transcribed the data from the audio-recordings verbatim ensuring that all verbal utterances and punctuation were transcribed, this allowed for a more accurate interpretation of the dialogue. The researcher then further familiarised herself with the data by re-reading the data and beginning the stage of systematically generating initial codes. Codes were then collated into initial themes and subthemes. The researcher then further analysed the coded themes to ascertain if the themes were a reliable representation of the coded data. Data saturation occurred when there was repeated information from participants and no new themes were emerging. For thematic analysis to be of good quality and for there to be enough information to replicate the study one needs content validity through data saturation (Sim et al., 2018). Analysis of the data was then further refined for each theme and codes that were reflective of theme were extracted and included in the final analysis of results.

Results

Figure 1. Themes and Related Subthemes

This section describes the themes that emerged from the analysis of the interviews conducted with the eight participants. Utilising Braun and Clarke’s (2006) methods, a thematic analysis was conducted and five salient themes were identified: self-blame and self-doubt, adjusting expectations, gender specifics, coping, and navigating the autism journey. The related subthemes are discussed within the context of each theme. Exemplar quotations are provided. Figure 1. details the five main themes and related sub themes.

Theme 1: Self-Blame and Self-Doubt

Both self-blame and self-doubt were intrinsically linked throughout the interviews by all participants. Participants were confused by a lack of direction from support services and health professionals which left them with the feeling of self-blame and doubt about what direction to take next. One participant relayed,

> What I'd like....is for somebody to sit with me and say, you know, you're wasting........ like I'm doing it but know knowing what I should do?.... am I doing the right thing? Could I be using the time and money and energy on something else? (Participant 3).

These feelings often came about in the context of rhetorical questions. These were as a result of lack of direction from services or a feeling of inadequacy to act in the best interests of their child,

> we were waiting on the services to come and there was nobody really that was able to tell us what needed to happen next. We were very much trying to figure it out ourselves. Which can lead to you having the stresses of : are we doing enough? Do we need to do this or that? (Participant 2).

Some participants struggled to interact or form a bond with their child. One participant testified,

> We were wondering why, why, why is he? ....do I struggle to maybe interact with him and my son was our eldest so we had nothing to go on before…. my interaction

> with him as a child and my interaction with my daughter are apples and oranges kind of a scenario (Participant 1).

Other parents felt a sense of regret about not having the tools to be able to deal with their child and spoke of the importance of interventions for not just the child but for the parents also,

> my son we've learned he's learned. We've learned a lot. There is a bit of regret that had I known earlier I would have been a different father I would have been a different person - there was this helplessness and we are lucky to have had the money to pay for the extra interventions to help him but also help ourselves (Participant 4)

Theme 2: Adjusting Expectations

Parents sense of loss with the diagnosis of ASD was significant throughout the research interviews. What they expected for their child did not match with their ASD diagnosis and one participant explains, “My wife is still grieving… she is grieving that she's lost a child and all she wanted was a healthy, normal child” (Participant 8). Other parents reported fear in what is to become of their child now that they have ASD,

> and now I have to change everything that I thought my child was going to grow up and become........ you kind of lose this idea of who your child is going to be and you have to get this new idea of expectations of who your child is now going to be and how that life might be different (Participant 2).

One participant captures the frustrations of parental expectations,

> they're growing and they're developing but you're just wondering, you know, what is it that is not clicking? I'm a pretty logical person, so that just does not make sense to me. I find that difficult because I think if, you know, if you apply yourself long enough and hard enough…but not in my child’s case (Participant 6).

All eight parents perceived the public expectations of children and how they should behave socially, distressing to them. Four parents did however mention that people are more accepting of autism and that there is more awareness, “In terms of awareness, and understanding, you know, I think things are probably progressing well”, “I think positive as there is more awareness’’. Participants spoke of how ASD isn’t visible, “ My problem and this is one of the biggest problems ok, is that my son doesn't look autistic”. Parents sometimes feel the need to disclose to people that their child has ASD to prevent them making assumptions based on the child’s behaviour,

> I say it to people so that when they meet him they so don't just apply the bad behaviour rule to him and negatively judge him……because the child doesn't look any different, it can be, it can be easily mistaken with bad behaviour or, you know, unruly behaviour or whatever (Participant 5).

Parents disclosed how challenging it can be being out in public, ‘’it's a full on, like, full on stress…..you know everybody watches’’, “people would look at you and judge you but they wouldn't see his disability because he looks like a normal kid”. One participant captures their experience,

> And it can be stressful, bringing your child into social circumstances where people don't understand autism, like being out in public you can't see autism. Some people kind of look at your child and turn around and go, ‘oh my God what a brat or that parent doesn't know what they're doing why can't they control their child and when he has a meltdown, they look at me and go, ‘oh (disgust sound)......what an annoying child, you know, stuff like that. That's really stressful but as you get..... as you progress, you become thick skinned (Participant 2).

Theme 3: Gender Specific

There were apparent gender differences between mothers and fathers in terms of acceptance of their child with autism. Fathers adopted a factual and practical sense of acceptance which was sometimes seen as detached or avoidant to their partners, “So it's purely about us. My son is who he is. So, we have to acknowledge that”, “I'm quite happy applying myself to figure out my child and what works for him and how we can navigate the world together’’. Fathers frequently spoke of having to “just deal with it” and “get on with it” and one father spoke of normalisation, “it doesn't make a difference because it is the norm for us now, So everything is as it is, it's very hard to imagine being any other way”. One father explains his feelings,

> His concentration is all over the place…….. he's up, he's down, he's here, he's there…….We have to manage our son and he is never going to be cured and we have to get on with it and just manage him (Participant 6).

