A Qualitative Study on the Experience of Parenting a child with Dyslexia: An Irish perspective

Simone Cosgrave

18101666

Supervisor: Dr. Conor Nolan

Thesis Presented in Partial Fulfilment of the Requirements for the Bachelor of Arts (Hons) Degree in Psychology, submitted to the National College of Ireland, March 2022.

Submission of Thesis and Dissertation

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

Name: Simone Cosgrave

Student Number: 18101666

Degree for which thesis is submitted: B.A. (Hons) in Psychology

Title of Thesis: The Experience of Parenting a Child with Dyslexia: An Irish Perspective

Date: 13th March 2022

Material submitted for award

A. I declare that this work submitted has been composed by myself. ☐x

B. I declare that all verbatim extracts contained in the thesis have been distinguished by quotation marks and the sources of information specifically acknowledged. ☐x

C. I agree to my thesis being deposited in the NCI Library online open access repository NORMA. ☐x

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) ☐x

Acknowledgements

Firstly, I would like to thank the participants who gave up their time to help me with my research. I would like to thank my supervisor, Conor, who guided and reassured me along the way answering my questions with patience and guiding me back on track when I veered off course. I really appreciate his help and guidance. I'd like to thank my husband Simon and three children Emma, Sean and Grace who put up with me through the trials and tribulations of every assignment and my final year project. I couldn't have done it without your support. Finally, I'm so grateful for the friendship and constant support from my college friends Valerie and Samantha over the last four years in NCI.

Table of Contents

Abstract

Background and Aims**:** Dyslexia is a common learning disability affecting approximately 10% of the population. Previous research found dyslexia places unique challenges on parents. Findings highlight mothers undergo stress in coping and can develop mild anxiety levels by the time this hidden disability is diagnosed. There is little qualitative research on Irish parents exploring their subjective “lived experience” on the stressors and the psychological impact of dyslexia. ***Method*****:** Participants who have a child with dyslexia attending school in Ireland were recruited by purposive sampling. Eight mothers participated (N=8) in semi-structured audio-recorded interviews. The data was analysed adhering to Braun and Clarke’s (2006) six phases of thematic analysis. ***Results:*** Five key themes were identified: (i) Lack of understanding and guilt (ii) Navigating system challenges (iii) Psychological impact (iv) Coping (v) Perseverance and hope for the future. ***Conclusions:*** The experiences of dyslexia are unique to everyone. Insufficient resources and supports from school can affect parental wellbeing. Conversely, parents advocating successfully for their child can result in positive outcomes providing parents with new meaning to their dyslexic journey. These findings provide evidence for the importance of supporting parents of dyslexic children during their school years.

Keywords: Dyslexia; parental wellbeing; psychological impact; thematic analysis; parental empowerment

Introduction

Dyslexia is a specific learning difficulty associated with persistent problems with word recognition and decoding (Leitao, Dzidic, Claessenk, Gordon, Howard, Nayton et al., 2017; Snowling & Melby-Lervey, 2016; Shaywitz, Shaywitz, Fletcher, & Escobar, 1990). The DSM-5 categorises it as a 'Specific Learning Disorder' describing difficulties with reading accuracy or fluency that are inconsistent with the person's chronological age, educational opportunities, or intellectual abilities' (American Psychiatric Association, 2013). Dyslexia is universal across languages affecting approximately 10% of people globally (Thomson, Leong, & Goswami, 2012). Dyslexia can occur across all levels of intelligence, and while problems in phonological processing are a characteristic feature, other characteristics can include deficits in verbal memory and processing speed (Rose, 2009). There is controversy among experts and no consensus has been reached on the specific criteria for diagnosing dyslexia (Elliott & Grigorenko 2014). For this reason, dyslexia can be difficult to diagnose which can be traumatic for parents and children (Bajaj & Bhatia, 2019; Elliott et al., 2014).

In recent studies, mothers of dyslexic children report undergoing significant emotional adjustments, especially in the early years of diagnosis, resulting in feelings of guilt, blame, self-doubt, frustration, and helplessness and perceiving themselves as bad parents (Bajaj et al., 2019; Delany, 2017). It is important that parents of dyslexic children have the personal coping abilities and the necessary supports from school to fully assist their child.

These factors are essential because without them, their unique contributions can place parents and their children at increased risk for negative psychological distress and wellbeing (Karande, Kumbhare, Kulkarni, & Shah, 2009). Although dyslexia is an educational construct, it is associated with a range of adverse psychological outcomes. (Leitao et al., 2017). There is mounting evidence on the positive association between dyslexia, negative mental health, and lack of support (Boyes, Leitao, Classen, Badcock, & Nayton, 2016; Ewing, 2021). Even though, child-parenthood relationships can be complex, parental wellbeing can be negatively affected if their child is unhappy (Nelson, Kushlev, & Lyubomirsky, 2014). Terras, Thompson, and Minnis (2009) concluded parental support and understanding is a protective factor for the psychosocial adjustment of children with dyslexia. Therefore, it is surprising given the influence of parental support that there is such a lack of research on parental "lived" experiences (Norwich, Griffiths, & Burden, 2005; Leitao et al., 2017).

Parents' Emotional adjustments

As literacy skills are the key to educational attainment and reading is a fundamental core skill of the early school years, dyslexia can place elevated stress and worry on parents (Earey, 2013). In a study by Delany (2017), mothers spoke about "grieving the loss of normal" when their child was diagnosed with dyslexia. Mothers report feelings of hopelessness when they do not entirely understand what dyslexia means (Karande & Kuril, 2011). Other studies found mothers show higher levels of stress and anxiety becoming emotionally drained trying to teach their children (Bonifacci, Montuschi, Lami, & Snowling, 2014; Poon-McBrayer & McBrayer, 2014). Homework results in constant conflict and frustration, causing a strain on the mother-child relationship (Bajaj et al., 2011). Concern about children's academic future is a genuine concern for any parent, but parents of dyslexic children will have additional factors to consider (Karande, Mehta & Kulkarni, 2007). Findler, Jacoby & Gabis (2016) reviewed some of the most frequent criticisms of parents with a child with a developmental disability. They found access to resources and social support have a more significant direct effect on parents' wellbeing than the severity of the disability. There were similar findings on mothers of children with dyslexia regarding the implications of the lack of resources and support (Earey, 2013; Resch, Benz, & Elliott, 2012). However, these findings should be interpretated with caution as parental wellbeing is dependent on many other variables such as parents' relationship, parents' personal attitudes and coping strategies and financial constraints (Minness, Perry & Weiss, 2015).

Parents have reported positive and negative outcomes when diagnosed with dyslexia (Earey, 2013). A study by Riddick (2010) with 22 mothers found that diagnosis of dyslexia led to an overall sense of relief as it offered a legitimate explanation for the difficulties they were experiencing. Another study found parents felt relieved they weren't to blame for their child's reading difficulties (Ho, 2004). However, others found their children felt "different" or "ashamed", which resulted in underachievement (Alexander-Passe, 2015). In addition, parents' express confusion and frustration trying to navigate appropriate and beneficial supports for their child's learning difficulty (Earey, 2013; Karande et al., 2011). These findings highlight the lack of knowledge and understanding among parents about dyslexia. This literature supports the establishment of professional support groups to provide parents with guidance and information, especially in newly diagnosed cases.

