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"I Have Fought This System from the Moment He Stepped Into School": Exploring Sources of Uncertainty for Mothers of Children With Dyslexia

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ABSTRACT

This study adopts the lens of uncertainty management theory to understand how mothers of children with dyslexia construct and negotiate the uncertainty they face. Dyslexia is academically, mentally, financially, and emotionally challenging for families, but the voices of parents are often missing from the conversation. Interpretive thematic analysis of a large online support group for parents illustrated four major sources of uncertainty: the future, advocacy, communicating about the diagnosis, and the financial cost. Exploring the uncertainty of mothers themselves offers a more textured understanding of the meaning and sense-making processes of families as they navigate a common yet widely misunderstood learning disability.

KEYWORDS: Dyslexia, uncertainty, families, parenting, online social support.

While researchers suggest that "raising and educating a child with dyslexia is a challenging task for parents" (Multhauf et al. 2016, p. 1204), little scholarship qualitatively investigates the lived experiences of parents of children with dyslexia. Dyslexia is academically, mentally, financially, and emotionally challenging for families but the voices of parents of children with dyslexia are often missing from the conversation, despite a critical need in the United States. In the last seven years, more than two-thirds of all U.S. states have debated or passed dyslexia-specific legislation, positioning schools to figure out how to support an invisible and widely misunderstood learning disability with lack of training (Peltier et al., 2022).

Van Bergen et al. (2011) points out that "dyslexia is commonly seen as a complex, multifaceted disorder with numerous genes involved that interact with one another and the environment" (p. 4). In other words, dyslexia exists on a continuum and presents differently for different individuals (Elliot, 2020). Approximately 80% of people with learning disabilities have dyslexia, making it the most common learning disability (Elliot, 2020). The International Dyslexia Association (2022) defined it as follows:

> *Dyslexia is a specific learning disability that is neurobiological in origin. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. These difficulties typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the*

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> *provision of effective classroom instruction. Secondary consequences may include problems in reading comprehension and reduced reading experience that can impede growth of vocabulary and background knowledge.* (para. 1)

Children with dyslexia are often in education settings where they are expected to succeed without the appropriate support or intervention they need (Gibson & Kendall, 2010). Progress can be slow and frustrating, as students and their families encounter an educational path lined with obstacles along the way (Camilleri et al., 2019). Because children with dyslexia exhibit average or above-average intelligence but continue to struggle with literacy skills (Rahul & Ponniah, 2021), they are frequently misunderstood, and even thought of as unintelligent, unmotivated, or lazy (Thompson et al., 2015). Traditionally, dyslexia has been defined as a discrepancy between reading achievement and intellectual potential as measured by standardized intelligence tests (Tunmer, & Greaney, 2010). Importantly, this discrepancy-based approach means that children are not often identified until they have been presented with reading instruction for two to three years or longer. While early intervention is the best step to helping dyslexic children, these children are commonly positioned as late bloomers, rather than possessing skill deficits (Earey, 2013). Without early intervention, the gap between struggling readers and their peers continues to widen over time. Indeed, throughout elementary and secondary school, the gap between struggling readers and their peers remains consistent, with longitudinal studies indicating a 90% chance that poor readers in first grade will remain poor readers (McNamera et al., 2011).

With decades long myths persisting among educators and policy makers, along with a lack of training and resources in schools (Peltier et al., 2022), the children and families affected by dyslexia are often left feeling “lost, disempowered, and caught in an in-between space” (Woodcock, 2020, p. 1639). While the correlation between self-esteem and dyslexia is multi-faceted (Gibson & Kendall, 2010), students with dyslexia often have to spend more time and effort on their work than their neurotypical peers, potentially leading to feelings of incompetence as they perceive themselves as less intelligent or capable than their classmates (Kannangara, 2015). Children with poor reading abilities are also more likely to have depression and anxiety (Arnold et al., 2005). Further, as reading is not just a key aspect of education, but a marker of successful adulthood, parents of students with dyslexia show higher levels of anxiety than parents of neurotypical students, particularly when attempting to advocate for their child (Earey, 2013).