Mothers described more perceived isolation and fear and this was highlighted through the challenges faced from lack of information received and although one mother did report a sense of acceptance, “I definitely wouldn't change him for anything in the world’’ she also added, “but yeah, it was kind of it was the whole just being left with no guidance and no information and not having a clue where to start”. “Because you're constantly when you're left on your own with an autism diagnosis, you constantly go, am I doing things right? Am I ? ” explained another mother. All four mothers also spoke about the ‘constant battle’ and ‘constant fight’ and one mothers relays this experience,

> It's just it's a subject that's am....difficult. It's leaves you with a .....you know, it's, it's just, it's shocking. I was shocked. I have been shocked the last few years....... you're shocked with the diagnosis and then you're shocked with like the aftermath. Yeah, you're, you're alone like it's …… you're alone as in.... finding a suitable school like I’ve had to apply to forty-five schools and she hasn’t been accepted and early interventions…..(Participant 4).

Participants mentioned the impact that parenting life has had on their relationship, “that's a hard one because it's been hard, especially on our relationship - myself and my wife, it's been a struggle big time”. Another participant spoke of the impact these extra parental duties of having a child with ASD entails,

> I have a lot of balls to juggle and I'm kind of holding the whole family together. My wife has said she is going to leave many, many, many times because she can't cope with it and she finds it very, very difficult but she won't go to counselling. She’s just not........ she's not ready for it’’ (Participant 7).

One parent concisely captured the challenges and the struggles for parents of a child with ASD,

> It's very stressful for parents and you read about this a lot and I didn't realise it was an issue but that it leads to a lot of stress in your own relationship……It's been, I suppose for us, about different opinions on how to deal with things and also, just the stress. I mean, you can't, you can't live a normal life (Participant 5).

Participants spoke of differences in the challenges and experiences that men and women have, “The challenges are completely different between me and my husband. My husband wouldn't really bring our son out’’, and some parents associated the different challenges with their inability to accept the diagnosis, “he sort of buried himself. He still can't say our son has autism”. He just kind of...buried himself and avoided the discussion”. Whereas others associated the differences in how they approach the situation,

> The other challenge would be first like, like that my husband and I would approach him kind of differently. Sometimes like that behaviour would drive my partner so mad that he'd kind of give him a more authoritarian kind of parenting ...... even though we both know, it's nearly impossible for him to stop behaving that way, you know, but it gets to the really frustrating for my partner (Participant5).

Theme 4: Coping

How parents dealt with coping with their child with ASD was seen from two perspectives both from a personal stance, that being strategies adopted by parents for their own personal growth, maintaining a positive outlook and from a social perspective, those supports that they had to seek from external sources and receiving supports from other parents. Three parents spoke about getting outdoors with their child with ASD and how that benefitted both themselves and their children,

> my coping strategy is getting him out and on the bike, when he's doing that he is suddenly more relaxed, which means he's more interactive which means he's..... I find him easier; I find it's easier to interact with him (Participant 1).

Another parent said, “He loves the park. Like it's like his place to burn off all his energy’’. Participants expressed the benefits of exercising for them personally, “I thought exercise was a huge way to get rid of a lot of stress’’. The power of positive thinking was also key in parents coping and although some parents found the question relating to positive aspects challenging, there was an overall positive outlook from parents,

> They're still your beautiful baby, and you're just gonna have to get to know them a little bit better than maybe you would have and you're gonna have to get your head around what their take on the world is a bit better and not to leave them off to figure it out themselves. You will have to..... you have to get insight......... where they're coming from, to try and help them....... (Participant 7).

Three parents spoke of attending therapy in the form of counselling and that this was a strategy applied to help coping and parents spoke of a positive outcome and an increased awareness and of personal growth,

> Through searching within for ways to cope, and ways to change and whatever, and as I mentioned before, I went to therapy and especially, I found that very beneficial for me, she really reframed ways of communicating, and ways of questioning and I hope. It actually has made me much more tolerant of a person and more forgiving of myself and others and more....more aware of what people go through (Participant 5).

Participants all spoke of the importance of becoming more informed and the benefits of reaching out to other parents for support in coping with the challenges, “I found out so much information from talking to people and using online support groups’’ another parent also spoke of the value in other parents’ support,

> another mother helped me a lot and told me and I was lucky ………she let me in on who I need to contact, this is what they do, this is what an OT is, this is what the psychologist does, this is what SLT, this is ABA if you might be interested, that information is nowhere (Participant 1).

One parent described in depth the benefits of reaching out,

> about my coping strategies and one was to become more informed. To find out, who we should be going to, who was going to give us this roadmap? I was disappointed that there was no one to advise you, but the advice and the support has come from am other parents. other people who have journeyed the road ahead of you, and they're able to tell you hey, this is what's ahead, you know (Participant 8).

One participant describes their experience and explains why attending OT sessions with their child as a family unit helps them to better cope and be better parents for their child,

> because our son is so dysregulated that when you have two parents that are on different pages, that that could actually affect his progression…it's a reason why our son's behaviour.... it feels like it's escalating. …..and the OT had said that because of the difference in our parenting that it's possible that it is causing our son to be confused and if he doesn't know who to listen to.......so I'm hoping this will help is all we will both be on the same page after the sessions (Participant 4)

Theme 5: Navigating the Autism Journey

The fifth and final theme that concludes this research and also the most comprehensive and complex of all the themes is that of navigating the autism journey and this encompasses a broad range of sub-themes all intertwined and related to the experiences as a parent across the areas of services and education and how that impacts on parents fear for the future of their child. Every parent encountered challenges faced by the lack of the services available when they needed them, ''in my personal opinion and experiences there are no supports'' while another participant said, "you know this child needs support and there's just there's nothing". Another parent said, " you are really taken aback by how bad it is.....with everything with school with early intervention with everything''. One participant suggests what might be of benefit to parents,

> I would say one very important support would be respite, definitely one of the key supports. We don't get any respite but we've applied for it. I think counselling would be very, very, very, very important one for both the parents (Participant 4).