Challenges and stressors

Parents of dyslexic children have reported immense challenges navigating school systems with stigmatisation and lack of understanding by teachers (Alexander-Passe, 2015). Previous research confirms schools can be a challenging environment for children with dyslexia (Leitao et al., 2017), therefore, getting appropriate educational support is crucial (Collier, Keefe & Hirrel, 2015; Nalavany, Carawan, & Rennick, 2011; Riddick, 2006). However, it is important to note these challenges vary widely depending on everyone's individual experience (Delany, 2017). Research has found early diagnosis and intervention is crucial for laying the foundation for future academic and psychosocial success (Nalavany, Carawan, & Brown, 2011). Parents report frustration when teachers do not recognise the signs of dyslexia and label children as "disruptive", "stupid" or "lazy" (Alexander-Passe, 2006; Armstrong & Humphrey, 2008; Thompson, Bacon & Auburn, 2015). Teachers are among the most influential figures in the lives of children after parents, so encouragement, positive reinforcement, and understanding of dyslexia will have a positive impact on their child's school experience (Earey, 2013). In a recent survey on Irish parents in October 2021, 60% of parents were not satisfied with the level of support their child receives at school (Ewing, 2021). In the same survey, 79% of parents reported waiting for more than two years for an educational assessment from the Department of Education, with 39% waiting more than four years (Ewing, 2021). This resulted in having to pay for costly private educational assessments. Similar findings on parent's frustration with lack of teacher training in dyslexia are widespread across the UK, USA, Hong Kong, India, Scandinavia, and Australia (Bajaj et al., 2019; Collier et al., 2015; Delany, 2017; Rimukte, Torppa, Eklund, Nurmi, & Lyytinen, 2104; Rose, 2009; Poon-McBrayer et al., 2014).

Research has found parents yearn for greater diversity in learning opportunities and different teaching strategies tailoring interventions for individual learning needs (Armstrong & Humphrey, 2008; Bishop & Snowling 2004). Without these parents must employ tutors, placing added financial pressures on the family (Bajaj et al., 2015; Harkin, Doyle & McGuckin, 2015). Therefore, appropriate support is essential for parents' wellbeing. Basic dyslexia training for all teachers, enhanced training for Special Education teachers and the introduction of immediate free educational assessments would alleviate these substantial worries for parents.

Psychological impact

The most common maternal worries include loss of child's self-esteem, behavioural issues, or becoming withdrawn due to poor academic performance (Earey, 2013; Karande et al., 2009; Terras et al., 2009). Although a young person's ability to deal with difficulties can be attributed to individual factors such as personality, age, support and coping styles, research has identified reduced self-esteem in many children with dyslexia (Haft, Myers, & Hoeft, 2016). Self-esteem is an evaluation of overall self-worth (Gurney, 1986). A recent survey by Dyslexia Ireland in October 2021 highlighted the impact on children's self-esteem, especially when dyslexia is unidentified and unsupported (Ewing, 2021). Another study on Norwegian adolescents with reading difficulties reported higher levels of school stress and depressive symptoms than their peers (Sund & Undheim, 2008). Similar studies with dyslexic parents reported their children exhibited more internalising behaviours such as anxiety, depression, and withdrawal than siblings without dyslexia (Terras et al., 2009; Dahle & Knivsberg, 2014). Although these studies report disruptive behaviour, they should be interpreted cautiously as there could be multiple risk factors at play such as social, environmental, and biological factors such as child’s temperament, personality traits, relationships with peers and family environment (Leve, Hyoun, and Pears, 2005).

Even though recent studies report attitudes towards dyslexia have changed, negative impacts and stigmatisation found in studies twenty years ago are still present today (Delany, 2017; Riddick, 2000). Findings conclude if dyslexic children are not supported, they will experience negative emotions, such as feeling overwhelmed, disappointed, incompetent, anxious, sad, and angry (Carawan, Nalavany, & Jenkins 2015). Ingesson (2007) found that coping ability and increased confidence is due to being diagnosed early with dyslexia. It is evident from the literature that parents face challenges with behaviour and negative emotional consequences if their experiences with schools are unsatisfactory.

Parental influence

Existing literature highlights the significance of parental involvement in successful academic achievement (Poon-McBrayer & McBrayer, 2014; Rimkute, Torppa, Eklund, Nurmi & Lytinen, 2014). As parents are the primary caregiver, their support is crucial as they can advocate for better educational support and resources for their child (Alexander-Passe, 2008; Norwich et al., 2005). Some studies found mothers quit full-time employment to focus on their child's education (Poon-McBrayer et al., 2014). Many studies found that despite considerable and sustained stresses involved with parenting a child with a disability, for some parents, their experiences have been personally transformative (Scorgie, Wilgosh, & Sobsey, 2004). Mothers speak about "personal empowerment", expressing satisfaction of gaining strengths they weren't aware of, resulting in a personal transformation from parenting a child with dyslexia. They discuss assertively navigating support to fight and advocate for their children, which gave them "new meaning" and confidence. These feelings evolved from a previous position of grief, worry and stress to a position of confidence (Delaney, 2017). In this scenario, "parental psychological empowerment" can be related to the process of advocating successful outcomes for their children with self-determination, motivation, and competence (Zimmerman, 1995). As a result of navigating system challenges with schools, teachers and principals, parents strengthened their competencies, acting and making decisions which enhanced their wellbeing and their child's confidence (Delaney, 2017; Damen, Veerman, Vermulst, Nieuwhoff, de Meyer, & Scholte, 2016). It is important to understand parental empowerment, perseverance and coping skills will be affected by their individual attitudes, psychological state, cultural and social backgrounds, and we need to consider other factors such as work demands, stressful life events and relationships (Damen et al., 2016).

However, this literature does highlight the necessity to understand the advocacy journey of parents of children with dyslexia. Parental empowerment and coping strategies are strong predictors to alleviate parental distress (Poon-McBrayer et al., 2014). In addition, parents voiced the benefit of support groups for positive adjustment to address the many questions and concerns when their child has been diagnosed with a disability (Resch et al., 2012). This literature concludes dyslexia is a "journey" and highlights the importance of a myriad of supports and resources that would reduce these challenges and stresses parents face of parenting a child with dyslexia.

Present Study

It is evident from the literature that parents face unique challenges and stressors of having a child with dyslexia, both from a personal level and from a broader level. Specifically, there is a clear gap in the literature on qualitative research conducted in this area, especially regarding the subjective experiences of Irish parents. Therefore, this research aims to explore Irish parents' perspectives to establish if there are common themes regarding stressors, emotional challenges, and the psychological impact of dyslexia and to fully understand possible determinants of parental wellbeing. Ultimately, professionals' understanding and awareness of "lived experiences" will help promote future interventions and supports for parents and dyslexic children during their school years.

Method

Research Design

A qualitative research design was employed using semi-structured interviews via Microsoft Teams. A thematic analysis was used as the researcher was interested in parents' experience of having a child with dyslexia. A phenomenal interpretative analysis is ideal for the systematic exploration of personal experience. The objective is to understand lived experiences and explore how individuals make sense of their personal experiences (Noon, 2018). The interview consisted of open-ended questions that could be re-ordered, added, or deleted depending on the participant's responses. This approach is suited to this type of questioning (Sutton & Austin, 2015).

