

Insights from a Web-based survey into the psychosocial experiences of adults with dyslexia: Findings from a final comment question

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Not seemingly measuring up to Western societies' educational and occupational expectations for success, adults with dyslexia are at risk for discrimination, humiliation, low self-esteem, low self-efficacy, depression, and anxiety. We analysed 113 responses to the final comment question that was incorporated at the end of a quantitative survey on the socioemotional experiences of adults with dyslexia. The final comment question was not intended for conveying personal experiences, yet the final comment responses were personal, in-depth, and substantive – indicators of quality recommended in survey research. Thematic analysis was used to analyse the data and develop themes. One overarching theme was yearnings for understanding and acceptance. Its associated sub-themes included (1) “This stuff is torture”, (2) “Thank God I'm not normal”, (3) educational experience, (4) coping strategies, (5) family support, and (6) generational dyslexia. This study contributes to the small but growing body of literature on the socioemotional experiences of adults with dyslexia. Among the implications for practice, policy and research, a larger challenge at the broader society level that embraces diversity, equity, and inclusion for individuals with dyslexia is forefront.

KEYWORDS

adults, dyslexia, final comment survey question, socioemotional, thematic analysis

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1 | INTRODUCTION

Dyslexia refers to difficulty acquiring and processing language that is typically manifested in affected individuals by challenges with reading and writing (Shaywitz, 2003) along with short-term or working memory, visuospatial attention, rapid auditory processing, and motor functioning (Eide & Eide, 2011). A growing body of evidence suggests that dyslexia does not resolve during the life course; children with dyslexia become adults with dyslexia (AWD) (Goldberg et al., 2003). Dyslexia is the most common specific learning disability in the United States (US) (Shaywitz & Shaywitz, 2020). As a lifelong disability, inferring inquiry into the lives and concerns of AWD is warranted. This research study was undertaken to better understand this invisible population's psychosocial experiences with the goal of informing dyslexia-related practice, policy, and research.

As part of the second phase of a multi-phase study of AWD, findings reported in this paper are limited to participants' written responses to what is known in the survey research literature as a "final comment", "general open-ended question", or a "non-directive feedback question" (Decorte et al., 2019; Schonlau, 2015). The use of open-ended questions in predominately quantitatively structured online surveys that explore the experiences of AWD has not gained attention in the literature. Since articles addressing the methodological implications and findings of final comment questions are seemingly nonexistent (Decorte et al., 2019) and given that the readership may be unfamiliar with their use, it seems wise to review the literature on final comment questions in survey research. This could provide important background in helping readers understand the conundrum we faced in determining whether and how to analyse the data from the final comment question. We will first provide a brief overview of the psychosocial aspects associated with AWD in various life domains, followed by the research context for this study.

2 | LITERATURE REVIEW

Awareness of dyslexia ostensibly began in the U.S. with the 1937 publication of Orton's *Reading, Writing, and Speed Problems in Children* (Chinn, 2012). Since Orton's pioneering research on dyslexia, there has been a growing body of research on the genetic and neurocognitive origins and profiles of dyslexia in both child and adult populations. In comparison to non-dyslexic adults, AWD are likely to encounter challenges including reading proficiency, processing speed, executive functioning skills, working memory, prospective memory, and structural language skills (Bradshaw et al., 2021; Del Tufo & Earle, 2020; Leather et al., 2011; Smith-Spark, 2018; Smith-Spark et al., 2023; Wiseheart et al., 2009). While neurocognitive differences commence in childhood, they persist into adulthood, severely impacting individuals' experiences in key life domains, including postsecondary education and employment.

2.1 | Academic and workplace settings

In Western society, academic and occupational prowess are markers for success. Accordingly, a majority of the past and extant research on AWD has focused on psychosocial experiences in college and occupational settings and, to a lesser extent, in other life domains, including their familial, social, and everyday lives. During the transition to postsecondary education, AWD are confronted with losing accommodations (e.g. Individualized Education Plans) that their primary and secondary education may have provided. The increased academic demands of postsecondary education can tax their neurocognitive challenges and the academic coping skills that they developed in earlier school experiences. The neurocognitive skills that are required to proficiently complete such tasks as reading long texts, taking notes, searching databases for information, taking exams, completing assignments before due dates, and negotiating coursework with external internships can make the college experience emotionally unpleasant for students with dyslexia (Abbott-Jones, 2022; Gant & Hewson, 2022; Jacobs et al., 2020; Stoeber & Rountree, 2021).

With more demanding postsecondary coursework and expectations, it is not surprising that in comparison to their non-dyslexic peers, AWD experience higher levels of academic anxiety (Abbott-Jones, 2022; Bazen et al., 2023; Lithari, 2018), lower frustration tolerance (Potard et al., 2022), low academic self-efficacy (Brunswick & Bargary, 2022; Stagg et al., 2018), internalizing problems such as low self-esteem, depression and somatic discomfort (Bazen et al., 2023; Ghisi et al., 2016), exhaustion (Gant & Hewson, 2022), lower life satisfaction (Kalka & Lockiewicz, 2018), and perfectionism and self-stigma (Stoeber & Rountree, 2021). Abbott-Jones (2022) suggests that for students to navigate the trials of college successfully, cognitive and emotional coping skills are essential.

