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A Preliminary Study on the Challenges of Mothers Raising Children with Dyslexia in Pseudo-Single Parenting Families of Johor Bahru

Wong Sheau Tyan, Teoh Gaik Kin*, Serena In

School of Psychology and Social Sciences, Faculty of Business and Social Sciences, IMU University, 57000 Kuala Lumpur, Malaysia

*Corresponding author: GaikKinTeoh@imu.edu.my

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Abstract

The mental strain of the main caregivers (who are often the mothers) of children with special needs is well documented. However, the challenges of mothers who support a child with dyslexia when resources are scarce and the spouse's presence is intermittent are less understood. Particularly, pseudo-single parenting is increasing in Johor Bahru, Malaysia due to its proximity to neighbouring Singapore and the attraction of the Singaporean currency. This phenomenon refers to families in which one parent assumes the primary role of parenting and caregiving, in the physical absence of the spouse. To understand the experiences of mothers who are left behind, a qualitative study was conducted to explore their challenges. Two mothers volunteered to share their stories, despite the stigma and sensitivity of this subject matter. The themes that emerged from the findings of the study have shown that the mothers' emotional struggles are constantly confronted by the uncertainties in educational support and interventions; stigma due to cultural factors; low awareness and delayed intervention; the struggle of juggling multiple responsibilities; interruption in career progression and long waiting period to seek relevant expertise in the government hospitals. Although the findings have shed light on how the support system can perpetuate the struggles of these mothers, it cannot be generalized to all mothers. Particularly, variations among the mothers, according to educational levels, resources, geographical contexts, and cultural backgrounds, should be taken into consideration. Future research could further explore the experiences across various geographical locations in Malaysia to increase generalisability of the findings. The implication of this study has shown that support for families should be multipronged and multisystemic to address these struggles.

Keywords: Dyslexia, pseudo-single parenting, caregiver's burnout, support, dyslexia intervention, Malaysia

Abstrak

Ketegangan mental penjaga utama (selalunya ibu) yang mempunyai anak berkeperluan khas telah banyak didokumentasikan. Walau bagaimanapun, cabaran yang dihadapi oleh ibu yang menyokong anak dengan disleksia apabila sumber adalah terhad dan kehadiran pasangan tidak konsisten masih kurang difahami. Khususnya, keadaan keibubapaan pseudo-tunggal semakin meningkat di Johor Bahru, Malaysia disebabkan oleh kedudukannya yang bersempadan dengan Singapura dan tarikan mata wang Singapura. Fenomena ini merujuk kepada keluarga di mana salah seorang ibu bapa mengambil peranan utama dalam keibubapaan dan penjagaan anak-anak tanpa kehadiran fizikal pasangan. Untuk memahami pengalaman ibu yang ditinggalkan, satu kajian kualitatif telah dijalankan bagi meneroka cabaran mereka. Dua orang ibu secara sukarela berkongsi kisah mereka, meskipun topik ini sensitif dan seringkali berdepan stigma dalam masyarakat. Tema-tema yang dikenal pasti daripada penemuan kajian ini menunjukkan bahawa perjuangan emosi para ibu sentiasa berhadapan dengan ketidakpastian dalam sokongan dan intervensi pendidikan; stigma disebabkan oleh faktor budaya; tahap kesedaran yang rendah dan intervensi yang tertangguh; kesukaran mengimbangi pelbagai tanggungjawab; gangguan terhadap perkembangan kerjaya dan tempoh menunggu yang panjang untuk mendapatkan kepakaran yang relevan di hospital kerajaan. Walaupun penemuan kajian ini memberikan pencerahan terhadap bagaimana sistem sokongan sedia ada boleh mengekalkan perjuangan ibu-ibu ini, ia tidak boleh digeneralisasikan kepada semua ibu. Secara khususnya, variasi dalam kalangan ibu dalam tahap pendidikan, sumber, konteks geografi, dan latar belakang budaya wajar dipertimbangkan. Kajian pada masa hadapan boleh memperluas penerokaan ke lokasi-lokasi geografi lain di Malaysia bagi meningkatkan tahap kebolehgunaan umum hasil kajian ini. Implikasi kajian ini telah menunjukkan bahawa sokongan untuk keluarga perlu bersifat pelbagai pendekatan dan multisistemik bagi menangani perjuangan yang dihadapi.