Participants

Participants were recruited using a purposive sampling strategy which is useful when research does not aim to generate results that will be used to create generalisations pertaining to the entire population (Etikam, Sulaiman & Alkassin, 2016). Participants have defined characteristics for this study with inclusion criteria of parents whose child had an official dyslexic diagnosis attending school in Ireland. Participants were recruited on social media parent support groups for dyslexia. Permission was sought from the group administrator and approved by the CEO. Recruitment posters outlined the nature of the study where potential participants were invited to email their interest to the researcher. The participants selected were not known to the researcher.

All participants (n=8) met the inclusion criteria and consisted of eight mothers. Participants ranged in age from 31 – 48 years old (M=40.2) and were married or in partnerships. Five participants were from urban areas, while three lived in rural areas. Four out of eight participants had more than one child diagnosed with dyslexia. The age range of children with dyslexia ranged from 7 – 16 years. All were attending primary or secondary schools in Ireland.

There are conflicting opinions on the correct number of participants for qualitative research. However, data saturation is when data collection and analysis become repetitive, and no new data is gathered, which is important for determining sample size. There has been conflicting evidence of when data saturation occurs (Marshall, 1996; Guest, Bunce, and Johnson, 2006). For the current study, a total of 12 people showed interest, but due to cancellations and lack of time available, the final sample consisted of 8 people.

Ethical considerations

NCI granted ethical approval for this study. A recruitments poster (Appendix A) was posted on the support group's Facebook and Twitter page. An information sheet (Appendix B) outlining the study was emailed to potential participants when they showed interest. Informed consent (Appendix C) was sought before interviews commenced. Participants had to reply via mail to give consent and return the information sheet stating they were happy to proceed. Support group contact details and phone numbers were provided in the event of a parent becoming upset during an interview which was clearly documented in the information sheet. It was also highlighted that interviews would be recorded and deleted after transcribing the data to a word document. Participants' names were disclosed in their email addresses; however, all personal information was omitted when data was transcribed for confidentiality purposes. Finally, participants were advised they could withdraw at any time, take breaks, or stop questioning at any stage throughout the process. A debrief sheet was emailed immediately after the interview (Appendix D).

Data collection

The interviews were conducted on a one-to-one basis to enable the researcher to gain a perspective from the parents of what it is like having a child with dyslexia. The participants were encouraged to explore their experience without adhering to a strict questioning structure. Questions were created based on studies from the literature review. Open-ended questions were used to keep participants on track or to probe further or elaborate more on their answers (Appendix E). The researcher began asking them to relay their experiences of having a child with dyslexia. This led to questions relating to challenges, supports, coping strategies and the psychological impact of dyslexia. The schedule was designed to be flexible to allow participants to elaborate on important points.

Data Analysis

It is important to acknowledge that the researcher's beliefs can influence the interpretation of the data, but the interviews were designed to allow for flexible exploration of the individual's experience of having a child with dyslexia.

Data analysis was conducted once the data was transcribed, using the six-phase inductive thematic analysis (Braun and Clarke, 2006). It is a process to identify, analyse, and pick out themes/patterns that emerged from the data itself. As this type of analysis is not based on existing theory and focuses on the subjective experiences of everyone, it seeks to generate themes to get a greater understanding of the topics that arose. This inductive approach is, therefore, data driven. The first step is to familiarise themselves with the data by reading the transcripts repeatedly to increase familiarity and search for patterns. Codes were produced and patterns highlighted and sorted into meaningful groups. Data saturation occurred when there was no new information. Then the groups of codes were organised into themes. A thematic map was produced (Appendix F) in which themes were defined.

Study procedure

Participants were recruited online via Dyslexia Irelands website (Appendix A). Participants emailed their intended interest to the researcher who set up a specific email address for the research. The researcher then forwarded the information sheet (Appendix B) and consent form (Appendix C). The interview time and date were agreed via email. The participant had to email back consent and acknowledge they read the information sheet and understood the interview would be audio recorded. The researcher sent an invite via Microsoft Teams to conduct the interview. The interview was audio-recorded via Teams and transcribed accordingly. The researcher highlighted this again verbally before the interview commenced and gave the participant the chance to ask any questions. The researcher transcribed data after the interview and deleted the audio recording. Participants were fully debriefed after the interview, and a debrief form was emailed to the participant immediately (Appendix D). Interviews generally lasted 30-45 minutes and took place over a three-week period.

Results

A thematic analysis gathered themes and subthemes which emerged from interviewing the 8 participants regarding their experiences of having a child with dyslexia. Using Braun and Clarke’s (2006) thematic analysis, five themes were identified (i) lack of understand and guilt, (ii) navigating system challenges, (iii) psychological impact, (iv) parental influence and coping and finally (v) perseverance and hope for the future. See Appendix E for a thematic map illustrating the themes and sub-themes within them.

Theme 1: Lack of understanding and guilt

Both lack of understanding and guilt were mentioned by all participants. Feelings of guilt for not picking up their child had dyslexia and then lack of understanding about what dyslexia meant was evident in their interviews. All parents expressed feelings of inadequateness at not knowing how to help their child when they started showing problems with reading. One participant relayed

> I was harsh with my son as I thought he was lazy. After his diagnosis I felt so guilty and I feel so sorry, I was crying when I got to know my son had dyslexia. I always noticed my son was trying his best, but he was not getting there, he was exhausted….but I did not realise it might be dyslexia (Participant 6)

> I went to a parent teacher meeting and sat there and cried with frustration on why my child could not read. I needed to know what was wrong, homework was supposed to take 10 or 15 minutes, but we’d be sitting for two hours which was causing major stress for me and my child (Participant 7)

Both participants were deeply affected by the overwhelming sense of guilt. However, other participants who had a family history of dyslexia recognised the warning signs and were able to take immediate action to get their child assessed. For these parents even though it was going to be a difficult journey ahead they understood early intervention was key to success. One participant relayed

> I got her diagnosed early as my husband is dyslexic, I did worry about her self-esteem, but her father is dyslexic and he’s successful. So, for starters they could see that dyslexia never stopped him…….and what I did with my daughter was to research people with dyslexia, Einstein, Richard Branson and we made a folder of successful people (Participant 3).

While most parents expressed relief when their child was finally diagnosed, they then realised they had to face the challenge of trying to get the best supports for their child.

> Initially we were relieved when we got the diagnosis but then we realised it was only the beginning. I didn’t know where to go next. I couldn’t find access to the right information, that is research based……. there is so much conflicting advice…….Learning strategies should be more researched based (Participant 4).

This last comment was supported by all participants who agreed there was no clear pathway after diagnosis and a complete lack of direction on how to access the best supports with the school, which brings us to the next theme.