AWD are also likely to encounter neurocognitive challenges in employment settings (de Beer et al., 2014; Leather et al., 2011). For example, Smith-Spark et al. (2023) found that in a virtual reality workplace environment, AWD performed poorly on tasks that require executive functioning skills (e.g. planning and selective thinking involved in completing a work project) and prospective memory (e.g. remembering and carrying out tasks to be completed at a later time point like attending a meeting or attaching a document to an email) compared to adults without dyslexia. Difficulty in reconciling neurocognitive differences may partially explain low work self-efficacy (Nalavany et al., 2018), decreased job satisfaction (de Beer et al., 2022), and an assortment of negative work-related emotions, including anxiety, depression, frustration, and exhaustion (de Beer et al., 2014; de Beer et al., 2022; McNulty, 2003; Nalavany et al., 2018; Wissell et al., 2022) among working AWD.

2.2 | Social environment

Research on AWD in general (i.e. community samples) is similar to that found in research on academic and workplace contexts, such as high occurrences of internalizing problems such as anxiety, depression, and low self-esteem (Basta et al., 2022; Kirkegaard, 2022; Livingston et al., 2018; McLoughlin & Leather, 2013; McNulty, 2003; Nalavany et al., 2011; Wilson et al., 2009). In addition to the impact of the neurocognitive dynamics associated with dyslexia on psychosocial experiences, the field of disability studies suggests that the social environment generates and aggravates the disability (Denhart, 2008; Barbara Riddick, 2001). AWD are likely to encounter dyslexia-related social misunderstandings and stereotypes across academic, workplace, and community settings. For example, a US national study on public beliefs about learning disabilities such as dyslexia indicates that the majority believe that dyslexia is not a bona fide learning difference but is the result of laziness or home environment (Roper Public Affairs & Communications, 2010). Furthermore, over half of the public and educators (teachers and administrators) falsely associate learning disabilities with mental retardation and autism (Roper Public Affairs & Communications, 2010). A more recent US nationally representative survey of adult perceptions (the public) of children indicates that knowledge of dyslexia is improving (e.g. that dyslexia is not synonymous with low intelligence) (Castillo & Gilger, 2018). Nonetheless, most of the general public believes that children with dyslexia do not possess any personal and intellectual talents and that a positive attitude and hard work are sufficient to make the child's dyslexia better (Castillo & Gilger, 2018).

Past (Ingesson, 2007; McNulty, 2003; Nalavany et al., 2011; Riddick et al., 1999) and current research (Jacobs et al., 2020; Kirkegaard, 2022; Lithari, 2018, 2023; Stagg et al., 2018) illuminates how misunderstandings and stereotypes about dyslexia among primary and secondary school teachers and administrators can jeopardize emotional well-being well into adulthood. A common theme is that many AWD describe their early school experiences as traumatizing, with recollections of being stigmatized and feeling different, stupid, insecure, and lazy. Such distressing experiences do not cease after primary and secondary school. Not fitting in with mainstream society's expectations of success (e.g. educational and occupational competence) combined with the social misconceptions of dyslexia have been associated with experiences of discrimination and feelings of being judged, patronized, inadequate, unsupported, and shamed across postsecondary (Abbott-Jones, 2022; Denhart, 2008; Gant & Hewson, 2022; Jacobs et al., 2020; Lithari, 2018, 2023; Livingston et al., 2018) and workplace (de Beer et al., 2014; de Beer et al., 2022; Deacon et al., 2020; Kirkegaard, 2022; Wissell et al., 2022) contexts. In other words, negative emotional

consequences experienced by AWD (e.g. anxiety, shame, depression, and frustration) may be dependent upon perceived invalidating relational experiences (e.g. being ridiculed by an instructor or supervisor for needing more time to submit an assignment or report) and lack of adequate environmental supports (e.g. the needed technology or accommodations needed to complete an assignment or job task) over and beyond their neurocognitive ability (Deacon et al., 2020; Riddick, 2001).

3 | FINAL COMMENT QUESTIONS

Utilizing open-ended questions in quantitative Web-based surveys is an innovative method of collecting qualitative data (Denscombe, 2008) and has garnered increased attention within the survey research community (Zuell et al., 2015). Open-ended questions afford respondents the opportunity to convey thoughts in their own words without being biased by the response options provided in closed-ended questions (Holland & Christian, 2009). It is common for online surveys to conclude the survey with a non-directive, final comment question such as “Is there anything else you would like to share (or add)” with a “free text” answer box for responses (Smyth et al., 2009).