Kata kunci: Disleksia, keibubapaan tunggal palsu, keletihan penjaga, sokongan, intervensi disleksia, Malaysia

1.0 INTRODUCTION

Dyslexia is a condition that affects literacy development throughout a person's lifespan (Kirby, 2020). Individuals with dyslexia often struggle with using words effectively (Delany, 2017). This can include difficulties with reading, writing, and spelling (Alias & Dahlan, 2015). It may also co-exist with oral language difficulties, working memory deficits, attention span issues, processing speed difficulty, poor motor coordination, and organization skills (Brimo et al., 2021; Alexander-Passe, 2015). The condition of dyslexia is further complicated when it manifests alongside other neuro-developmental problems, language disorders, dyscalculia, and nonverbal learning difficulties (Brimo et al., 2021b; Peterson & Pennington, 2015; Chien & Lee, 2013; (Russell et al., 2015).

Over the years, the origins and underlying causes of dyslexia remained debatable with diverse beliefs and findings (Al Lamki, 2012; Al-Shidhani & Arora, 2012; Protopapas, 2019; Vidyasagar & Pammer, 2010). More recent studies highlight that dyslexia is caused by multiple deficits (Brimo et al., 2021; Vidyasagar & Pammer, 2010). Children with dyslexia often struggle with socioemotional and behavioral problems as they face academic difficulty despite average or above average intellectual abilities (Al-Shidhani & Arora, 2012; Russell et al., 2015b; American Psychiatric Association, 2013). Limited understanding of dyslexia can lead to misinterpretation of behaviors, subjecting children to unnecessary disciplinary measures and even social exclusion (Abd Rauf et al., 2018; Al Lamki, 2012; Chan and Mo, 2021; Wilmot et al., 2022). Additionally, creating a universal theoretical framework, diagnostic tools, and training approaches for dyslexia continues to be a global challenge as research explores the multifaceted origins of this condition (Maunsell, 2020). According to UNESCO (n.d), after 145 years, the refinement and understanding of this "invisible disability" is a continuous effort.

Globally, dyslexia has a 5-15% prevalence among school-age children (Ramli et al., 2019). According to a 2006 statistic from the Department of Special Education, Ministry of Education Malaysia, around 314,000 students were reported to have dyslexia (Oga & Haron, 2012). By 2010, the registered cases had increased to 400,000, and it is expected to grow annually (Balakrishnan et al., 2017; Alias & Dahlan, 2015). In 2023, the estimated prevalence was 4-8% among school-going children (Abu Bakar, Ooi, & Che Pa, 2024). In Malaysia, diagnosing dyslexia involves lengthy processes with limited accessibility to standardized tests and comprehensive intervention (Ramli et al., 2019; Mohd Yuzaidey et al., 2018). Due to this, intervention programs often require further assessments, and the costs incurred raise barriers to accessing professional advice and assistance.

Language challenges often affect assessment accuracy and the effectiveness of educational plans (Oga & Haron, 2012). Private screenings have been associated with relatively high fees and sometimes face hesitation in acceptance from schools. Furthermore, imported or unverified programs dominate interventions, increasing uncertainties in supporting children with dyslexia and their families (Balakrishnan et al., 2017; Felizardo et al., 2016; Mohd Yuzaidey et al., 2018). Most mainstream schools have a scarcity of trained teachers and specialized teaching systems to address the unique learning needs of children with dyslexia, leaving significant gaps in personalised support (Suffiah & Cheng, 2022; Ramli et al., 2019). Although the Malaysian government has taken initiatives to support, identify and classify the learning challenges, there remain pertinent unresolved gaps in the system. As a result, targeted interventions are challenging to implement (Dzulkifli, 2023).