All participants spoke of having to pay for services and having to be strong advocates for their child when it came to dealing with services, “parents pay for the services’’, “we were also paying for my son to go to speech, language education’’, “And so now I've been fighting a lot in the background’’ and things were not described as getting any easier as the child progresses, ‘’My child is much older and I've been fighting for everything for last 10 years’’.

> we have to keep an eye on the school to kind of monitor on what they are up to…..to kind of guide them and to make sure that they're actually doing the best to support our child I'm kind of one of these parents who keeps an eye on things. If I don't see things being done that should be done, I'm proactive yeah proactive - but everything is like a fight basically (Participant 4)

The challenges that faced parents from an educational perspective was again clearly described by each participant and this started when trying to get their child into a school,

> now we have the, the giant task of trying to find a school. That's impossible, just keep applying to schools, like, I've applied to 45 schools and every single school is no, like she goes to an autistic preschool an ASD unit preschool and she loves it..... there's a good chance that she........she won't have a school and ammm it's just....... it's left to the parent to try figure that out (Participant 3).

Once their children were in schools’ parents then spoke of additional challenges faced by them,

> and I cried, it's just this constant, your child's the problem, your child's the problem, your child's the problem, and it's like, well, you knew he had autism before you accepted him into your school (Participant 4).

> you do feel very isolated, and you do feel you're the problem and your child is the problem and they do the proper speeches about inclusion, and then two seconds later in the next sentence talking about how hard it is for the school to deal with the level of children on the spectrum (Participant 2)

The challenges faced by parents may perhaps contribute to their fears for the future outcome of their child, "Your consideration is he won't achieve or what he won't achieve". Parents catastrophised about the future of their child and one participant stated their fear,

> we pay for my son's private therapies right now, when he is 16.......we won't be paying for therapy anymore. We're going to have to pay somebody private to come into the home and look after him, like home care, the system is never going to help us, but that's what you're looking at. ....when the child is 16 years old you'll have to get the home care yourself because this system is not offering anything which is really difficult so it's... it's a never ending cycle (Participant 6)

The fear that's parents spoke of were that of the challenges that their child will face in the future, "I would have concerns about where or how will he progress? How will things work for him in the real world?" and similarly this participant speaks of their fear for the future,

> you're getting closer to........them being standalone in the real world and you just wonder how many of the necessary skills will he be able to get his head around and acquire as those milestones move on, you know, and that would be....... that's probably my primary concern, not in the here and now, but the medium to long term future (Participant 6)

> You just have to get on with it really. My wife has this big worry that when our son is 20 he's still gonna be living at home, still not speaking, still not going to be able to manage himself, support himself, cope with independent living or whatever (Participant 8)

Two parents capture the essence of this theme in relation to their perspectives surrounding how to navigate the autism journey,

> People think it's all about access to resources, well, actually, the resources aren't fully informed on, you know, if you provided the resources, the people in the morning, the knowledge wouldn't be there to deal with the demand (Participant 8)

> My advice to parents is that it's not all bad but you're not going to get any help from services so forget about it. You need to go get yourself supports around yourself, from your family, your friends, or whatever it is and then try and get supports, like the domiciliary care allowance, which might pay for a few kinds of interventions. You just have to get on with it really (participant 7).

Discussion

This study used a qualitative approach to explore parent's subjective experiences of parenting a child with ASD. The following areas were covered with the objective of seeing whether there are common themes between mothers and fathers: parents stresses and coping strategies and parents perceived supports. A thematic analysis of the interviews conducted revealed five main themes: self-blame and self-doubt, adjusting expectations, gender specifics, coping, and navigating the autism journey.

In relation to the theme "self-blame and doubt" participants often worried whether they were making the right decisions that would result in the best outcome for their child. This was revealed through participants expressing a host of rhetorical questions and this had a negative impact on participants' self-efficacy and self-reported stress levels which contributed to them doubting their competence as parents. DePaupe and Lindsey (2015), found similar results in a literature review and highlighted the importance for parents to be educated in ASD and the impact it can have on families. Regret was evident as an emotion for participants particularly in relation to their reactions to behavioural and communication challenges that come with autism. They expressed blame and regret for not having patience, on not being able to connect or communicate appropriately with their child. These findings resonate with previous studies (DePape & Lindsay, 2015; Keenan et al., 2016).

The theme of "adjusting expectations" was seen through two lenses, that of a personal lens and a public lens. Participants' expressed a sense of loss for their child which mirrors findings in autism research (Hutton & Carron, 2005; Schwartz, 2001). Parents expressed a host of intense negative emotions such as, grief, fear and disappointment which continued to occur as they had reminders each day of what their child might not achieve during their life.

Public expectations of how children should behave was evident and participants reported feeling judged in public, and pre-emptively would disclose to strangers that their child had autism. Participants reported experiencing negative looks and remarks in public and research suggests that this not only adds stress but creates stigma for those involved (Farrugia, 2009). Dillenburger et al., (2015), however, in an Northern Irish context found that participants had a positive view of persons with ASD and of parents that have a child with ASD. Research in this area is limited and is an area that requires future studies.