Only a few articles appear to intentionally focus on final comment questions (Decorte et al., 2019; O’Cathain & Thomas, 2004; Schonlau, 2015), despite being routinely asked in Internet surveys (Decorte et al., 2019). In addition, a few researchers make an intentional approach to analyse the responses (Decorte et al., 2019), as the responses often fail to produce data rich enough to achieve the qualitative research goal of understanding human experience due to the brevity of responses (LaDonna et al., 2018). However, Decorte et al. (2019) argue that it may be unethical to disregard the final comment results when it is implied that the researchers will value and act upon the concerns of participants. As AWD are often stigmatized (Deacon et al., 2020), we decided that ignoring these final comment responses would be unethical.

4 | CURRENT STUDY

The aim of this study was to highlight and better understand the psychosocial experiences of AWD to both amplify their voices and inform dyslexia-related practice, policy, and research. Although we did not intentionally design the final comment question as a catalyst for sharing personal narratives, many of the comments were personal, focused on a life lived with dyslexia, and met objective standards for quality. Accordingly, we decided to conduct a thematic analysis of the final comment question to help amplify the voices and experiences of AWD. Given our atypical approach, a secondary aim was to demonstrate that responses to final comment questions can embody the characteristics of response quality discussed in the literature, which in turn can inform future research.

5 | METHODS

5.1 | Participant recruitment

Because personalized contacts with respondents before the actual survey are the factors most related to higher response rates (Cook et al., 2000), it was important to us that potential survey respondents have some type of “connection” with the team. To accomplish this goal, we developed a project website that hosted the URL link to the survey, a video and narrative overview of the study, biographies of the researchers and contact information, a summary of Phase 1, and project updates. Respondents were recruited via a modified version of Dillman’s Tailored Design Method (Dillman, 2000) for Web-based surveys. Responses to the survey were anonymous and confidential. Using nonprobability sampling, adults aged 21 years and older with diagnosed or self-reported dyslexia were eligible for

the University Institutional Review Board-approved study. Due to anticipated difficulties in gaining access to a population of individuals with dyslexia (Gerber, 2009), we communicated information about the study using a wide variety of sources, including the aforementioned project website, dyslexia-oriented social media sites, and organizations and schools that advocated for or instructed individuals with dyslexia. Participants who completed the survey could choose to enter a lottery to win one of ten \$25 prizes.

5.2 | Survey and measures

We utilized feedback from participants to improve the design of the survey (e.g. number of questions on a page relative to horizontal and vertical scrolling, question clarity). The final comment question followed a 200-item survey that focused on the sociocultural experiences of adults aged 21 and over with dyslexia. The survey was deployed in the fall of 2010. The final comment question, “Please share any final comments, thoughts, or feelings about any aspect of this survey or topics we covered”, was placed at the end of the survey and asked without word limits. Further information about the first and second phases of the mixed-methodology informed study have been published elsewhere (Nalavany & Carawan, 2012).

5.2.1 | Response quality of open-ended questions

We utilized three approaches for evaluating the quality of the final comment question: 1) nonresponse bias, 2) length of response, and 3) unique contribution beyond the quantitative findings. First, due to the cognitive burden involved in responding to open-ended questions, many survey participants do not answer them (Barrios et al., 2011). With a less than 40% completion rate (Poncheri et al., 2008), the overall quality of the qualitative data in open-ended questions can be questionable. The subgroups of participants who complete and do not complete open-ended question may differ enough with respect to key demographic variables (for example, gender, race) to introduce “nonresponse bias” in survey research (Dillman, 2000). Poncheri et al. (2008) recommend that it is imperative to evaluate any essential differences between responders and non-responders to open-ended questions. This analysis determines whether those who elect to respond to open-ended questions are characteristically different from those who do not. With greater representativeness of the comments, the implications of the findings can be confidently disseminated.

Second, longer responses are likely to yield in-depth data that can shed additional light on the topic of interest (Barrios et al., 2011). Denscombe (2008) found that women and those who are more highly educated tend to write more detailed responses. Similarly, Zuell et al. (2015) found that women tend to answer open-ended questions more often than men. Third, while the length of response may be an indicator of quality, another consideration concerns the degree to which the data presents a novel contribution beyond the quantitative findings (LaDonna et al., 2018). Rigorous qualitative methods (e.g. content analysis and thematic analysis) should be used to analyse the open-ended responses and not the quantitatively based frequency of keywords that are often reported (LaDonna et al., 2018).

5.3 | Data analysis process

We ultimately choose to use thematic analysis as a foundation, as it is an established and flexible qualitative method (Braun & Clarke, 2006). We approached this from a constructionist and relativist paradigm (Braun & Clarke, 2022), as we assert that participant experiences of dyslexia are subjective and based on contextual, historical, and socially constructed views on dyslexia as a disability, as well as contemporary views that consider dyslexia to be a declaration of neurodiversity (Adam-Bagley, 2022; De Beer et al., 2022). With our epistemological and ontological viewpoints in mind, participant statements are original and unaltered unless doing so protected their identity (e.g. school name) or adding a word

to facilitate understanding, as noted by the square bracket symbol. We employed the following six-stage process described by Braun and Clarke (2006) to analyse participants' narrative responses: data familiarization, initial code generation and sorting, searching for themes, reviewing themes, naming themes, and producing the report (i.e. this paper).