As parents themselves are grappling with the best ways to support their child, they must become de-facto advocates as they face educators who are misinformed and lack training, administrative processes that are drawn-out and muddled, and school districts that push back on using their limited resources for special education (Connor & Cavendish, 2018). This is often well illustrated within the process of seeking an IEP (Individualized Education Plan) for one’s child. The IEP is a legal document under United States law that is developed for each public school child in the U.S. who needs special education. Parents are an important part of helping their children secure an IEP, which is intended to be created in an equitable environment for partnership between parents and administrators (Connor & Cavendish, 2018). However, there is often a power imbalance between parents and administrators in the IEP process. Because it is often up to parents to approach the school and advocate for their child, there is added mental and emotional cost, especially for parents faced with barriers such as job and family demands, limited English-speaking skills, or other socio-economic roadblocks to taking a more active role in their child's education (Singh & Keese, 2020).

The process of having a child evaluated for learning difficulties, meeting with educators and administrators, interpreting test results, and advocating for an intervention plan is daunting. Navigating legal regulations, school systems, and interactions with professionals is often an uncertain and challenging time for parents. Thus, this study relies on the posts of parents in a large online support group for dyslexia and the lens of uncertainty management theory (UMT; Brashers, 2001) to understand how parents construct and negotiate the uncertainty they face parenting a child with dyslexia. Exploring how this uncertainty is talked about by parents themselves offers a theoretically and practically important perspective into the meaning and sense-making processes of parents navigating a common yet widely misunderstood learning disability. The way parents describe the experiences of having a child with dyslexia gives critical insight into how families talk about and navigate dyslexia within and outside of the family.

Theoretical Perspective

This study adopted the theoretical perspective of Uncertainty Management Theory (UMT) (Brashers, 2001) which suggests uncertainty is ubiquitous in daily life. According to Brashers (2001), “Uncertainty exists when details of situations are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge or the state of knowledge in general” (p. 478). UMT is used largely within the discipline of communication studies, but because uncertainty is a universal human experience, the theory is inherently interdisciplinary.

While uncertainty is not inherently negative, it can be an anxiety-provoking state that we manage through information-seeking behaviors (Brashers, 2001). Acquiring the appropriate information to make informed decisions helps us choose the path forward as we navigate difficult life events. People may want to reduce the uncertainty they experience about many things: chronic and acute illnesses (Babrow et al., 1998); unclear disease screening results (Sah et al., 2013); or interpersonal contexts, such as divorce (Abetz & Wang, 2017) or motherhood (Abetz, 2019). The meaning and experience of uncertainty varies across contexts, but it is complex and often multilayered as it can be about the self (e.g., one’s own capabilities, behavior, beliefs), others, relationships, and others cultural aspects such as social norms and procedures. In the context of dyslexia, parents are navigating many questions after their child’s diagnosis, such as their own abilities to advocate for appropriate intervention, how supportive their child’s school will be, how the IEP process works, and what resources are available.

Understanding various types of uncertainty increases our ability to articulate and understand its influences on behavior and develop strategies for bettering our lives across interpersonal, organizational, and health contexts (Brashers et al., 2006). In the context of dyslexia, researchers’ understanding of the impact of this learning disability on children and their parents is challenged by a lack of consistent understanding of dyslexia from the outset (Elliot, 2020). As dyslexia is largely misunderstood, exploring the uncertainty of parents themselves can enable a more textured understanding of how families navigate dyslexia as well as how their experiences are enabled and constrained by their school-based interactions. Using UMT as a theoretical lens, this investigation aimed to explore experiences of dyslexia through the following research question: What are the sources of uncertainty for parents of children with dyslexia?

Methodology

I centered this study on the interpretive paradigm to understand “the perspectives and language choices of the individuals being studied from the ‘native’s point of view’” (Baxter & Braithwaite, 2010, p. 8). I adopted a thematic approach to analyze naturalistic accounts of parenting a child with dyslexia. The research question was addressed through a detailed exploration of one large online parent support group for dyslexia. Where interviews and focus groups allow researchers to structure questions and probe for more depth, I desired a more organic context to analyze the questions generated by parents themselves. While online support communities in the form of listservs, forums, and email threads have existed for many years, only more recently have online support communities emerged on social networking sites. These sites allow individuals to access and connect to a virtual social network of individuals in similar circumstances where they can share information, personal experiences, and resources (Pi et al., 2013).