Overall, the themes that emerged were common between mothers and fathers, however one theme from the findings revealed some differences. “Gender Specific” as a theme presented itself as the way in which fathers and mothers spoke of their acceptance of their child’s ASD and approach to parenting. Fathers expressed a more direct and matter of fact way of describing both their child and their autism in terms of accepting it and how they approached it. Fathers mentioned having to “just get on with it” and “deal with it”, and this corroborated with other findings (Gray, 2003). Mothers described feelings of emotion, isolation, having to battle and fight and having to become a powerful advocate for their child. These findings are consistent with previous research (Fong et at., 1993; Woodgate et al., 2008). This research also found that both fathers and mothers perceived their ability to adapt and their approach to be different from their partners. Participants acknowledged the impact that having a child with autism can have on their relationship and previous research has indicated similar findings (Kuo et al., 2011). Goetz et al. (2019) found that as a result of high parenting stress mothers found it difficult to engage in positive communication with their partner and suggested psychoeducation as a form of intervention for parents. The findings in this study may suggest that conflicting approaches contribute to parental dispute however, this is an area that requires further investigation as there may be other contributing factors.

Coping with autism was a broad and significant theme. The main findings were that social supports such as that of other parents' who have a child with ASD were helpful and informative. This for many was a personal journey of exploration which had positive outcomes for participants. Many previous studies have focused on coping and the impact of social supports on parental outcomes (Dabrowska & Pisula, 2010; Gary, 2003; Hastings et al., 2005a; Higgins et al., 2005; Hutton and Carron, 2005; Kiami & Gold 2017). In this study the benefits of social supports and "becoming more informed" are twofold - They alleviated stress and changed their perspective on life. Participants reported having more resilience, greater empathy and optimism. Additionally, parents felt the benefits of "not going it alone" and that by helping each other they had increased strength to face the challenges that arise. Sourcing supports such as personal counselling therapy, and both parents and child attending an ASD intervention were being used as an effective coping mechanism. These coping mechanisms varied with gender and may be an area that requires future research. From the study one can hypothesise that parents who attend intervention together with their child will adopt a similar parenting style to cope with the behavioural challenges thus leading to a positive impact on the child and parental bond.

Finally, having to navigate the journey of autism, which is a constant for parents and encompasses the trajectory of their child across the lifespan, was the most robust theme to emerge from the study. This theme revealed the experience of participants relating to services, education and the future of their child. They felt that they were not supported by the services that are meant to provide parents with guidance interventions and adequate information relating to their child's ASD. They reported being ignored, left on long waiting lists or dealing with inadequately trained staff. These findings corroborate with previous research (Byrne et al., 2018; Legg & Tickle, 2019; Rubin, 2019). Consistent with previous studies, participants, regardless of socioeconomic status, spoke of the requirement to pay for care and interventions privately (Saunders et al., 2014). Although some parents spoke of being satisfied with their child's schooling, they spoke of the importance of their own presence and vigilance to ensure their child's needs were being met. Others spoke of frustration and anger at how their child was being treated by staff inadequately trained or unwilling to deal with a child with a developmental disorder. The fear of the future was evident in participants, leading to them catastrophizing about the future and how their child will navigate the outside world alone. This too presented as a common theme in other studies (Fong et al., 1993; Gray, 2003).

Clinical Implications and Future Direction

There are several important clinical implications from these findings. Similar to Swinth et al., (2015) this study found that for professionals to meet the need of families who have children with ASD they must have an awareness of their “lived reality”. This study noted that the lack of information can impact on self-esteem and self-efficacy of parents

It was also apparent that parents leaned on other parents and the effect of this was twofold; they received emotional support and functional advice. Professionals should build on parent to parent support systems by establishing networks e.g., D15 Autism, linking individuals and aiming to emulate their support.

The impact that autism can have on a couple’s relationship was also evident, and parents expressed the strain that this has had on their relationship. Peer support cannot always provide the appropriate care in these instances and a counselling service for families should be provided in order to counsel them through the challenges. Parents also spoke of the constant care that a child with autism imposes on a family, this may be important information for national health care when considering facilities e.g., home based respite, residential care and occupational care.

Future research may develop this study further by increasing the sample size, where both qualitative and quantitative methods are employed and this will allow for a better representative of the population and a broader picture of the research area. Another important area for future research from the findings is that of comparing parents' experiences of their children at different stages across the autism educational system and at different ages to gain a better understanding of the requirements that are faced by parents over time which might include day care facilities and occupational outcomes. Research should also consider non-traditional families e.g., one parent families and same sex parents.

Methodological Considerations, Strengths and Weaknesses

The aim of qualitative research is not to generalise but to gain an in depth subjective report of individuals' experiences relating to a particular phenomenon. This can be regarded as a weakness in the methodology but in light of the intentions of the study the researcher did achieve what was intended. Purposive sampling was used for the study and can be prone to selection bias, however, the researcher's judgement was based on clear criteria and this was stipulated in all related information to the research. The number of participants was limited however due time restrictions the researcher had to cease data collection. Another limitation worth considering is that of the interview process and the variation in interview locations. This may have an effect on: comforts levels, distraction, time pressure and confidentiality and may impact on information quality. There were concerns that because of the sensitive nature of the subject and because the researcher was conducting an undergraduate study that had no direct advantage to participants, that this would pose as a challenge in recruiting voluntarily participants. The researcher however, received interest from more potential participants than could be accommodated. The sensitive nature of the topic may present situations where participants may not be forthcoming with information relating to the specifics of parenting life. However, this was not so and the data appeared to be relevant and parents disclosed personal and challenging topics that were similar to previous studies relating to ASD research. The clear research questions aimed at a specific cohort of parents, the consistent nature of the questions in the interview all contribute to the strength of this study. This research focused on the inclusion of fathers and adhered to that, albeit challenging to recruit, the researcher remained loyal to this objectives and this is a significant strength to the study.