During the initial analytical phase, one of the researchers and two research assistants familiarized themselves with participants' narrative responses. The initial research team identified codes and used the codes to label the data. The team then collaboratively reviewed and, using a consensual process, reviewed and revised codes; recorded and sorted data; examined patterns in the data; and ultimately identified themes. During the second phase of analysis, a research team member (Author) who had been un-involved in the initial phase of data analysis independently reviewed the data and the codes developed in phase one. The team reconvened to compare and discuss the themes and discovered consistency in all but one theme. After reviewing the data and deliberating further, we collapsed two categories of data and achieved consensus on the initially disputed theme. An additional researcher served as an external auditor conducting an independent review of the data. Additionally, due to conditions beyond our control, such as a global pandemic and team member retirements, there was a gap between the initial thematic analysis and the development of this paper. Due to this, two additional researchers were brought on to the project and independently reviewed the qualitative data. The new team members had high interrater reliability in the identification of the final themes, so we proceeded with the themes identified in phase two by the original team members and research assistants.

6 | FINDINGS

6.1 | Participant characteristics

Of the 224 participants who completed the survey, half (50%; $n = 113$) answered the final comment question. Of those, 60% ($n = 68$) identified as men and 40% identified as women ($n = 45$). They primarily identified as Caucasian (85%; $n = 96$), with 4% ($n = 5$) indicating Hispanic/Latino/Latina ethnicity; and 4% ($n = 4$) indicating African American, Asian/Pacific Islander, or mixed ethnicity. A majority of the participants declared the US (94%) as their home country, while four and two declared Canada and the UK, respectively, as their country of origin. Their average age was 50.1 years ($SD = 13.61$). A majority (59%; $n = 67$) indicated working part or full time, while 65% ($n = 74$) had earned at least a Bachelor's level college degree. Most final comment participants (79%) responded "yes" to having a specific diagnosis of dyslexia, while all participants self-identified as having dyslexia.

6.2 | Nonresponse bias and comment length quality

There were no significant differences between final comment responders and non-responders with respect to age, gender, marital status, educational attainment, ethnicity, or employment status. Comments varied in length from 1 to 726 words, with an average of 91 words ($SD = 111.73$). Women ($M = 114$; $SD = 149.3$) tended to write more detailed responses than men ($M = 75$; $SD = 74.56$); however, this did not reach statistical significance ($p = 0.06$). Excluding two women whose comments contained 726 and 633 words, the difference in means was still not statistically significant ($p = 0.37$). Length of response was also not dependent upon age, marital status, employment status, or educational history.

6.3 | Themes: Common threads of experience for individuals with dyslexia

Through thematic analysis of the final comment responses, we developed one overarching theme, yearnings for understanding and acceptance, and six associated subthemes: "This stuff is torture", "Thank God I'm not normal", educational experience, coping strategies, family support, and generational dyslexia.

6.4 | Theme 1: Yearnings for understanding and acceptance

Participants revealed that dyslexia had a pervasive, powerful, and ongoing impact on their lives. The impact began in childhood, especially in the context of school experiences, and continued into adulthood. They noted the lifelong negative effects of dyslexia related to their own and others' misunderstandings about dyslexia and its consequences. One wrote, "Dyslexia is something people joke about having, like ADD and it is just not funny. Not being able to learn well can be the beginning of a very long, painful way into adulthood, and a lonely place once you get there." Many participants wrote about facing barriers and challenges in all aspects of their lives that they associated with misjudgments or lack of acceptance by unaffected or ill-informed others. They longed for a future in which people recognized, understood, and accepted them for who they were as people. The participants' desire for sociocultural understanding and acceptance was informed by five subthemes discussed below.

6.4.1 | "This Stuff is Torture"

The perception that living with dyslexia was "torture" reflected the experience of intense emotion that participants associated with dyslexia and the negative social perceptions they perceived accompanied it. For many, having dyslexia meant living with a painful, frustrating, exhausting, and stigmatizing disability. Participants specified dyslexia-related attributes that were personally challenging for them, such as timeliness; spelling; reading; including being a slow reader or becoming a late reader; and experiencing issues with disorganization. Having dyslexia precipitated a host of negative personal feelings, including grief, frustration, disadvantage, and worthlessness. For many participants, living with dyslexia was "frustrating and exhausting", particularly since it often necessitated arduous work on their part to compensate for its effects. As two participants revealed,

I just felt a freak of nature and having to admit this still makes me cry inside even though I know I am loved by friends and family. I still feel worthless. Maybe one day these feelings will go and I can feel whole. Until then, I will not allow dyslexia to be my prison cell.

I really feel disadvantaged with my brain, my learning difference. I know I am different but I can't put a finger on it. I know I work my butt off, I work harder and longer than others and [get] less results. This is the way it was in college. I spent almost every night and every weekend in the library and graduated with a "C" average. It's so frustrating.

Participants tended to conceal their disability from others. As a participant revealed, "Fear, frustration, Fear, Fear, Fear of being found out as an adult with dyslexia is crippling."