Data Sampling

To address the research question, an online support group for parents of dyslexic children was chosen for analysis. This group is one of the largest (nearly 70,000 members) and longest-running groups focused on dyslexia (since January 2012), providing a rich context to analyze. To gather data, the author analyzed the posts of the group over a time period of six months, from November 1, 2021 to May 1, 2022. The group is a place for parents to share information, encouragement, and personal stories, as well as vent and ask questions, resulting in thousands of posts. To pare down the sheer volume of posts, the author used the search function for uncertainty markers such as “unsure,” “I don’t know,” “questioning,” “worried,” “unconfident,” and “unclear” (Babrow & Kline, 2000, p. 1813) as well as all posts using question mark punctuation. This sampling technique resulted in 658 posts for analysis. Notably, while this support group is for parents, the overwhelming majority of posts were made by mothers. A few group members posted anonymously and others used combined names (e.g., MarkandJesssica Smith). However, 640 of the 658 posts were made by mothers specifically. In the following analysis, I focused on the 640 posts made by mothers.

Data Analysis

Using UMT as a sensitizing framework, I conducted a thematic analysis (Braun & Clarke, 2006). Thematic analysis (TA) is often conceptualized as an expansive term for multiple approaches that share some common traits but differ in critical ways with regard to paradigmatic and epistemological underpinnings, as well as in analysis procedures (Braun & Clarke, 2021). My approach aligns with TA as originally articulated by Braun and Clarke (2006) and reconceptualized and deepened in more recent years as reflexive TA (Braun & Clarke, 2019, 2021). I followed a six-stage approach (Braun & Clarke, 2006), which included immersing myself in the data, generating categories after a systematic and careful reading of the posts, and forming broader “chunks” of meaning (e.g., advocacy, IEPs, encouragement), confirming that identified themes captured the essence of posts, finalizing themes for clarity (e.g., seeking to clarify what to ask for in an IEP to ensure they advocated successfully) and completing a final write-up. Although I approached the data analysis with UMT as a sensitizing concept to guide data analysis, I also remained open to other possible important findings that emerged in these data.

The identification of uncertainty was an interactive and inductive process where my goal was to provide a “concise, coherent, logical, non-repetitive, and interesting” analysis of the data (Braun & Clarke, 2006, p. 23). To do so, I interspersed exemplars from mothers’ posts with the goal of telling the story of the data and making arguments that tied the exemplar to the research question in meaningful ways (Braun & Clarke, 2006). I also conducted in-vivo coding, in which I extracted examples of language used in the posts to illustrate the themes (Charmaz, 2006). Because some individuals are potentially identifiable because of the details they share, all exemplar quotes are pseudonyms and I did not collect any identifying information. For any member who did not post anonymously, I altered the quotes slightly so that entering the text of the quote into Google’s search engine did not lead to the original thread (Moreno et al., 2013).

I kept original punctuation, capitalization used for emphasis, and use of emojis. Because my approach was interpretive, I focused on meaning-making about dyslexia from individuals’ points of view rather than quantifying the frequency of each type of uncertainty (Lareau, 2012).

Trustworthiness and Reflexivity

I attempted to increase credibility through a rigorous data collection and analysis process, transparency about the methods and challenges, and “showing rather than telling” (Tracy, 2010, p. 10). I aimed to provide thick, rich descriptions that captured mothers’ realities. As an interpretive researcher, I believe in the importance of self-reflexivity and researchers “asking whether they are well-suited to examine their chosen sites or topics at this time” (Tracy, 2010, p. 10). In exploring this topic, I sought to “work the hyphen” (Fine, 1994) between self and other. That is, I consciously reflected on my own position and my desire not to speak for “others” or hide my own investment in this topic. As the mother of two children with dyslexia, I have personally experienced the challenges of understanding and navigating school systems. However, my analytic method (Braun & Clarke 2019, 2021) views subjectivity as a resource and emphasizes its importance in intentional interaction with theory, data, and interpretation.

Findings

Throughout this inductive analysis, I identified four major sources of uncertainty mothers faced as they talked about the experience of parenting a child with dyslexia: the future, advocacy, communicating about the diagnosis, and the financial cost. In what follows, I present and discuss each source.