Theme 2: Navigating system challenges

This second theme undoubtably is broad as it deals with education and support. Starting with the assessment and diagnosis of dyslexia, all participants expressed feelings of frustration at the length of time and lack of funding prioritised for assessing children for dyslexia. One participant said,

> To try and get assessed by the school was a joke, I scrambled to save the cost because my husband is just a factory worker and it cost us 550 euro to get her assessed privately in the end (Participant 6)

All parents' felt diagnosis was dependent on teachers experience and knowledge of dyslexia to be able to spot the signs of dyslexia. While some participants expressed satisfaction that their child's dyslexia were picked up early, two participants, participant 5 and participant 6 were never informed that their child might be dyslexic which resulted in them not being diagnosed until they were in secondary school

> I trusted the school, we're so dependent on them……I've never heard the word dyslexia once in national school, not one time, all I heard was not working hard enough, not doing his best (Participant 5)

Most parents spoke about the challenges of having to advocate for their child's resources with mixed outcomes, one participant

> Year by year, I must fight to get her the support and request meetings with the special educational resource teacher which takes forever, they never rang me back, it is exhausting (Participant 6)

Several participants expressed concern due to the "lack of flexibility in teaching approaches" (P2, P3, P4, P8), and all would love for greater diversity in learning opportunities to meet their intelligent but dyslexic child's needs. One participant said

> Mainstream school and the curriculum is so rigid, its only for academic people. It's for people that are A type personalities and all about points….there needs to be more

> diversity, different teaching approaches because people learn differently………and even how they assess children (Participant 8)

Another participant claimed the years her son had inexperienced teachers with dyslexia had a major negative impact on him and set him back academically and emotionally. She believed the whole family suffered the consequences for his "negative emotional state". She relayed,

> It's unbelievable, all teachers need to be trained and educated as I noticed with XXXX in years where he had teachers that were previously resource teachers, the difference is another level in terms of support for him. They have the knowledge and understanding of dyslexia, and it makes a huge difference (Participant 8)

Four participants had to get tutors due to lack of support which caused a huge financial burden. The cost and extra time was challenging and there has been mixed reports regarding success of tutors.

Comparatively, other parents spoke of their positive experiences with their school when their child's teacher and school were on board. One participant highlighted how teachers are "in a massive position to give hope and encouragement", (P1) and the following participants had positive experiences with their schools

> my experience in our school is extremely positive…....resource teachers have been fantastic, and they got individual tuition on reading, and she goes out in a group of four, but she loved going and enjoyed it immensely. And she did well. My son got one to one support, just him (Participant 3).

> our school was very accommodating and wanted to work with us which made a huge difference so you're not coming up against a teacher...the resource teachers would be sent on a lot of courses and came back to me saying, this app is really good or this program is very good so they're constantly coming back to us (Participant 1).

Many participants acknowledged that stigmatisation about dyslexia is becoming less of an issue, however there was still some negative attitudes and denial "I'll be honest with you, his father did not accept that his son has dyslexia……it has caused huge conflict between me and him" (P6). While another participant was advised by the school principal "not to get her child assessed, as it would label them." (P4). Another parent was told her "child is horribly dyslexic." (P5). However, labelling can be seen as a positive or negative as another parent exclaimed "

> you know sometimes people see a label as a negative but certainly from our perspective it was a positive because now, we understood that there was a reason that his brain worked in a different way….and we were able to start seeking the help he needed to get through it (Participant 1)

While all parents felt our education system has made advances with dyslexia support, they all feel there is much more to be done

> teacher training is key, it should be compulsory in teacher training college to train teachers that children learn to read differently and there needs to be more research in the different learning strategies, as one size does not fit all (Participant 4)

These challenges gave participants the motivation to adapt and learn to cope with situations by advocating with schools which brings us to the next theme 'coping'.

Theme 3: Coping

All parents spoke about various coping strategies they adopted on a personal level. Becoming more informed by completing webinars and courses on dyslexia in order adopt appropriate teaching strategies.

> I have three children with dyslexia and all of them learn differently, I found some learned visually as they had no phonic awareness so couldn't break down words unlike my other two. They had different learning strategies that suited them. This was a huge breakthrough for us as we finally understood how they learned best (Participant 3).

Two participants gave up full-time employment to focus on supporting their child with dyslexia. They joined support groups for parents of dyslexic children which they found invaluable. They gained confidence and became more assertive year on year negotiating with teachers, principals, resource teachers. One parent said

> it gave me new meaning after giving up my job….it strengthened my relationship with my children in a positive way……I would say the more effort you put in and the more support you get the greater the output. You must advocate for your child, so before they start secondary school, you need to meet resource teachers, meet the principal and discuss what your son or daughter will be getting in terms of resources (Participant 3).

Participants coped by reaching out to other parents for support to gain more knowledge of what supports are available to children with dyslexia. One participant spoke about the benefits from reaching out to other parents as she learned about accommodations

> spelling waivers, extra exam time, DARE, readers for exams in secondary school, Irish exceptions (Participant 1).

Most parents encouraged activities or hobbies their child excelled at to give them confidence.

> we encouraged our son with his soccer as he was very good, this gave him confidence in something other than academia……I find its nearly like therapy after the stress of homework and school he can go out and kick a ball (Participant 3).

> I decided to leave the education side to the school and instead of focusing on education, I would focus on the outside, ballet and Irish dancing in order to give her confidence from other areas…I got her interested in baking and she's so good that she now bakes birthday cakes and cupcakes in the local area to earn some money….she organises everything herself, buys ingredients and sorts it out me and her Dad to deliver the cakes (Participant 7).

Another participant whose child excelled at taekwondo, said "I absolutely encourage him will as he feels so much better about himself, you know." (P1).

However, through the school years parents emphasised that dyslexia even though it is seen as an educational disadvantage, it can have a negative impact on confidence and self-esteem.

Theme 4: Parents perspective: psychological impact of dyslexia

All parents mentioned the psychological impact of dyslexia on their child and them. Participants reported their child experienced periods of distress related to their dyslexia which effected their confidence and self-esteem. One participant relayed

> when my child was stressed, I was stressed, from a parent's point of view you want your child to be happy and if they're not happy it'll have an impact on you as a parent and on the rest of the family (Participant 1).

> school has always been a massive challenge for him, he has low confidence and feels different and singled out, especially around tests when classmates compare scores…...he would get very frustrated with test results, and you know he thinks he would have learned something really well and do poor in it so it affects his overall confidence (Participant 8)

This participant found it stressful trying to find the right words to reassure her son that he would be okay. She said he would mask his frustration in school but when he came home, he would be "angry and just explode." (P8).

Therefore, participants were keen to highlight the emotional and possible behavioural effects of dyslexia. Participants believe their child behaved badly due to avoidance and coping strategies possibly to camouflage their dyslexia in front of their classmates.

> they learn to mess at a young age so that they can get out of other stuff and I think messing is part of it actually, the whole class clown thing, they can hide behind it…so I think dyslexia is behavioural problem and not just an educational problem... everything you know about dyslexia is misunderstood if you've never seen it before, someone in my family said is he bad at spelling? There is a whole lot more to it than that (Participant 5)

Another participant acknowledged that children with dyslexia are often the first to acknowledge their disability which impacts their confidence

> The one thing I'd like to say about kids that have difficulties in school, nobody knows their difficulties as well as they do…so instantly from the time they get an inkling something is not right, both my girls retreated and would not read out loud or do spellings in front of anyone….her confidence was way down…can you imagine a child in fourth class begging you not to send her to school (Participant 7)

Research has shown that early diagnosis is crucial for laying the foundations for successful learning strategies for children with dyslexia, however one participant whose child wasn't diagnosed until secondary said

> he was not picking up things the same way as other students for his age….so he carried the luggage with him every year and it got harder and harder….always

> negative comments…he needs to focus, he needs to make more effort, he did not get the support he needed in primary which lead to a disaster in secondary…it really affected his self-esteem…and now he suffers from depression and anxiety (Participant 6).