Conclusion

This study has contributed to ASD research focusing on parenting a child with ASD and how it can lead to increased challenges for families. The research findings also show that parents' challenges and stresses are not just influenced by their child that has ASD but by the broader community, such as society, teachers, and other professionals. This research shows that a vast amount of knowledge and education is required surrounding ASD and that not only will parents’ of children with ASD benefit from education and information provided to them but also, that professionals within the area of ASD are fully informed of every aspect and avenue to instil confidence in parents that the services and education provided are in the best interests of their children It also adds to the minimal amount of literature on qualitative studies including fathers and hopefully will encourage further research that includes both parents. The themes that occurred were the same for mothers and fathers generally except for “adaption” and “approach to parenting” and the impact that this has on parental relationships. Due to the quality of the data, the researcher hopes to further develop this study in the future.

References

American Psychiatric Association. (2013). *Diagnos- tic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5). Arlington, VA: Author.

Altiere, M. J., & von Kluge, S. (2009). Searching for acceptance: Challenges encountered while raising a child with autism. *Journal of Intellectual & Developmental Disability*, *34*(2), 142–152. https://doi.org/10.1080/13668250902845202

Argumedes, M., Lanovaz, M. J., & Larivée, S. (2018). Brief Report: Impact of Challenging Behavior on Parenting Stress in Mothers and Fathers of Children with Autism Spectrum Disorders. *Journal of Autism & Developmental Disorders*, *48*(7), 2585–2589. https://doi.org/10.1007/s10803-018-3513-1

Aylaz, R., Yılmaz, U., & Polat, S. (2012). Effect of difficulties experienced by parents of autistic children on their sexual life: A qualitative study. *Sexuality and Disability*, *30*(4), 395-406.

Baker-Ericzen, M. J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities, 30*(4), 194–204. doi:10.2511/ rpsd.30.4.194.

Baio J, Wiggins L, Christensen DL, (2014). *Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years* — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. MMWR Surveill Summ 2018;67(No. SS-6):1–23.

Benson, P. R. (2010). Coping, distress, and well-being in mothers of children with autism. *Research in Autism Spectrum Disorders*, *4*(2), 217-228.

Benson, P., Karlof, K. L., & Siperstein, G. N. (2008). Maternal involvement in the education of young children with autism spectrum disorders. *Autism*, *12*(1), 47-63.

Booth, J. (2016). *Autism Equality in the Workplace : Removing Barriers and Challenging Discrimination. Philadelphia*: Jessica Kingsley Publishers

Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, *17*, 208–215

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101

Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism: The International Journal of Research and Practice*, *8*(4), 409–423.

Byrne, G., Sarma, K. M., Hendler, J., & O'Connell, A. (2018). On the spectrum, off the beaten path. A qualitative study of Irish parents' experiences of raising a child with autism spectrum conditions. *British Journal of Learning Disabilities*, *46*(3), 182-192.

Connolly, M., & Gersch, I. (2016). Experiences of parents whose children with autism spectrum disorder (ASD) are starting primary school. *Educational Psychology in Practice*, *32*(3), 245–261. https://doi.org/10.1080/02667363.2016.1169512

Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research*, *54*(3), 266-

Dale, E., Jahoda, A., & Knott, F. (2006). Mothers' attributions following their child's diagnosis of autistic spectrum disorder: Exploring links with maternal levels of stress, depression and expectations about their child's future. *Autism*, *10*(5), 463-479.

Dardas, L. A., & Ahmad, M. M. (2014). Predictors of quality of life for fathers and mothers of children with autistic disorder. *Research in developmental disabilities*, *35*(6), 1326-1333.

Department of Health, (2018). Estimating Prevalence of Autism Spectrum Disorders (ASD) in the Irish Population: *A Review of Data Sources and Epidemiological Studies.*

DePape, A. M., & Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder. *Qualitative Health Research*, *25*(4), 569-583.

Dillenburger, K., McKerr, L., Jordan, J. A., Devine, P., & Keenan, M. (2015). Creating an inclusive society… How close are we in relation to Autism Spectrum Disorder? A general population survey. *Journal of Applied Research in Intellectual Disabilities, 28*, 330–340.

Divan, G., Vajaratkar, V., Desai, M. U., Strik-Lievers, L., & Patel, V. (2012). Challenges, Coping Strategies, and Unmet Needs of Families with a Child with Autism Spectrum Disorder in Goa, India. *Autism Research*, *5*(3), 190-200.

Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *40*(10), 1274-1284.

Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X. H., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, *13*, 375–387. 10.1177/1362361309105658

Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness*, *31*(7), 1011-1027.

Flippin, M., & Crais, E. R. (2011). The need for more effective father involvement in early autism intervention: A systematic review and recommendations. *Journal of Early Intervention*, *33*(1), 24-50.

Fong, L., Wilgosh, L., & Sobsey, D. (1993). The experience of parenting an adolescent with autism. *International Journal of Disability, Development and Education*, *40*(2), 105-113.

Goetz, G. L., Rodriguez, G., & Hartley, S. L. (2019). Actor-partner examination of daily parenting stress and couple interactions in the context of child autism. *Journal of Family Psychology*, *33*(5), 554–564. https://doi.org/10.1037/fam0000527

Gray, D. E. (2003). Gender and coping: the parents of children with high functioning autism. *Social Science & Medicine*, *3*, 631.

Gray, D. E. (2006). Coping over time: the parents of children with autism. *Journal of Intellectual Disability Research*, *50*(12), 970–976. https://doi.org/10.1111/j.1365-2788.2006.00933x

Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinoza, F. D., and Remington, B. (2005a). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism* 9, 377–391. doi: 10.1007/s10803-005-0007-8

Heinrich, M., Böhm, J., & Sappok, T. (2018). Diagnosing Autism in Adults with Intellectual Disability: Validation of the DiBAS-R in an Independent Sample. *Journal of Autism & Developmental Disorders, 4*8(2), 341–350

Higgins, D. J., Bailey, S. R., & Pearce, J. C. (2005). Factors Associated with Functioning Style and Coping Strategies of Families with a Child with an Autism Spectrum Disorder. *Autism: The International Journal of Research and Practice*, *9*(2), 125–137.