“Sometimes When I Think Too Far Ahead It Can Feel Quite Scary”: Uncertainty Surrounding the Future

The diagnosis of dyslexia was met with a mix of emotions: overwhelm, confusion, helplessness, and validation to have an answer after years of educational struggles and “wait and see” messages from schools. Mothers’ uncertainty hinged on what dyslexia meant for their child’s academic, emotional, and professional futures, and how they could ease the challenges. They carried the weight of feeling that their child’s future success fell heavily on individual choices they made in the present. Carrie admitted that the most difficult part of dyslexia is “wondering if the choices I have made were the best for my child and the fear for what his future will hold.” Indeed, many mothers wrote with uncertainty about college. Aimee wrote:

> *I need advice from parents with children who went to or who are in college. Where did they go? What field? What accommodations did the college give? What preparations did you do starting junior year in high school? I started doing research and honestly, fear filled me so fast. 34% of dyslexics go to college. I need some encouragement. The expectance tests (SATs, entrance exams) really have me scared.*

While Aimee wrote about college, some mothers were at a crossroads in making decisions about better school environments for their children and needed to weigh academic and social concerns. Jessica described how her 9-year-old daughter may have the opportunity to attend a highly regarded elementary school geared toward dyslexic learners. However, this potential shift brought uncertainty as she considered her daughter's happiness at her current school:

> *The thing is, she is very happy at her current school. She loves her friends and her teacher and enjoys learning. When I brought up potentially changing schools, she broke down in tears, telling me she loves her school. It breaks my heart to move her from a school where she is happy and engaged (but not thriving) but I am concerned she will continue to fall further behind her peers. I am leaning heavily toward moving her to the dyslexia school but I'm feeling so guilty. I just need a crystal ball to see into the future to know I'm making the right decision* 😩

While mothers worked to meet the needs of their children in the present, they grappled with what challenges they would encounter in the future. As Sarah wrote, "my 9-year-old still struggles to spell his first name. Sometimes when I think too far into the future it can feel quite scary. What kind of life will he have? Who would hire him?" Across the posts, mothers' willingness to do anything and everything in their power to foster a positive future for their children was palpable. Many times, this willingness meant they wrote asking for guidance about changing their professional paths, quitting their own careers to homeschool their children, or going back to school for specialized training or certifications. Abby asked:

> *I'm desperate to help my child and others too if possible. Should I go back to school and get my masters in literacy? I just wish I could make life easier for my daughter…. and if this helps then I'm in. I already have two master's degrees so hopefully I'd be accepted to start right away. Thoughts?? I'm just so lost and feel I haven't done enough.*

Some mothers acknowledged that their child's severely dyslexic profiles may limit options for their future and wanted advice on how to develop and foster their future independence. As Gabby explained:

> *I'm looking for advice on how to help my son develop long-term life and career skills. He is about to finish 4th grade. Testing puts his IQ at normal but in the bottom 1% "severely dyslexic". After lots of money and 3+ years of IEP and OG tutoring, he is at a first-grade reading level. I will keep working with him on reading but am accepting and heartbroken that he*

> *will probably never catch up. How can I best support a very limited reader so he can eventually function in society independently?*

Many mothers posted with urgency and looking for hope after discouraging interactions with school administrators. Often they expressed overwhelm and desperation at the lack of options and were unsure where to turn. Elizabeth wrote:

> *I am feeling very worried and desperate, and there is no light at the end of the tunnel. I am afraid that it is too late for us, despite all the efforts and all the fight. I feel like a failed my son. My son, age 11. There are NO educators trained to deal with dyslexia in our district. No teacher or specialist is trained to deal with dyslexic kids in the entire area here!!!! There are no private schools accepting special needs of any kinds here. There is no cooperation or any program with the big university we have here. He has IEP, but the instruction in reading at the public school is not suitable for him, He is really struggling, and is several years behind in reading and writing. I am really desperate. I have been totally alarmed and in a state of panic, not knowing how to help him. Not sure where to turn, and it all seems overwhelming.*

As a whole, mothers sought support, guidance, and hope regarding what the future could look like for their children. They focused heavily on what they, as individuals, could do in the present to foster an easier and more accessible future for their children.