6.4.2 | "Thank God I'm Not Normal"

Despite the many negative dyslexia-related personal challenges participants described, at some point in their lives, some participants recognized that, in the words of one individual, "there are also certain gifts which accompany this condition." In the following statement, a participant's comment crystallized the coexistence of both perspectives, "The emotional feelings when discussing this topic still hurts, even though I am proud I've got it." Those who recognized the positive aspects of dyslexia relayed that the difference enabled them to discover, pursue, or capitalize on unique talents or attributes that contributed to a positive appreciation of self or personal achievements. They named multiple positive aspects, including creativity, creative thinking, and high levels of intelligence. A participant shared experiences of dyslexia as a positive quality in the following way:

Dyslexia is a gift—not a handicap. I have found that once I got beyond my school years, dyslexia has been an asset because it has allowed me to think outside of the box. I often have said, “Thank God I’m not normal!” I have spent the last forty years working on tools that enhance intuition.

One participant, however, disagreed with ascribing any positive attributes to dyslexia, as exemplified by the following statement: “I do NOT see it [dyslexia] as a gift, and do not see any connotations with ‘success’ and dyslexia.”

6.4.3 | Educational experience: Schooling as hurtful unless dyslexia-informed and supportive

Some study participants shared profoundly negative, hurtful schooling experiences related to having dyslexia, while others described wholly positive educational experiences in the context of a dyslexia-informed and supportive educational culture such as private boarding schools (PBSD). Participants recalled often hurtful memories of public schools, including struggling with schoolwork, disliking school, being ridiculed, and feeling anxious and insecure when engaged in educational environments in general and schoolwork in particular. Such schooling-related difficulties arose regardless of educational level. One participant, for example, observed, “It was shocking to me that some of the rudest unsupportive teachers were at the universities.” Another participant divulged that derision from important others had a lasting impact, “As an adult dyslexic, with continuing spelling and typing and organization problems, it is very embarrassing to make any mistakes due to previous ridicule from parents, teachers, and others.”

They observed that educational system personnel tended to ignore problems posed by dyslexia or misunderstand those affected by it. Several participants revealed that their own school experiences or those of their children led them to become teachers with the aim of making a positive difference in children’s lives or becoming change agents in school systems. An individual with dyslexia who became a teacher, for example, recalled the lifelong impact of negative early school experiences.

I became a special education teacher due to my experiences in school. I am very self conscious and anxious about my poor spelling. I still struggle with my confidence when reading aloud, even to my students.... As a child I always thought I was dumb and everyone was going to find out. I was always driven to get high grades but even when I did I always felt like an imposter.

Parents’ comments included the difficulties they faced when advocating for their similarly affected children in school. One participant who was intent on becoming an educational system change agent provided the following insight into children with dyslexia in school, parental help-seeking experiences, and a school system that ignored the problem.

It is almost heretical to even say the word in a conversation inside the school building. I see children every day struggling to understand why school is so difficult and parents who feel powerless to help [p] them. I am walking a tight rope with a mine field below me as I try to help these sad and frustrated children in an institution that refuses to acknowledge the elephant in the room. I am determined to continue my own education and hope to change public education one mind at a time.

The importance of positive, supportive, dyslexia-informed schooling was reflected in participants’ comments about private boarding schools that focused on meeting the needs of students with dyslexia (PBSD). Participants who attended such schools attributed their experiences in them to, in the words of three individuals, providing “*valuable skills*”, helping them “*overcome dyslexia*”, and ultimately “*saving*” them. Their PBSD experiences contributed to the quality of their lives and eventual careers. As one participant observed, “The [PBSD]...really save(d) me.

I do not believe I would be where I am at today without them.” Two participants similarly expressed appreciation for their experiences in a PBSO; one wrote,

As a seventy-nine year old with a learning disability and dyslexia from day one thanks to The [PBSO] and my innate determination to overcome, I was able to succeed and enjoy life!

6.4.4 | Coping strategies: “You Never Get Over Dyslexia. You Can and Do Learn to Deal with It”

Participants had various coping strategies to reconcile neurocognitive challenges and deal with society's misperceptions, misrepresentation, and stigma of people with dyslexia. Some participants developed innovative strategies to compensate for their neurocognitive differences, only to feel stigmatized and emotionally wounded despite their perseverance as noted by the following participant:

I cannot spell, I am disorganized, creative and have always felt different. My grades have always been “all over the place” but I figured out how to study in college and I got a BS in Nursing from...[a S]tate university. I had to go to all lectures, rewrite my notes a few times and made up stories to remember concepts. I have always felt misunderstood and have struggled with depression.

For some participants, coping with dyslexia involved efforts to camouflage their difference or avoid situations that would reveal their difference to others. They thus tried to prevent the potentially stigmatizing revelation of dyslexia that would leave them vulnerable to being criticized for negative reactions or assumptions by others. A participant wrote, for example, “I think as (an) adult you learn to compensate in everyday life and try to avoid those situations that might reveal it. I have learned how to talk people into doing things for me.”