This parent had to attend therapy in the form of counselling so she could "work on his emotions and build up his self-esteem". All of which is helping them cope with a positive outlook going forward.

Some parents did courses and webinars on dyslexia to help them understand more about how to help their child which they found hugely helpful.

> I did everything, I did every course I could with XXX, which gave me confidence and finally helped me to understand the way my child's brain worked. They gave great tips on how best to advocate with schools, tips to help children adapt and loads of other stuff, like all the technology apps that would help us (Participant 5)

Theme 5: Parental empowerment

This brings us to our last theme and concludes this research which focuses on perseverance from a parent's perspective. All participants agreed with the correct support and resources in place there have been many success stories where their children began to "love learning" and had success in school

> I really cannot reinforce how hard it got, especially in the early years, I'd say 7, 8, 9, and maybe 10 are the hardest years….but I will say to anybody who is in the early stages that it will get better…… at the end of the day, we said, you're going to be able

> to read. It just means that the process you're going through, and reading is just a lot slower than other kids. But it will come (Participant 1).

This last theme recognises parental empowerment, parental support and parents' perseverance resulting in competence and success advocating appropriate supports for their child which will have a positive impact on their dyslexic journey.

Discussion

This qualitative study aimed to explore parents' subjective experiences discussing stressors, emotional challenges, and the psychological impact of dyslexia. Semi-structured interviews were conducted, and a thematic analysis was undertaken where various themes emerged. This discussion is structured according to findings from early diagnosis moving towards broader factors such as perceived failings in teacher training. Some of these challenges are out of participants' control but play a significant role in their lived experience. The psychological impact of dyslexia resulting in the child internalising behaviours also has a negative impact on mother’s wellbeing. Themes found in this research are not specific to Ireland with commonalities across the UK, USA, Australia, India, and Scandinavia. Five themes captured parental perspectives: (i) Lack of understanding and guilt (ii) Navigating system challenges (iii) Coping (iv) Psychological impact (v) Perseverance and hope for the future.

The theme "lack of understanding and guilt" relates to mothers who did not understand their child was dyslexic and feeling guilty for not recognising the signs. Dyslexia is not a visible disability; therefore, it may not be easy to identify, especially in the early years and even more so with inexperienced teachers. All parents identified this early diagnosis stage as a stressful, challenging, and confusing period. Parents complained about lack of understanding on how to get the best supports for their child. Alias and Dahlan (2015) found similar results where parents expressed "hopelessness" not knowing how best to help their child. Feelings of frustration by parents was an emotion highlighted in a study by Fernadez-Alcantara et al. (2017), especially in newly diagnosed cases. This resulted in feelings of guilt regarding their child's dyslexia, which was found in a similar study by Findler et al., 2016. However, even after diagnosis, some participants reported the lack of a clear pathway for children with dyslexia which seems to be widespread (Karande et al., 2009)

The next theme, "navigating system challenges," reveals parents' experiences of dealing with assessments and advocating school support. Early diagnosis is vital for early intervention (Nalavany, Carawan, & Brown, 2011) and a major setback for some participants was the teacher not picking up the warning signs for dyslexia. This resonates with findings by Dyslexia Ireland regarding the negative mental impact on children that are undiagnosed and unsupported (Ewing, 2021; Thompson, Bacon & Auburn, 2015; Collier, Keefe & Hirrel, 2015). All participants expressed dissatisfaction with the lengthy waiting times for assessments, which resulted in costly private assessments. Parents voiced opinions that training in dyslexia should be compulsory in teacher training colleges which resonates with previous findings (Hassall et al., 2005; Collier et al., 2015; Thompson et al., 2015). Some parents had no option but to get tutors due to a lack of appropriate support from school, consistent with previous research (Bajaj et al., 2015; Harkin, Doyle & McGuckin, 2015). Each participant's experience differed depending on access to resources and supports resulting in positive and negative experiences with implications for both risk and protective factors. It should be noted, there is variances in parental perspectives as there are positive experiences when schools are on board. Schools who sent teachers on training courses for dyslexia made a massive difference to the parent's overall wellbeing. However, there was evidence of stigmatisation and labelling from teachers, which research has shown may negatively impact the child (Nalavany et al., 2011). One participant's husband refused to acknowledge his son had dyslexia which caused conflict in their marriage. This issue of stigmatisation moves us on to the next theme dealing with the psychological impact of dyslexia.

The next theme relates to the psychological impact of dyslexia. In keeping with the findings of Early, 2013; Karande et al., 2009; Terras et al., 2009, parents reflect on teachers' significant influence and attitudes in shaping their "lived experience". Participants in this study reported periods of distress due to comparing test results with peers and being asked to read in class. Low self-esteem and confidence were negative emotions that parents highlighted as adverse emotional effects of dyslexia which coincides with findings by Ingesson (2007) on negative school experiences. In this research, one parent confirmed how stressful and upsetting it was for her to try and reassure her child every day. A new insight regarding the behavioural effects of dyslexia is where a parent believed her son's disruptive behaviour was a coping strategy to camouflage his dyslexia in front of peers. Previous studies by Snowling, Muter & Carroll (2007) found students with dyslexia shows higher levels of anxiety and behavioural problems (Eissa, 2010). Recently, more research has examined the relationship between reading difficulties and mental health issues such as low self-esteem, low confidence, and, specifically, negative behaviour patterns in school (Leitao et al., 2017).

This theme highlights how participants adapted and coped with their situations. All participants confirmed dyslexia is somewhat a gradual process and a "journey". Some participants acknowledged they had to be a "different" sort of parent whose role extends beyond that of an average parent. They become a tutor, advocate, and counsellor for their child, highlighting the need to be multifaceted when dealing with a child with dyslexia and their educational and psychological needs. Participants who joined support groups and did webinars and courses on dyslexia found it hugely beneficial for their wellbeing, giving them increased self-satisfaction and strengthening their relationship and bond with their child. In addition, it enabled them to become better advocates. These findings are mirrored in an

Australian study by Delany, 2017. Other studies found that support groups for parents a child with a disability to be invaluable (Resch, Benz & Elliot, 2012). An interesting find in this study found parents coped by encouraging their child at hobbies and activities they excelled at to give their child confidence. Examples were football, ballet, Irish dancing, baking, and taekwondo. These findings confirm that children with dyslexia need specialist support in school but also the opportunity to explore subjects outside the narrow-focused curriculum. Creative and practical subjects such as art, drama and music allow dyslexic students to demonstrate their talents, giving them considerable confidence and self-esteem that they do not get in the classroom (Bacon & Bennett, 2013). Perseverance was evident throughout the interviews, bringing us to the final theme.

The final theme is short but centres around continued parental support and perseverance successfully advocating for their child which results in parental empowerment. Despite considerable stresses involved, some participants' experiences have been personally transformative. Nearly all participants noted positive impacts on their journeys due to their continuous perseverance in advocating for their children, providing them with personal meaning, which is supported in findings by Scorgie et al., 2004; Poon-McBrayer et al., 2014; Minnes et al., 2015; Karande et al., 2011. Their children see the benefits, which ultimately leads to achieving goals. Other studies support these findings where parents' input changes circumstances for a child with a disability or special needs in a positive way (DePape & Lindsay, 2015). Most participants faced challenges along the way but had developed the capacity to cope and succeed, giving them a sense of hope for the future.