"I Voiced My Concerns and Was Dismissed Over and Over, What Do I Do?": Uncertainty Surrounding Advocacy

From learning the terminology to pushing back against unsupportive school environments, to understanding the IEP process, uncertainty surrounding how to be the best voice for their children's learning dominated mothers' posts. They faced resistance at every step, in many cases describing how they had to be the one to approach the school and demand their child be tested. Heidi wrote, "the school WILL NOT acknowledge dyslexia UNTIL you've gone about it in such a way they can't deny it." Indeed, many posts focused on getting school leadership to even acknowledge the existence of dyslexia. Hannah questioned:

> *Why are people telling me that dyslexia is not real? I see my child struggling every day. We recently had a meeting with the school team to set up an IEP. I asked what were the steps to getting her tested for dyslexia. The psych informed me that basically he didn't believe in dyslexia. So how can I get her the help that she needs if the team that is supposed to help her refuses to believe that the condition she possibly has even exists?*

Mothers also pointed out that a school acknowledging a learning disability was not enough to guarantee an IEP. Indeed, the burden of proving that dyslexia impacted their child's learning enough to warrant school-based intervention fell on parents. Alexis captured this commonly voiced struggle. She explained:

> *My sons IEP meeting is today and I'm trying to be prepared. We received the results last night and in it they say that he doesn't need an IEP because he isn't "bad enough". We had him privately diagnosed with dyslexia and dysgraphia back in November and he started private OG tutoring in January. He has jumped 6 reading levels since starting the tutoring so we know it's working. He literally couldn't read at all before we started tutoring. Anyway, what should we do? How should we be prepared?*

One of the most common sources of uncertainty mothers faced surrounded what exactly to ask for on the IEP. Mothers who were in the beginning the advocacy process wrote asking for how to be a strong advocate while seeking and what specific intervention and accommodations to seek. Nicole voiced:

> *I'm in NY, my son is 9 years old. I have an upcoming IEP meeting and I just need guidance on what should I ask for. Are there any specific classroom classes or help I should ask for him? I am lost, he is really behind in reading and writing. I have attached a draft of what he currently receives.*

Mothers also commonly turned to one another with questions about how to decipher the wording of the IEP. Molly asked, "is there a convenient resource that will provide that information in plain English rather than all jargon and legalese?" Tara asked "forgive me, but can someone help me with all of the common acronyms used? We're new to all of this." Kate summed up many mothers' feelings when she described the emotions of trying to navigate new terminology:

> *Fighting for your child is overwhelming when you're trying to master the wording used. I'm not good with my words and don't understand all the acronyms they use. I want to make sure I communicate clearly and leave understanding everything. Know my rights. I've done research on dyslexia and it's so overwhelming.*

Understanding the terminology and arming themselves with as much knowledge as possible was especially essential as mothers faced attitudes that their child was simply not trying hard enough. After an IEP is in place, mothers often posted with uncertainty about how to monitor their child's progress, update goals, or ensure that the programs used were carried out with fidelity. Riley asked: "I am curious if you ask for your child's progress monitoring objective data how often do you ask for it? And if there is no reply how long do you wait before you send another email?" Mothers continually voiced the exhaustion of "fighting the system" at every step in the process and many asked for advice on how to cope with the anger associated with advocacy. As Kate described:

> *We're about a month into this, and I am already struggling with anger at how all of the systems work. Having to fight for the basics, being gaslighted over everything (being told you're overreacting, denying that they said things...), and knowing that a lot of parents don't have the same knowledge, time, or resources to advocate for their child this way- it's maddening. So, how do you all fight the fight without living in a perpetual state of anger and frustration? I need to find a way to switch it off and take a breather from "Mama Bear" mode. Ideas?? I'm tired of angry crying.*

While witnessing their child's struggles, adjusting to the diagnosis, and working to understand their child's needs was daunting, mothers overwhelmingly illustrated that the difficulties were severely and unnecessarily exacerbated by the resistance within school systems.