Hutton, A. M., & Caron, S. L. (2005). Experiences of Families with Children with Autism in Rural New England. *Focus on Autism and Other Developmental Disabilities*, *20*(3), 180–189.

Johnson, N., Frenn, M., Feetham, S., & Simpson, P. (2011). Autism spectrum disorder: Parenting stress, family functioning and health-related quality of life. *Families, Systems, & Health*, *29*(3), 232–252

Khan, S. N. (2014). Qualitative research method-phenomenology. *Asian Social Science*, *10*(21), 298.

Kayfitz, A. D., Gragg, M. N., & Robert Orr, R. (2010). Positive Experiences of Mothers and Fathers of Children with Autism. *Journal of Applied Research in Intellectual Disabilities*, *23*(4), 337–343. https://doi.org/10.1111/j.1468-3148.2009.00539.x

Keenan, B. M., Newman, L. K., Gray, K. M., & Rinehart, N. J. (2016). Parents of Children with ASD Experience More Psychological Distress, Parenting Stress, and Attachment-Related Anxiety. *Journal of Autism and Developmental Disorders*, *9*, 2979. https://doi.org/10.1007/s10803-016-2836-z

Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities*, *23*(4), 390-397.

Kiami, S. R., & Goodgold, S. (2017). Support Needs and Coping Strategies as Predictors of Stress Level among Mothers of Children with Autism Spectrum Disorder. *Autism Research and Treatment*, *1*–10. https://doi.org/10.1155/2017/8685950

Kuo, D. Z., Cohen, E., Agrawal, R., Berry, J. G., & Casey, P. H. (2011). A national profile of caregiver challenges among more medically complex children with special health care needs. *Archives of Paediatrics & Adolescent Medicine, 165,* 1020–1026.

Lai, W., Goh, T., Oei, T., & Sung, M. (2015). Coping and Well-Being in Parents of Children with Autism Spectrum Disorders (ASD). *Journal of Autism & Developmental Disorders, 4*5(8), 2582–2593. https://doi.org/10.1007/s10803-015-2430-9

Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal on Intellectual Disability Research, 5*0(3), 172–183. doi:10.1111/j.1365-2788.2005.00732.x

Legg, H., & Tickle, A. (2019). UK parents’ experiences of their child receiving a diagnosis of autism spectrum disorder: A systematic review of the qualitative evidence. *Autism*, *23*(8), 1897-1910.

Lindsay, S., Proulx, M., Scott, H., & Thomson, N. (2014). Exploring teachers' strategies for including children with autism spectrum disorder in mainstream classrooms. *International Journal of Inclusive Education*, *18*(2), 101-122.

Luborsky, M. R., & Rubinstein, R. L. (1995). Sampling in qualitative research: Rationale, issues, and methods. *Research on Aging*, *17*(1), 89-113.

Mahmood, H., Saleemi, M., Riaz, H., Hassan, Y., & Khan, F. (2015). Coping Strategies of Mothers with Asd Children. *Professional Medical Journal*, *22*(11), 1454–1463. https://doi.org/10.17957/TPMJ/15.3078

Marshall, M. N. (1996). Sampling for qualitative research. *Family Practice*, *13*(6), 522-526.

Miranda, A., Mira, A., Berenguer, C., Rosello, B., & Baixauli, I. (2019). Parenting Stress in Mothers of Children With Autism Without Intellectual Disability. Mediation of Behavioral Problems and Coping Strategies. *Frontiers in Psychology*. https://doi.org/10.3389/fpsyg.2019.00464

Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). “My greatest joy and my greatest heart ache:” Parents’ own words on how having a child in the autism spectrum has affected their lives and their families’ lives. *Research in Autism Spectrum Disorders*, *3*(3), 670-684.

Neely-Barnes, S. L., Hall, H. R., Roberts, R. J., & Graff, J. C. (2011). Parenting a child with an autism spectrum disorder: Public perceptions and parental conceptualizations. *Journal of Family Social Work*, *14*(3), 208-225.

Peters-Scheffer, N., Didden, R., & Korzilius, H. (2012). Maternal stress predicted by characteristics of children with autism spectrum disorder and intellectual disability. *Research in Autism Spectrum Disorders, 6*(2), 696–706. doi:10.1016/j.rasd. 2011.10.003.

Rivard, M., Terroux, A., Parent-Boursier, C., & Mercier, C. (2014). Determinants of Stress in Parents of Children with Autism Spectrum Disorders. *Journal of Autism & Developmental Disorders*, *44*(7), 1609–1620. https://doi.org/10.1007/s10803-013-2028-z

Saunders, B. S., Tilford, J. M., Fussell, J. J., Schulz, E. G., Casey, P. H., & Kuo, D. Z. (2015). Financial and employment impact of intellectual disability on families of children with autism. *Families, Systems, & Health*, *33*(1), 36–45. https://doi.org/10.1037/fsh0000102

Schwartz, M. A. (2001). *Understanding the Well-being of the Primary Care-takers of Autistic Children* (Doctoral dissertation, New York University, School of Social Work).