Other participants embraced dyslexia as an asset that fostered in them unique skills or characteristics of which they were proud and on which they capitalized. For instance, participants noted, “Dyslexia causes a brain to work much faster and as a child it causes a problem with all the info coming at you at once, but once you learn to handle that constant feed of information and learn to harness it, you can find it to be a blessing.” As they strived to discover meaning in their lives, some participants worked hard to overcome personal obstacles associated with the disorder, in part so they could assist others, particularly children, who faced circumstances akin to their own situation.

Study participants also identified positive attributes such as becoming more self-accepting and assured, especially as they grew older and learned strategies to circumvent or overcome dyslexia-related limitations. They adopted various technological or logistical strategies and intrapersonal attributes that enabled them to live more confidently or effectively with their difference. One participant wrote about attaining a post-graduate degree by becoming more cognitively self-confident, organized, and aware of personal time requirements.

It wasn't until I started college and realized that I was smart that I actually began to excel as a student. I am 40 you and just completed my masters degree. I found that organizationa and allowing ample time to complete my tasks has been the key to academic success.

Regardless of on-going efforts to adapt to, cope with, and make the most of the consequences of their difference, the participants acknowledged the continuing legacy of their earlier life experience with dyslexia by saying, “Dyslexia is a life long issue – even though I am successful I constantly live with the fear of failure.”

6.4.5 | Family support

Participants identified support and encouragement by significant others as important and sometimes critical contributors to their lives. Although several participants mentioned the role of teachers, overwhelmingly, it was parental support and parental advocacy that made a significant difference to participants in terms of the quality of their everyday lives, ability to effectively address their learning needs by, in the case of two participants, “providing the best learning environment they [parents] could find,” and, “I was able to do something with my life because I have great parents who knew I was smart. I know that not all dyslexic persons are that lucky.” Participants identified family support as an important resource factor in attaining a foundation of knowledge for their careers and instilling a sense of perseverance as two participants recounted,

Dyslexia is a hurdle, but if appropriate steps are taken early in childhood development it can be overcome. I have dyslexia, but was able to completed medical school. There were several big bumps in the road for me, but with family support and hard work, I was able to attain my goals. I have been practicing medicine for nine years.

Because of strong early family support I never “suffered” because I was dyslexic. Rather it was something to work on. You never get over being dyslexic. You can and do learn to deal with it. I'm interested in my special qualities maybe because I'm dyslexic.

6.4.6 | Generational dyslexia: Hope and advocacy for offspring with dyslexia

Participants often recognized dyslexia in members of previous generations of their families, citing their own and past family members whose personal histories suggested the possibility of learning challenges. Several participants recognized the basis of their learning struggles with dyslexia when one or more of their own children was diagnosed, as one participant noted,

I have two out of 3 children with Dyslexia. I found out my “problem” through their diagnosis.

The participants' recognition of personal issues with dyslexia due to a child's diagnosis could be a mixed blessing in their lives. On one hand, they experienced relief in recognizing the nature of the problem with which they had long struggled. On the other hand, they lamented having experienced many, often painful years of uncertainty or mistreatment at the hands of others due to a problem that went unrecognized or undiagnosed. As one participant acknowledged,

As an adult who went undiagnosed with dyslexia until her child was diagnosed in 1998, it was very difficult to work through all the deep buried feelings of my childhood.

The participants who parented children with dyslexia wrote that the lifelong emotional toll that accompanied living in a society that was not dyslexia-aware or helpful had fuelled a passion and resolve in them to advocate for and support their own and other children with dyslexia. They wanted to assist children in a way that they themselves had never been assisted or supported, particularly in public school systems. Their own challenging experiences with dyslexia prompted them to engage in advocacy efforts for children with dyslexia. The following statements reflected the participant's commitment to and advocacy for the well-being of their offspring with dyslexia:

I'm just glad I can instill a positive esteem to my Dyslexic son, something my dyslexic mother never did for dyslexic me.

For the time being I have both [children] in a special school for dyslexia. I hope and pray that I am not hindering their growth in any way, but rather providing them with the advantages that I never had.

In addition to seeing their own struggles mirrored in the children, participants often recognized dyslexia in members of previous generations of their families, citing their own and past family members whose personal histories suggested they possibility of learning challenges. As one participant wrote, "I am a 3rd generation dyslexic and now my child has been diagnosed with Dyslexia." Suggesting that participants recognized a generational pattern within their own families.

7 | DISCUSSION

To our knowledge, this is the first study that presents findings from a final comment question from a quantitative Web-based survey of AWD. Final comment questions are commonly used in Web surveys but rarely reported in published work due to low response rates and lack of depth and nuance (Decorte et al., 2019; O'Cathain & Thomas, 2004). The volume and depth of the responses from our final comment question were unexpected, particularly given the length of the survey and the attributes that typify AWD. The responses represented the voices of those with experiences of dyslexia. One core theme and associated subthemes corroborated and extended the value of the questionnaire data and findings.