"How Do You Explain It?": Uncertainty Surrounding How to Discuss Dyslexia

Because supporting and advocating for their child was paramount for mothers, part of their worry was how to approach discussions of dyslexia with intentional and mindful care. This uncertainty manifested in questions about how to talk about dyslexia with their child and other family members. Many asked for guidance on how to present dyslexia, with some questioning whether or not to use the word dyslexia with their child. Michelle asked:

> *I was initially hesitant to tell her because I don't want her to feel different. However, I think it's important for her to know so she can advocate for herself and explain to others why she might be different from her peers. What I'm looking for is any advice on how to tell her in a way that empowers her and doesn't make her feel ashamed or increase her anxiety?*

Some mothers struggled with presenting dyslexia as a disability, arguing that framing it as a disability exists only because educational systems privilege one type of learning over another. They emphasized how dyslexia is always positioned as a deficit. Cara questioned:

> *Is dyslexia a disability or just a difference? If the written language is a construct that humans developed to communicate through written means, but doesn't resonate with 20% of the population, is that 20% suffering from a disability? Because I think that population (the 20%) has strengths to offer that the 80% doesn't have. Are we really approaching intervention adequately by assuming that it's a deficit?*

Woven through mothers' posts is how supporting dyslexic children is not simply about the right academic interventions but also understanding and empathizing with how emotionally difficult it can be for children to feel isolated in the classroom or notice differences from peers. Some mothers questioned if therapy might be a place for children to feel supported to talk about these challenges:

> *Has anyone sought counseling/therapy for their dyslexic child to help them cope with the difficulty that is dyslexia, the challenge that it presents scholastically and emotionally, the sadness and frustration that comes with struggling? If so did you feel as though it helped at all? We are 18 months into our journey. Diagnosed in 1st grade, attending 3rd now. We've had good teachers and bad. He is very hard on himself. I work very hard to boost confidence and self-esteem, withhold his grades from him, control the message, etc. We celebrate all victories and let him be as much of a kid as possible. This is a question of coping with the emotional side of the struggle and if anyone has done therapy to help with the emotional aspect and how that worked.*

In some cases, mothers questioned how to interact with extended family members surrounding dyslexia. Sarah explained, “No one in our family is dyslexic, so this is challenging enough.” Julia asked for any short resources she could provide to others:

> *Out of your arsenal of dyslexia memes, short stories, quotes— really anything that is a short read—What do give to family members and friends, who just can’t see that your dyslexic student, is putting in the effort, and maybe is just beaten down by a school system and friends network that just doesn’t “get him?” Because my 14-year-old is just tired of trying and not getting any success— he feels as though he’s always swimming “upstream” and my “supportive people” think he just needs to put in the effort and to care a little more.... ugh.*

While many mothers described supportive extended family members, others struggled with the best way to approach the conversation and handle comments from extended family members. Morgan asked:

> *How to you handle unsupportive family members? It seems like my 90-year-old grandma is well-meaning but speaking from ignorance (why don’t you just make her read more?, etc.) but she tends to make “suggestions” in front of other people and that embarrasses my daughter. My parents and in-laws make comments about my daughter’s school. They don’t like that she goes to Montessori so they try to blame her delays on the school.*

What emerged across mothers’ posts is an unwavering commitment to supporting and protecting their whole child, academically and emotionally. Within a system that positioned them not as different but deficient, mothers were hypervigilant about discussing dyslexia in a way that empowered and protected their children while attempting to correct and enlighten those who misunderstood dyslexia.

“Anyone Here That Just Can’t Afford Intervention?”: Uncertainty Surrounding How to Afford Dyslexia

As mothers attempted to navigate the myriad components of advocating and supporting their children, they quickly encountered the cost of dyslexia. Learning disabilities are expensive, often prohibitively so. As Emily wrote, “the assumption that everyone can get an advocate, pay for private tutoring, or send their child to a private school is so out of touch with what the average family can do.” Another mother echoed, “As I have worked with families through the years, I have come to realize that only those privileged with location or money tend to get effective instruction.” Mothers often battled with schools to screen their child, but many did not have the option to access private evaluations that ranged from $2,000-$5,000. Indeed, many mothers wrote asking about the cost after their child’s school pushed back against testing and instead opted for a “wait and see” approach. Anna wrote:

> *Now that we are attempting to have him tested outside of school, I am wondering if anyone would be willing to tell me what the total cost I might expect to pay for a neuropsychological evaluation might, on average, be? Did insurance cover it? If not, how much does the eval cost?*