Shechtman, Z., & Gilat, I. (2005). The effectiveness of counseling groups in reducing stress of parents of children with learning disabilities. *Group Dynamics: Theory, Research, and Practice*, *9*(4), 275–286. https://doi.org/10.1037/1089-2699.9.4.275

Sim, A., Vaz, S., Cordier, R., Joosten, A., Parsons, D., Smith, C., & Falkmer, T. (2018). Factors associated with stress in families of children with autism spectrum disorder. *Developmental Neurorehabilitation, 21*(3), 155–165. https://doi.org/10.1080/17518423.2017.1326185

Sim, J., Saunders, B., Waterfield, J., & Kingstone, T. (2018). Can sample size in qualitative research be determined a priori?. *International Journal of Social Research Methodology*, *21*(5), 619-634.

Sutton, J., & Austin, Z. (2015). Qualitative research: Data collection, analysis, and management. *The Canadian Journal of Hospital Pharmacy, 68*(3), 226.

Swinth, Y., Tomlin, G., & Luthman, M. (2015). Content analysis of qualitative research on children and youth with autism, 1993–2011: Considerations for occupational therapy services. *American Journal of Occupational Therapy*, *69*(5), 6905185030p1-6905185030p9.

Tomanik, S., Harris, G. E., & Hawkins, J. (2004). The relationship between behaviours exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disability, 2*9(1), 16–29. doi:10.1080/13668250410001662892

Wachtel, K., & Carter, A. S. (2008). Reaction to diagnosis and parenting styles among mothers of young children with ASDs. *Autism, 12*(5), 575-594.

Weiss, J., MacMullin, J., & Lunsky, Y. (2015). Empowerment and Parent Gain as Mediators and Moderators of Distress in Mothers of Children with Autism Spectrum Disorders. *Journal of Child & Family Studies, 24*(7), 2038–2045. https://doi.org/10.1007/s10826-014-0004-7

Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research*, *18*(8), 1075-1083.

Appendices

Appendix A.
Interview Guide

1. How many children do you have, which children/child has autism?
2. Tell me a bit about your experience of having a child with autism
3. What is a typical day like? Are there particular challenges that you experience?
4. Are there positive to parenting a child with ASD ?
5. Do you think having a child with autism leads to increased stress for parents? Why?
6. Can you give an example of when you felt like this? What are the main factors you find stressful (if they say it is stressful) etc.
7. Do you think yourself and your partner/husband have a similar experience or different? Are the challenges different for mothers compared to fathers in your opinion? In what way? Can you give me an example?
8. Are there particular strategies you use to cope? What things do you do to help you to cope?
9. Do yourself and your partner use similar coping styles/behaviours…etc.
10. Do you feel like you have adequate support? Who/what are your key sources of support?
11. Can you tell me about a time you felt like you were not supported? A time you received good support? How did that make you feel? Etc.
12. What do you think are the most important supports?
13. Do you think parents of children with autism are supported in general?
14. How do you think family/friends/wider community view children with autism etc..

And finally, what advice would you, if any, give to a parent with a newly diagnosed child with autism.

Appendix B.
Study Information Sheet

Parenting Life: A Child with Autism

I would like you to take part in a research study. Before deciding whether to take part, please take the time to read this document, which explains why the research is being done and what it would involve for you. If you have any questions about the information provided, please do not hesitate to contact me and I will be more than happy to explain.

Who am I and what is this study about?

My name is Louise Enright, and I am a final year student studying psychology in The National College of Ireland. As part of our degree we undertake a final year research project. I have decided to do my research on parenting life of caregivers of children with Autism. I am looking for both male and female parents/caregivers of autistic children to take part in an interview as part of this research.

What will taking part involve?

If you decide to take part in this study, you will be asked to take part in an interview, at a time and a place that is convenient to you. The interviews will last for approximately 30 to 60 minutes. If a face to face interview is not convenient for you, it is also possible to conduct the interview by phone/skype. During the interview, you will be asked about your family life, and your experiences as a parent/caregiver of an autistic child. An audio recording of interviews, using a Dictaphone, will be used to collect the data. All information will be strictly confidential. You will be asked to sign a consent form before the interview, to indicate your agreement to take part in the research and to have the interview recorded.

Who can take part?

You can take part in this study if you are over 18 years of age and have a child diagnosed with Autism for at least 6 months.

Do you have to take part?

Participation in this research is voluntary. You do not have to take part and a decision not to take part will have no consequences for you. If you do decide to participate you have the right to withdraw from participation at any time during interview, and you also have the right to refuse to answer any question that you do not feel comfortable to answer. You will not suffer any penalty for withdrawing from the research at any stage. You can withdraw your data from the study after the interview has been completed, up to the point that the results have been written up for submission in my thesis.

What are the possible risks and benefits of taking part?

Benefits – There will be no direct benefit to the participant in this study. However, information gathered here may be of benefit to future research within this area and may contribute to a greater understanding of the area of research.

Risks – There is a possibility that some participants may experience minor distress, if the interview causes them to reflect or discuss difficult experiences they have had. If you feel distressed or upset for any reason during the interview, you are free to take a break or stop the interview completely. Information about relevant support services are as follows:

Samaritans

www.dublinsamaritans.ie

Telephone: 116 123
24 Hours helpline. Drop in centre at 112 Marlboro Street, Dublin 1 from 10am to 10pm.

Autism Helpline

http://www.autism.org.uk/

Telephone: 0808 800 4104
Monday to Thursday 10am-4pm / Friday 9am-3pm

Aware Support Line

Freephone: 1800 80 48 48 Monday to Sunday 10am-10pm

Will taking part be confidential?