7.1 | Social perception

To conceptualize social perception, themed Yearning for Understanding and Acceptance, it is necessary to acknowledge that individuals with dyslexia are often challenged with reading, writing, and spelling, and a host of neurodiverse differences (Eide & Eide, 2011). This "neurological variation" can, under certain contexts, negatively impact the individual (Deacon et al., 2020).

Yet, it seems unlikely that the neurocognitive challenges such as reading, writing, and executive functioning differences associated with dyslexia *fully* explain the painful emotional experiences illustrated in this study or the high incidences of anxiety, depression, and low self-esteem reported in the lived life of AWD (Denhart, 2008; Kirkegaard, 2022; Livingston et al., 2018; McNulty, 2003; Nalavany et al., 2011; Wilson et al., 2009). Disability studies has challenged the medical model emphasis of dyslexia as an individual deficit, and, rather, asserts that the social environment both creates and exacerbates the disability (Denhart, 2008; Riddick, 2001). To situate this in context, dyslexia is known to be a "hidden disability" (Hussein et al., 2008), and thus an invisible stigma (Crocker et al., 1998). Individuals who possess an invisible stigma like dyslexia, HIV/AIDS, drug abuse, and mental illness may be perceived by others as possessing undesirable attributes that define their character or group membership.

In Western society, educational and occupational ability are seemingly the yardsticks that determine life success. These metrics of success interact with dyslexia-related social myths (i.e. perceptions and stereotypes). Therefore, it may be unfathomable for a person who struggles with reading and writing to be considered intelligent. As such, people with dyslexia are regarded as having limited ability and lower intelligence (May & Stone, 2010), and that they use accommodations to cheat or gain unfair advantages (Denhart, 2008). Society misperceives dyslexia as a disability rather than validate AWD differences, unique strengths, and resolve in completing tasks that might require double or triple the time to finish compared to non-dyslexic individuals (Denhart, 2008). The findings suggest that AWD juxtapose their genuine experiences with mythology, treating social myths as fact, and their reality as myth. For example,

some participants internalized society's yardsticks for success and used terms like "stupid" (or similar words) to define their personhood. Given this, it is no surprise that several participants expressed feeling misunderstood and sometimes treated with discrimination and humiliation, particularly in educational and occupational contexts as represented in the subthemes of educational experience and coping strategies.

The final comment responses also complement our findings on family support, emotional experience, school experience, and coping/compensation from the quantitative data (Nalavany & Carawan, 2012; Nalavany et al., 2011; Nalavany et al., 2012). However, we developed one subtheme that has a "new, unique or rare" influence over and beyond the quantitative findings (Ladonna et al., 2018, p. 348): Generational Dyslexia.

7.2 | Generational dyslexia

Some study participants reported being a third-generation person with dyslexia. It is not surprising that some participants reported raising a child with dyslexia, as research shows that upwards of 66% of children with dyslexia have a parent with dyslexia (van Bergen et al., 2011). Yet it is not the fact that dyslexia tends to run in families that was perhaps the most surprising finding of this study, but rather how the experience of being an AWD intersects with parenting a child with dyslexia. Little empirical work intentionally explores the intersection between parents with dyslexia and their children with dyslexia in a psychosocial context. Rather, a large body of literature focuses on genetics and neurodevelopmental impairments of at-risk children of parents with dyslexia (Chan & Mo, 2023; Denton et al., 2022; Earey, 2013; Leitao et al., 2017; Skinner, 2011), and another growing area on parents' (i.e. mostly mothers) concerns about the educational experience of their children with dyslexia (Aberz, 2022; Wilmot et al., 2022). An exception is research by Skinner (2011) and Skinner and MacGill (2015), who explored the intersection of how mothering and work is affected among women with dyslexia. However, none of these studies intentionally considers the experience of parents with dyslexia raising children with dyslexia.

Parents of children with dyslexia adopt roles that go beyond the traditional notion of being a parent to that of being a "tutor, fighter, counsellor, and advocate" as a necessary means to meet the educational needs of their children (Leitao et al., 2017, p. 331). Assuming roles as a tutor, fighter, counsellor, and advocate rise to a different level when considering the experiences of parents with dyslexia raising children with dyslexia. These parents have a dual experience of reliving much of the past pain in their own stories while trying to help and protect their children as they watched them go through similar experiences. They were passionate about wanting a better life for their child with dyslexia, that included less heartache, an appropriate education, and less stigma associated with dyslexia. Some parents made the difficult financial decision to enrol their children in private schools that specialize in the education of students with dyslexia. Such a major life decision by these parents may be foreshadowed by the subtheme of Educational Experience. Participants who attended specialist schools reported the experience was life-changing to both the quality of their lives and their employment aspirations, a finding that is consistent with the existing literature on the impact of specialist schools on the socio-emotional and education of AWD (Nalavany et al., 2011). They felt that their own experience with dyslexia helped them better understand their child in a way that could make a positive difference in the child's life. As a means of possibly reconciling traumatic public school and family experiences in a positive way, some parents from this study vowed to instill a sense of self-esteem in their children with dyslexia by bolstering their child's educational and emotional well-being in ways that they may have yearned (Satir et al., 1991). Research by Alexander-Passe (2012) gives light to the subtheme of Generational Dyslexia, arguing that parents with dyslexia reported that the trauma they experienced in their early childhood school experiences propelled them to establish a more accommodating and validating school experience for their children with dyslexia. These parents either fervently advocated for their child's educational rights or sought "dyslexia-friendly" schools that were better suited to meet the educational needs of children with dyslexia.