Often mothers realized insurance rarely covers an educational evaluation and wrote questioning how coverage might work:

> *Has anyone had any success getting your medical insurance to cover Wilson therapy? The diagnosis code for dyslexia is R 48.0, has anyone found a CPT billing code that can be used to bill insurance for Wilson therapy? Dyslexia is being recognized as a neurological not educational diagnosis by some insurance carriers, which could make its treatment eligible for medical insurance coverage. I'm trying to learn as much as I can about this, any information you have is appreciated!*

While a private evaluation provides a comprehensive look at a child's cognitive profile and is an effective way to obtain an objective assessment, some mothers had to consider that obtaining the diagnosis of dyslexia does not automatically guarantee that their child would receive an IEP from their school with an evidence-based intervention program to remediate their reading difficulties. In other words, mothers had to weigh whether to stop fighting the school for support and instead put the money they would spend on an evaluation toward a tutor instead. There are decades of support that the Orton-Gillingham approach is what works to help children with dyslexia (Sayeski et al., 2019). This approach advanced the multisensory perspective to teaching reading and is specifically designed to help struggling readers with its systematic and explicit connections between letters and sounds (Sayeski et al., 2019). A certified OG tutor costs $65-$100 or more an hour. Many mothers wrote with questions about private tutoring and seeking insight into how others fit it into their monthly budget:

> *How much a month are you spending on tutoring!? We found a great tutor semi close to our home, but the cost!! Don't get me wrong, I know teachers with skills it's going to cost us. I'm just semi freaking out on how to add this to our monthly budget and wanted to check and see if the price they were paying was similar to others.*

Upon seeing the costs, some asked about the possibility of investing in the long certification process so that they could begin tutoring their child themselves. Molly asked "How many of you chose to become tutors yourself for your own children? Pros cons? $85-$100 per hour twice a week, we simply can't afford that." Many mothers wrote not with questions of how much things cost but feeling defeated and heartbroken that they could not afford it and questioning if anyone else could relate. "I can't afford a private tutoring being a single mother. Anyone know free websites for a dyslexic teenager going to 8th grade?" Many mothers similarly admitted that no matter how they stretched their budget, no matter how many "corners" they cut, they simply could not afford it. They wrote in defeat, questioning if anyone else shared the uncertainty and guilt they carry:

> *There isn't a day that goes by that I don't feel guilty for not being able to provide these things for my son. He has wonderful teachers who are responsive and understanding - they root for him - but an IEP in a decent public school is not enough for the severity of his dyslexia. I feel like it's obvious to everyone that he will never be reading or writing close to grade level nor be able to truly navigate school independently. I'm so sad for him that he has this weight, this chain, he has to drag around with him and the*

> *idea that we can't lighten it enough for him is something I think about every day.*

While mothers shared guidance related to costs, budgets, and insurance, their posts simultaneously created a space for coping with how prohibitively expensive dyslexia can be. Mothers were desperate to access the resources their children needed, underscoring how high the stakes are for children to get the resources they need in schools.

Discussion

The purpose of this study was to understand how uncertainty manifests for mothers of children with dyslexia. While dyslexia is the most common learning disability (Mather et al., 2020), there is limited work exploring the way mothers themselves articulate and make sense of the experience. The present study takes up Woodcock's (2020) call to push methodological discussions further than just being "about disability" and instead examine the lived experiences of real people in multidisciplinary ways. In the present study, the lived realities of parenting a child with dyslexia illustrated four major sources of uncertainty: the future, advocacy, communicating about the diagnosis, and the financial cost. While the online group created a space for parental support, the overwhelming majority of posts were made by mothers. While researchers have shown that fathers are increasingly more involved with parenting (Mueller & Buckley, 2014), others illustrate that regardless of whether mothers work outside the home, they are often the primary source of contact for their children's education, health, and overall well-being (Robertson, 2014).

From beginning to have concerns about their child's reading, to the overwhelm of where to begin after diagnosis, to seeking guidance on the IEP process, to feeling desperation and wondering if others could relate, this study points to the beneficial aspects of online support groups. Not only could mothers overcome geographic barriers and have control over when and how much support they sought, but their posts demonstrated self-efficacy and empowerment as they took on the role of advocate for their children. Indeed, this is particularly true as mothers described feelings of being gaslit by school administrators (e.g., being told they were overreacting or being told they were misremembering conversations) and turned to the group to cope. Mothers' posts illustrate the necessity of having access to supportive environments.