Implications and Future Direction

One of the main implications of this research is the importance of supporting parents of dyslexic children and the direct impact on their wellbeing of not having the right supports at school . These findings highlight the need for teacher training on dyslexia across the education system. This study found children can become depressed, withdrawn and not want to attend school due to not getting appropriate support which causes enormous stress and anxiety for parents. Therefore, educators need to be aware of parents' "lived reality". Parents highlighted the lack of direction after diagnosis with no clear pathway in place. Another parent expressed disappointment at the lack of research-based evidence for different learning strategies. Two participants found support groups beneficial, but more support systems are needed nationwide especially with newly diagnosed dyslexia.

It was beyond the scope of this research but possible further exploration on the experiences of different parental demographic samples, and possibly a comparative study on experiences in public, private and specialist dyslexic schools. In addition, further research to expand these findings by exploring parents' experiences at various points during their child's education journey, such as early diagnosis in primary school, five years post-diagnosis and another cohort of parents of adolescents nearing the end of their secondary education to build a solid base of research in this field. Possibly, fathers may provide different insights.

Strengths and Limitations

This research aimed to gain an in-depth subjective account of parents' individual experiences relating to dyslexia. This information cannot be generalised to the overall population, but it does give a glimpse of challenges experienced by parents in Ireland. The clear research questions contributed to the study's strength allowing for further probing and elaboration on important topics. Even though participants were recruited from an organisation, they were from a mixture of rural and urban areas. Interviews were held online via Teams and audio-recorded and transcribed. Unfortunately, some participants requested phone interviews for their convenience, which the researcher could not accommodate. Due to the sensitive nature regarding the psychological impact of dyslexia, it may have been beneficial to undertake a separate research study on this due to time allocation and constraints and the vast nature of this topic.

Conclusion

In conclusion, this study has contributed to the limited qualitative research focusing on lived experiences of parenting a child with dyslexia in Ireland. Identifying parental stressors and challenges is a step towards removing them. Five key themes were revealed: (i) Lack of understanding and guilt (ii) Navigating system challenges (iii) Coping (iv) Psychological impact (v) Perseverance and hope for the future. Parental involvement advocating for the right supports can result in successful outcomes which is a strong predictor to alleviating parental stress. However, as challenges and stressors are affected by the broader community, findings should be considered by government officials and education professionals. They need to develop effective education strategies and relevant services that will benefit parents of and children with dyslexia in Ireland today to maximize positive outcomes during their school years.

References

Alexander-Passe, N. (2008). The sources and manifestations of stress amongst school-aged dyslexics, compared to sibling controls. *Dyslexia, 14*(4), 291-313. doi:10.1002/dys.351

Alexander-Passe, N. (2015). The Dyslexia Experience: Difference, Disclosure, Labelling, Discrimination and Stigma . *Asia Pacific Journal of Developmental Differences, 2*(2), 202-233. doi:10.3850/S2345734115000290

Alias, N. A., & Dahlan, A. (2015). Enduring Difficulties: The Challenges of Mothers in Raising Children with Dyslexia. *Social and Behavioural Sciences, 202*, 107-114. doi:10.1016/j.sbspro.2015.08.213

Armstrong, D., & Humphrey, N. (2009). Reactions to a diagnosis of dyslexia among students entering further education: development of the 'resistance-accomodation' model. *British Journal of Special Education, 36*(2).

American Psychiatric Assoiation (2013). *Diagnositc and Statistical Manual of Mental Disorders* (5th edn). Washington, DC: American Psychiatric Association

Bacon, A. M., & Bennett, S. (2013). Dysleixa in Higher Education: the decision to study art. *European Journal of Special Needs Education, 28*(1), 19-32. doi:10.1080/08856257.2012.742748

Bajaj, D., & Bhatia, S. (2019). Psychosocial Functioning in Children with Dyslexia: Perspectives from Parents, Counsellors and Teachers. *Disability, CBR and Inclusive Development*. doi:10.5463/DCID.v3014.847

Bishop, D. V., & Snowling, M. J. (2004). Developmental dyslexia and specific language impairment: Same or differnt? *Psychological Bulletin, 130*(6), 858-886. doi:10.1037/0033-2909.130.6.855

Bonifacci, P., Montuschi, M., Lami, L., & Snowling, M. J. (2014). Parents of children with dyslexia: Cognitive, emotional and behavioural profile. *Dyslexia, 20*(2), 175-190. doi:10.1002/dys.1469

Boyes, M. E., Leitao, S., Claessen, M., Badcock, N., & Nayton, M. (2006). Why are reading difficulities associated with mental health problems? . *Dyslexia* , 263-266. doi:10.1002/dys.1531

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*. doi:10.1191/1478088706qp063oa

Carawan, L. W., Nalavery, B. A., & Jenkins, B. (2015). Emotional experience with dyslexia and self-esteem: the protective role of perceived family support in late adulthood. *Aging and Mental Health*. doi:10.1080/1360783.2015.1008984

Collier, M., Keefe, E. B., & Hirrel, L. A. (2015). *Listening to parents' narratives: The value of authentic experiences with children with disabilities and their families*. Retrieved from www.schoolcommunitynetwork,org/SCJ.aspx.

Dahle, A. E., & Knivsberg, A. (2014). Internalizing, externalizing and attention problems in dyslexia . *Scandanavian Journal of Disability Research*, 179-193. doi:10.1080/15017419.2013.781953

Damen, H., Veerman, J. W., de Meyer, R. E., & Scholte, R. H. (2016). *Parental empowermnet: Constuct validity and reliability of a Dutch Empowerment Questionnaire (EMPO).* Retrieved from http://link.springer.com/article/10.1007/s10826-016-0568-5.

Delany, K. (2017). The Experience of Parenting a Child With Dyslexia: An Australian perspective. *Journal of Student Engagement: Education Matters, 7*(1), 97-123.

Earey, A. (2013). Parental experiences of support for pupils with dyslexia. *British Journal of Learning Support , 28*(1).

Eissa, M. (2010). *Behavioural and emotional problems associated with dyslexia*. Retrieved from http://www.currentpsychiatry.com.

Elliott, J. G., & Grigorenko, E. L. (2014). *Dyslexia: Developing the debae* . New York: Cambridge University Press .

Etikam, I., Sulaiman, A. M., & Alkassin, R. S. (2016). Comparison of Convenience Sampling and Purposive. *American Journal of Theoretical and Applied Statistics, 5*(1), 1-4.

Ewing, D. (2021). Retrieved from www.dyslexia.ie

Fernández-Alcántara, M., Correa-Delgado, C., Muñoz, A., Salvatierra, M. T., Fuentes-Hélices, T., & Laynez-Rubio, C. (2017). Parenting a Child with a Learning Disability: A Qualitative Approach. *International Journal of Disability, Development and Education, 64*(5), 526-543. doi:10.1080/1034912X.2017.1296938

Findler, L., Jacoby, A. K., & Gabis, L. (2016). Subjective happiness among mothers of children with disabilities: The role of stress, attachment, guilt and social support. *Reserach in Developmental Disabilities* , 44-54. doi:10.106/j.ridd.2016.03.006

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*(1), 59-82.