7.3 | Limitations

As for limitations, we recruited AWD using a single home-based website and nonrandom procedures, as this population is difficult to reach. The sample was primarily Caucasian, and many participants had achieved high academic success. We are unable to determine the degree to which our sample is representative of the general population of AWD. Future research should prioritize sampling methods that can garner a more diverse sample. The data were collected in 2010, and while this ages the data, AWD are a hidden population, so we felt it prudent to honour their time and effort by exploring their responses. To be sure, the themes and subthemes that developed through the thematic analysis are likely still salient with AWD and parents today. Finally, many participants discussed their experiences of dyslexia during childhood, adolescence, and early adulthood; given that the average age of participants was 50 years old, it is likely that there have been changes to schooling and the treatment of dyslexia since they were in school.

7.4 | Implications

There are two key implications of this study that relate to practice, policy, and future research. First, research that intentionally explores the intersection between parents with dyslexia and their children with dyslexia is virtually nonexistent. However, parents with dyslexia could be viewed as an incredible asset if allowed to help children with dyslexia live successful and satisfying lives. For example, parents with intergenerational knowledge of dyslexia could serve on boards as well as lead and/or inform sensitivity trainings for professionals who interact with the 12% of the population that has dyslexia. They could also inform mental health professionals, social workers, and teachers about the impact of intergenerational dyslexia—in short, they could serve as advocates for their own and other children with dyslexia. Furthermore, the findings of this study indicate a need for future research that explores how parents' experiences with their own dyslexia impact their children's self-esteem and self-efficacy related to dyslexia. Such research could better prepare educators, social workers, mental health professionals, human service providers, and policymakers in helping children with dyslexia and understanding the impact of intergenerational dynamics.

Second, for some parents, the indifference they experienced from the public school system became so intolerable that they decided to enrol their children in specialist schools. These findings have important implications for both the public school system and specialist schools. Recently, in the US, there has been a grassroots movement led by concerned parents that has pushed for dyslexia-related legislation in the US (Rice & Gilson, 2022). These dyslexia laws are intended to assess children for dyslexia at earlier ages, provide dyslexia training for teachers, and implement evidenced-based reading intervention (Rice & Gilson, 2022). While parent voices have been heard by law makers, this dyslexia-related legislative movement has been met with frustration among some teachers regarding implementing the provisions (Worthy et al., 2018) and mixed results regarding early identification (Gearin et al., 2021).

Unfortunately, as currently implemented, the dyslexia law provisions are unlikely to create the culture of support desired by its advocates, as there is a pervasive lack of awareness of dyslexia in schools and particularly inadequate teacher training in public schools (Nevill & Forsey, 2023). To be certain, state-level dyslexia laws may be better informed by adopting models implemented in other countries. Countries such as Norway (Nakai, 2020) and Australia (Maxwell, 2019) have been inspired by “dyslexia friendly schools” (DFS) of the British Dyslexia Association (British Dyslexia Association, 2018), which are housed within the traditional school setting. Further policy discussions and research are necessary to decipher the degree to which the US dyslexia laws are having their intended outcome and whether components of DFS can be adopted.

8 | CONCLUSION

Our study responds to calls for a more intentional and rigorous assessment of the responses to the final comment question in three important ways (Decorte et al., 2019; LaDonna et al., 2018). First, the absence of response and comment length bias strengthened the representativeness of the themes derived in this study. Second, although we were unable to probe participants' responses, the narratives were personal, reflective, and in-depth, with moving emotional context, thus meeting the criteria for high quality narrative data in Web-based surveys. Third, although not reported in the study, many participants' final comment responses indicated that they were pleased that their perspectives were validated. These comments showed an overall positive appreciation of the study, which suggests that the topic was of deep relevance to the target population. The overall participatory approach selected for this study may have further motivated participants to answer the final comment question with intent. Researchers considering a Web-based survey for AWD are encouraged to develop means by which relationships and trust can be achieved.

In sum, the findings of this study call to attention a greater challenge at the broader societal level that embraces diversity, equity, and inclusion for people with dyslexia. Such an initiative can complement the recent national and global movement toward inclusion and equity among vulnerable groups. The role of professionals in the field of learning differences includes bringing the invisibility of dyslexia to light via more professional and public recognition (Nalavany et al., 2011) and addressing dyslexia as a social justice issue (Schelbe et al., 2021). We also encourage researchers to adopt participatory research methods that emphasize empowerment and give voice to vulnerable groups (Petrucci & Quinlan, 2007).

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The authors declared no potential conflicts of interests with respect to the authorship and/or publication of this article.

DATA AVAILABILITY STATEMENT

Data available on request due to privacy/ethical restrictions

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