Understanding how mothers articulated uncertainty related to their child's dyslexia has significant utility for researchers, educators, and administrators alike. Given the significant distress experienced by mothers, my primary focus is on generating conclusions with practical value. One of the taboos is that administrators are often not even supposed to say the word "dyslexia" in schools, which only serves to exacerbate problems and muddy the waters around what resources are dedicated to the issue within schools. While this is far from the current reality, dyslexia specialists should be present at all schools and universal screenings to identify and address students with dyslexia should be mandated. Schools must also examine their practices in engaging and collaborating with parents. Consistent with existing researchers (Connor & Cavendish, 2018), parents often felt unprepared, confused, and frustrated as they navigated the academic jargon and legal requirements of the IEP meeting, highlighting the importance of schools taking on the responsibility to build more collaborative partnerships with parents. Indeed, parents frequently used words like "battle", "fight", "resistance", and "defeated" to describe their school-based interactions, illustrating the necessity that school-based decision-making between parents and professionals occur within a conversation that is equally balanced among all participants (Wagner et al., 2012). This is especially important when thinking about differing and ingrained cultural beliefs about educational responsibility.

While existing research has argued for the importance of school-based administrators approaching parents with a caring disposition and listening to parents about what matters to them, this study suggests going further to facilitate relationship building (Haley et al., 2018). One practice that is particularly well-suited to foster relationship building between schools and families is communicated perspective-taking (Koenig Kellas et al., 2013), which is the “manifested evidence of cognitive perspective-taking” (p. 327). In other words, during IEP meetings, administrators can intentionally adopt behaviors that interpersonally *communicate* that one has put themselves in another's shoes, which may offer evidence to the parent that he or she is cared about and understood. Because the cadence and structure of IEP meetings can take on a “production line” (Connor & Cavendish, 2018, p. 4) quality when parents do not feel heard or considered, taking time to intentionally recognize how parents may be feeling could make an impactful difference.

Perspective-taking is particularly relevant when it comes to being mindful of complex economic situations faced by families, such as the expense of private evaluations and tutoring. Indeed, parents are not a monolithic group, and schools are tasked with responding to a diverse body of parents, who may differ significantly from school personnel in terms of social class, race, ethnicity, and language. Negotiating school systems are difficult for all parents, but particularly for those who are not White and middle class with a college education (Lalvani & Hale, 2015).

Limitations and Future Directions

There are several limitations to this study that should be considered. First, using an online support community for analysis may lead to different perspectives than recruiting from the general population because this group may represent parents who have spent more time reading and engaging in research about dyslexia. Second, this study was based on an analysis of Facebook posts, meaning that interpretations of these posts were subject to the author’s judgment. While analyzing the posts in a naturalistic context is valuable, this method does not allow the author to probe for more information, ask follow-up questions, or understand the background story of the members of the group. Finally, because no background information was collected, this study cannot speak to the way race, class, or location plays a role in the experience of parenting a child with dyslexia. While indications of socioeconomic class emerged through posts about struggling financially, paying for private school tuition, or seeing progress with private tutors, this study cannot assess between-group differences.

Practices to address dyslexia are influenced by a number of factors, including culture, the orthography of a language, policies, dyslexia awareness, teacher training, and the availability of assessments and interventions (Mather et al., 2020). Although many countries have taken proactive steps to improve the education and overall lives of individuals with dyslexia, dyslexia is still not well understood and individuals face challenges in getting appropriate intervention. To gain a deeper understanding of the experience of parenting a child with dyslexia, future research should incorporate surveys, interviews, or fieldwork that allow participants to directly express their views and respond to questions of the researcher. Because so many of the posts discussed frustrating interactions with their child’s school, future researchers may find it useful to study dyslexia longitudinally, as parental knowledge and advocacy grow over time. For example, participants could keep a diary of their communication with their child’s school administrators. This would allow researchers to see how interactions unfold over time (Baxter & Babbie, 2004).

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