Gurney, P. W. (1986). Self-esteem in the Classroom. *Social Psychology International*, 199-209. doi:10.1177/0143034386074003

Haft, S. L., Myers, C. A., & Hoeft, F. (2016). Socio-emotional and cognitive resilience in children with reading disabilities. *Current Opinion in Behavioural Sciences*, 133-141. doi:10.1016/j.cobeha.2016.06.005

Harkin, E., Doyle, A., & & McGuckin, C. (2015). Screening and assessment of specific learning difficulities . *Journal of Psychologists and Counsellors in Schools*, 13-23. doi:10.1017/jgc,2014.15

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*(6), 405-418. doi:10.1080/10901020590955770

Ho, A. (2004). To be labelled, or not to be labelled: That is the question. *British Journal of Learning Disabilities , 32*(2), 86-92. doi:10.1111/j.14683156.2004.00284.x

http://www.dyslexia.ie. (n.d.).

Ingesson, G. S. (2007). Growing up with dyslexia: Interviews with teenagers. *School Psychology International*, 574-591. doi:10.1177/0143034307085659

Jones, R. S., & Heskin, K. J. (2010). Self-concept and learning disability: an experimental analysis. *Instights on Learning Disabilites, 7*(1), 49-55.

Karande, S., & Kuril, S. (2011). Impact of parenting practices on parent-child relationships in children with specific learning disabilty. *Journal of Postgraduate Medicine, 57*(1), 20-30.

Karande, S., Kumbhare, N., Kulkarni, M., & Shah, N. (2009). Anxiety levels in mothers of children with specific learning disabilty. *Journal of Postgraduate Medicine*, 165-170. doi:10.4103/0022-3859.57388

Krauss, M. W., Wells, N., Gulley, S., & Anderson, B. (2001). Navigating systems of care: Results from a national survey of families of children with special health care needs. *Children servies: Social Policy, Research, and Practice*, 165-187. doi:10.1207/S15326918CS0404_02

Leitao, S., Dzidic, P., Claessen, M., Gordon, J., Howard, K., Nayton, M., & Boyes, M. E. (2017). Exploring the impact of living with dyslexia: The perspectives of children and their parents. *International Journal of Speech-Language Pathology*, 1-13. doi:10.1080/17549507.2017.1309068

Leve, L. D., Hyoun, K. K., & Pears, K. C. (2005). Childhood Temperament and Family Environment as Predictors of Internalizing and Externalizing Trajectories From Ages 5 to 17. *Journal of Abnornal Pyschology*, 505-520.

Marshall, M. N. (1996). Sampling for qualitative research. *Family Practise, 13*(1), 522-526.

Nalavany, B. A., Carawan, L. W., & Brown, L. J. (2011). Considering the role of traditional and specialist schools: do school experiences impact the emotional well-being and self-esteem of adults with dyslexia? *British Journal of Special Education*. doi:10.1111/j.1467-8578.2011.00523.x

Nalavany, B. A., Carawan, L. W., & Rennick, R. A. (2011). Considering the role of traditional and specialist schools: Do school experiences impact the emotional well-being and self-esteem. *British Journal of Special Education*, 191-198. doi:10.1111/j.1467-8578.2011.00523.x

Nelson, S. K., Kushlev, K., & Lyubomirsky, S. (2014). The pains and pleasures of parenting: When, why, and how is parenthood associated with more or less well-being? *Psychogical Bulletin, 140*(3), 846-495. doi:10.1037/a0035444

Noon, E. J. (2018). Interpretive Phenomenological Analysis: An Appropriate Methodology. *Journal of Perspectives in applied academic practices, 6*(1), 75-83.

Norwich, B., Griffiths, C., & Burden, B. (2005). Dyslexia-friendly schools and parent partnership: Inclusion and home-school relationships. *European Journal of Special Needs Education* , 147-165. doi:10.1080/08865625-500055628

Poon-McBrayer, K. F., & McBrayer, P. A. (2014). Plotting Confucian and disability rights paradigm on the advocacy-activism continuum: Experiences of Chinese parents of children with dyslexia in Hong Kong. *Cambridge Journal of Education, 44*(1), 93-111.

Resch, J. A., Benz, M. R., & Elliott, T. R. (2012). Evaluating a dynamic process model of wellbeing for parents of childen with disabilities: A multi-method analysis. *Rehabiliation Psychology*. doi:10.1037/a0027155

Riddick, B. (2000). An examination of the relationship between labelling and stigmatisation with special reference to dyslexia. *Disability & Society, 5*(4), 653-667.

Riddick, B. (2006). Dysleixa friendly schools in the UK. *Topics in Language Disorders , 26*(2), 144-156.

Rimkute, L., Torppa, M., Eklund, K., Nurmi, J. E., & Lyytinen, H. (2014). The impact of adolescents' dyslexia on parents and their own educational expectations. *Reading and Writing: An Interdisciplinary Journal, 27*(7), 1231-1252. doi:10.1007/s11145-013-9484-x

Rose, J. (2009). *Identifying and Teaching Children and Young People with Dyslexia and Literacy Difficulities.* Nottingham: DCSF.

Scorgie, K., Wilgosh, L., & Sobsey, D. (2004). The experience of transformation in parents of children with disabilities: Theoretical considerations. *Developmental Disabilities Bulletins, 32*(1), 84-110.

Shaywitz, S. E., Shaywitz, B. A., Fletcher, J. M., & Escobar, M. D. (1990). Prevalence of reading disability in boys and girls. Results of Connecticut Longitudinal Study. *Journal of the American Medical Association, 264*(8), 998-1002.

Snowling, M. J., & Melby-Lervag, M. (2016). Oral language deficits in familial dyslexia: A meta-analysis and review. *Psychological Bulletin, 142*(5), 498-545.

Snowling, M. J., Muter, V., & Carroll, J. M. (2007). Children at family risk of dyslexia: A follow-up in early adolescence. *Journal of Child Psychology and Psychiatry*, 609-618. doi:10.1111/j.1469-7610.2006.01725.x

Sund, A. M., & Undheim, A. M. (2008). Psychosocial factors and reading difficulties: Students with reading difficulties drawn from a representative population sample. *Scandinavian Journal of Psychology , 49*(4), 377-384. doi:10.1111/j.1467-9450.2008.0061.x

Sutherland, K. S., & Oswald, D. P. (2005). The Relationship Between Teacher and Student . *Journal of Child and Family Studies, 14*(1), 1-14. doi:10.1007/s10826-005-1106-z

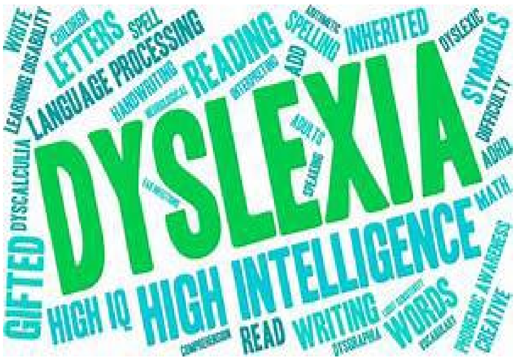
Terras, M. M., Thompson, L. C., & Minnis, H. (2009). Dysleixa and psycho-social functioning: An exploratory study of the role of self-esteem and understanding. *Dyslexia*, 304-327. doi:10.1002/dys.386

Thompson, C., Bacon, A. M., & Auburn, T. (2015). Disabled or differently-enabled? Dyslexic identiies in online forum postings. *Disability and Society*, 1328-1344. doi:10.1111/j.1469-7610.2006.01725,x

Thomson, J. M., Leong, V., & Goswami, U. (2012). Auditory processing interventions and developmental dyslexia: A comparison of phonemic and rhythmic approaches. *Reading and Wtiring: An Interdisciplinary Journal*, 139-161. doi:10.1007/s11145-012-9359-6

Zimmerman, M. A. (1995). Psychological empowerment: Issues and illustrations. *American Journal of Community Psychology, 23*(5), 581-599.