All data collected for this study will be treated in the strictest confidence. The participants will be interviewed alone, be it one to one with the researcher, or via telephone/skype call. The other participants will not be interviewed at the same time. The interviews will be conducted in a location that is convenient to the participant and provides sufficient privacy. All interviews will be recorded using a Dictaphone, and these interviews will then be transcribed verbatim for analysis. The audio recordings will be deleted once the interviews have been transcribed. Any information within the interview transcript that could identify a participant (for example names, locations) will be anonymised. Each participant will be assigned a unique ID code, and their data will be stored under this ID code, separately from their name or any other identifying information.
Only the researcher and academic supervisor will have access to the data collected. However, in the unlikely event that the researcher or academic supervisor believes that there is a significant risk of harm or danger to the participant or another individual, or a law has been broken, they would then be required to share this information with the relevant authorities. In this very unlikely event, the researcher would discuss this with you first, but they may be required to breach confidentiality with or without your permission.
All electronic recordings will be kept in password encrypted files on the researcher's computer which will be password protected. The files will be erased after the transcription has taken place. Paper records (consent forms) will be stored securely in a locked filing cabinet. Interview transcripts (with identifying information redacted) will be stored securely as electronic, password-protected files on a password protected computer, with access limited to the researcher. Interview transcripts and consent forms will be retained for 5 years in accordance with the NCI data retention policy.

What will happen to the results and information of the of the study?
The results of this study will be presented in my final dissertation, which will be submitted to National College of Ireland. As this is a qualitative study, direct quotes from the interviews may be included in the presentation of results, but these quotes will be anonymised and will not contain names or any other information that could identify a participant. The results of the project may be presented at conferences within the college and at a national level or submitted to an academic journal for publication.

Who should you contact for further information?
Louise M.Enright
Undergraduate researcher
National College of Ireland
Email – x17121574@student.ncirl.ie
Research Supervisor: Dr Caoimhe Hannigan, Lecturer in Psychology, National College of Ireland
Email: 51aoimhe.hannigan@ncirl.ie

Appendix C.

Informed Consent

Parenting Life: A Child with Autism

- I agree on a voluntary basis to participate in the above mentioned study.
- I agree to participate with the knowledge that I can withdraw at any stage during the interview without any penalties incurred.
- The study has been clearly outlined and explained to me in writing and verbally, and I have been given the opportunity to raise any concerns or queries in relation to the study.
- I understand that participation involves a semi-structured interview that will last 30-60 minutes in duration.
- I understand that I will not benefit directly from participating in this research.
- I agree to my interview being audio-recorded and that once this information is transcribed that the audio files will be erased.
- I understand that all information I provide for this study will be treated confidentially and that any information regarding names, places and other people will be changed and will not be identifiable.
- I understand that extracts from my interview may be quoted in a final year project and that it may or may not be published. These quotes will not contain any information (e.g., names, locations) that could identify me.
- I understand that the researcher is obliged to report to the relevant authorities any information that I relay that be potential risk to me or another party. They may do this with or without my permission.
- I understand that signed consent forms and interview transcripts will be retained in secure storage for 5 years, in accordance with the NCI policy.
- I understand that under Freedom of Information of legislation, I can access my information at any time by contacting the researcher.
- I understand that both the researcher and academic supervisor are available for me to speak with if required.

Date

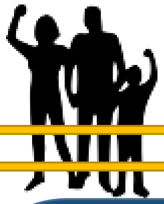
Signature of research participant

Date

Signature of researcher

Appendix D.

Recruitment Poster



National
College of
Ireland

PARENTING LIFE: A CHILD WITH AUTISM

Do you have a child with autism?

Is your child under 18 years old?

We are currently looking for mothers and fathers to take part in a psychology research project.

We want to better understand parents' experiences related to stress, **your** coping strategies and **your** support networks through an interview

If you are interested **in being a participant and to share your experiences** please call Louise on 085-1284045

or email her at **luenright@outlook.com**

and she will follow up with further details relating to the research **once you get in contact**

This **would** not mean you are required to take part in the research.

Louise Enright
Researcher
B.A (Hons) Psychology

Appendix E.

Demographic Questionnaire

1. Age(s) of parent(s):____

2. Child’s age: ____

3. Age at time of diagnosis: ____

4. School provision: Mainstream/ Special Educational Needs ?______________________

5. Has your child been diagnosed with learning disabilities? Yes No__________________

6. Are you the main caregiver? Yes No If no, who is?____________________________

Appendix F.
Debriefing Sheet

Title of the project: Parenting Life: A Child with Autism
Name of the researcher: Louise M. Enright

Thank you for taking part in this study. The purpose of this study is to explore the experiences of parents that have an autistic child and to investigate any similarities and/or differences in these experiences for mothers and fathers. In particular, the interviews aimed to better understand parents' experiences related to stress, coping strategies and their support networks. I will be conducting interviews with a number of parents for this research study, and will analyse the transcripts of these interviews to identify common themes.

The results of this study will be presented in my thesis, which will be submitted to National College of Ireland as part of my final degree. I also hope to present the results of the study at academic conferences or in academic journals. The results will not contain participants' names or any other information that could identify you.

If you wish to withdraw your data from this study, you can do so up to the point that the data has been analysed and written up within my thesis (February 2020). If you wish to withdraw your data, please contact me using the details provided below.

If you have any questions or concerns about the study, you can contact myself or my supervisor. If any part of this experience has caused you worry or distress, you may also with to contact one of the support agencies listed below.

Once again, thank you for taking the time to participate in this study.

Samaritans

www.dublinsamaritans.ie

Telephone: 116 123
24 Hours helpline. Drop in centre at 112 Marlboro Street, Dublin 1 from 10am to 10pm.

Autism Helpline

http://www.autism.org.uk/

Telephone: 0808 800 4104
Monday to Thursday 10am-4pm / Friday 9am-3pm

Aware Support Line

Freephone: 1800 80 48 48 Monday to Sunday 10am-10pm

Name of researcher: Louise Marie Enright
Email: luenright@outlook.com

Research Supervisor: Dr Caoimhe Hannigan
Email: caoimhe.hannigan@ncirl.ie