Appendix A



My Child and Dyslexia: Call for Research Participants

If you are a parent of a child or young person who is presently attending school in Ireland, you may wish to participate in a research project with the aim of better understanding parents' experiences relating to coping strategies, supports and the emotional impact of dyslexia.
If you are interested in taking part in this study and would like to share your experiences, please email Simone at dyslexia.research.ireland@gmail.com.

(You are under no obligation to reply to this post, participation in this research is voluntary.

Appendix B

Participant Information Sheet

Study Title: My Child and Dyslexia: A parents' perspective

You are being invited to take part in this study. Before deciding whether to take part, please take the time to read this document, which explains why the research is being undertaken and what it would involve for you. If you have any questions, please do not hesitate to contact me using the details at the end of this sheet.

What is this study about? I am a final year student in the BA Psychology programme at National College of Ireland. As part of our degree, we must carry out an independent research project.

The aim of the study is to explore parents' perspective of having a child with dyslexia and to identify possible emotional and academic challenges they face from diagnosis and during their school years. This includes questions about academic challenges, emotional experiences such as self-esteem and possible stress factors on parents/caregivers.

There is a lack of research in this area on the everyday experience of parents with dyslexic children. More research will lead to a greater understanding so that future interventions and policy changes may be implemented which could potentially improve the overall dyslexic experience.

Who can take part in the study? Participants who have a child with a diagnosis of dyslexia and for that child to still be attending either primary or secondary school. Behavioural diagnoses such as ADHD are excluded.

What will taking part involve? If you decide to take part in this study, we will arrange an interview 1:1 at a time of your convenience. Interviews will be held **online** and I will send you a meeting request via our college Teams app. You will be asked questions about your experiences of having a child with dyslexia and how it has affected you and your child academically, emotionally and any other issues and challenges you would like to discuss.

If you do not wish to answer various questions or you'd like a break during the interview, please let me know. Finally, you can withdraw at any time without any reason and there will be no consequences. Interviews will be conducted using Microsoft Teams and only using audio which will be destroyed after data has been transcribed.

Do you have to take part? Participation in this research is entirely voluntary. You do not have to take part. If you do decide to take part, you can change your mind and withdraw at any point in the interview. Even after the interview you can withdraw your data from the study up to 1st February 2022 by emailing me or my supervisor directly. There will be no penalty for withdrawing and data will be destroyed immediately.

What are the possible risks and benefits to taking part?

Benefits: There are no direct benefits. However, the information gathered may provide some insights into possible future interventions and policy changes that could benefit those with dyslexia. You may gain more insight into your own thoughts and feelings about dyslexia by discussing your experiences which may help you reflect on future aspirations for your child.

Risks: There is a possibility that some participants may experience minor distress as they discuss possible difficult experiences they may have had or going through. If you feel distressed at any time, you are free to take a break or stop the interview completely.

Will your taking part in this project be kept confidential? Only the researcher and academic supervisor will have access to the data. As this is a qualitative study, direct quotes from interviews may be included in the presentation of the results, but these quotes will be anonymised and will not contain any information that could identify the participant or any other individual. All data collected will be treated in the strictest confidence. Due to the nature of the research, the interviews with be audio-recorded but immediately after the data has been transcribed the recordings will be destroyed. The transcripts will be stored securely for five years as per the National College of Ireland's retention policy. Under the freedom of the information legislation, you will be able to access your data for those five years.

What will happen to the results and information of the study? The results will be written up and presented in my final year project of my psychology degree. The results may be presented at conferences and/or submitted to an academic journal for publication.

Who is organising the research? The research is organised by Simone Cosgrave, who is a final year undergraduate psychology student at National College of Ireland. The academic supervisor for this research is Dr Conor Nolan, Lecturer in Psychology at the National College of Ireland.

Contact for further information:
Researcher: Simone Cosgrave/ x18101666@student.ncirl.ie
Academic Supervisor: conor.nolan@ncirl.ie

Appendix C

Consent Form

My Child and Dyslexia: A parents' perspective

Participant Reference Code________________________

- I have read and understand the attached information sheet and by ticking box below, I agree to participate in this study on a voluntary basis.
- I understand I can withdraw at any stage during the interview without any consequences.
- The study has been clearly outlined with benefits and risks highlighted accordingly.
- I understand I will be audio recorded during the interview
- I understand all information will be treated with the strictest confidence and my identity will remain anonymous
- I understand that I can seek further information from the researcher and academic supervisor on the information sheet
- I understand that under freedom of information legislation, I am entitled to access my information any time until its destruction after five years

Participant ___________________

Researcher___________________

Appendix D

Debriefing Sheet

Dear Participant,

Thank you for taking part in this study and taking the time to enable me to complete this project. Your interview was to explore your experience as a parent of a child with dyslexia and to understand the issues and challenges you've encountered from diagnosis through their school years.

Data will be analysed with research from other parents of dyslexic children to establish common themes. The aim is to understand possible future interventions or efforts that can be implemented to improve the dyslexic experience for children and their families.

The results will be presented in my final year project as part of my final degree. Under Freedom of Information legislation, you may view your data up to five years after your interview has taken place. You also have the right to withdraw the data derived from your interview before 1st February 2022 with no consequences.

If you have any questions about this study, please contact me or my supervisor. Contact details are in the information sheet.

Thank you for your time which is really appreciated.

The following are sources of information/support you may find helpful.

www.dyslexiaireland.ie

(Telephone 01 8776001 Email: info@dyslexia.ie)

Appendix E

Research Aim

The aim of this study is to explore the subjective experience of having a child with dyslexia to understand the stressors, challenges, coping strategies and psychological impact involved.

RQ1: What is the overall subjective experience of a parent of a child with dyslexia?
RQ2: Do parents of children with dyslexia experience specific stressors?
RQ3: Do parents think their child's self-esteem is affected?
RQ4: How do parents cope with various challenges encountered?

Interview questions/guide:

1. **Diagnosis** – What were your initial feelings when your child was diagnosed with dyslexia?
2. **Knowledge** of Dyslexia – Did you understand what dyslexia meant? Is there a family history of dyslexia?
3. **Acknowledgement** – Did you explain the diagnosis to your child?
4. **Challenges** – How do you think your child feels about school? Do you think your child is able for homework? Negative/positives – frustration, anxious, able to cope
5. **Support** - How do you feel your child is being supported by their Teacher / SEN teacher?
6. **Parental stress** – Do you feel dyslexia has impacted your own wellbeing? Do you think it has affected other siblings? How have you found advocating for educational support stressful?
7. **Socio-emotional behaviours** – Do you think dyslexia has affected your child's self-esteem and/or behaviour?

Probes
Could you elaborate more on that?
Tell me more about a time…

Appendix F

Thematic Map