Given all these challenges, parenting a child with dyslexia can be particularly difficult. It often requires life adjustments that impact family roles and dynamics (Alias & Dahlan, 2015; Felizardo et al., 2016). In Johor Bahru, a district in southern Peninsular Malaysia, there are mothers who have found a way to adapt to this challenging situation while their partners are away due to work commitments. This creates new challenges for the parents as they undergo a process of role alteration (Hsu, 2018). Shouldering the responsibilities of caregiving for the child with special needs, while the spouse's presence is intermittent, can be traumatising for mothers (Delany, 2017). Schulte & Pabst (2021) found that sole-parenting often decreases work productivity and increases social, emotional, and psychological problems. Other studies show a rise in emotional exhaustion, leading to burnout, depression, and anxiety among this population (Greaves et al., 2017; Carotenuto et al., 2017).

Previous studies have shown that the mental health of the mothers of children with special needs is at stake (Bonifacci et al., 2013; Carotenuto et al., 2017; Greaves et al., 2017; Abd Hamid & Salleh, 2013; Huang et al., 2020; Russell et al., 2015). Besides, families with special needs children have a higher tendency to experience marital discord and career developmental issues, which can influence child development (Carotenuto et al., 2017). Meanwhile, this pseudo-single parenting phenomenon is closely tied to cross-border commuting and employment between Johor Bahru and Singapore. Data shows that approximately 300,000 Malaysians commute daily to Singapore and 400,000 Malaysians work or live there, driven by career development and financial opportunities (The Star, 2021). This phenomenon is unlikely to ease soon due to the favourable exchange rate and proximity.

Most studies on dyslexia in Malaysia focused on diagnosis, early identification and intervention strategies (Abd Rauf et al., 2020; Balakrishnan et al., 2017), yet the experiences and mental health of caregivers are still yet to be understood. Thus, understanding the perspectives and experiences of the mothers who take care of children with dyslexia and live in the context of pseudo-single parenting in Johor Bahru, holds significant social relevance. Particularly, the mental well-being of the caregivers is closely linked to children's development.

2.0 LITERATURE REVIEW

The challenges of the mothers who raise children with special needs were reviewed-and then framed into environmental, family relational, and personal challenges.

2.1 Environmental Challenges

In the school setting, often teachers are not equipped with relevant knowledge and skills to support children with dyslexia (Abd Rauf et al., 2020; Alias & Dahlan, 2015; Thwala et al., 2015). The issue is further exacerbated by the overall lack of teachers who are trained in special needs (Chan & Mo, 2021). Mothers have reported feeling disconnected from the schools (Washburn, 2014), as the children's behaviours are not properly managed (Alias & Dahlan, 2015; Chan & Mo, 2021; Woodcock, 2020). These can lead to delayed assessment and treatment (Abd Rauf et al., 2020).

Furthermore, the classroom environment and educational tools are usually unsuitable for children with dyslexia (Abd Rauf et. al., 2020). Suitable interventions are also constricted by schools' limited resources (Abd Rauf et al., 2020; Alias et al., 2015; Brock & Shute, 2001; Senarath, 2021). Despite parents putting in extra effort to communicate with school personnel or explore alternative options, they often feel powerless and intimidated by school authorities (Chan & Mo, 2021; Poon-McBrayer & McBrayer, 2014). Parents would also have to spend extra money to obtain support from private clinicians (Alias et al., 2015; Brock & Shute, 2001; Woodcock, 2020). The financial burden associated with interventions is compounded when support from banks and insurance companies is scarce (Abd Rauf et al., 2020; Alias et al., 2015).

In the healthcare system, there has been a lack of consensus among professional authorities on treatment protocols, thus leaving those who are affected by dyslexia feeling lost and confused. Particularly, as dyslexia is a literacy-related disability, some clinicians are hesitant or conservative in giving the diagnosis to young children as they think it is too early for identification, which leads to the child receiving a different diagnosis instead (Woodcock, 2020).

Low public awareness heightens parents' struggles as they attempt to understand dyslexia and find evidence-based therapies (Thwala et al., 2015; Abd Rauf et al., 2020; Chan and Mo, 2021; Maunsell, 2020). Particularly, general acceptance from society and accessible social support are minimal (Abd Rauf et al., 2018; Alias & Dahlan, 2015; Brock & Shute, 2009; Oga & Haron, 2012; Woodcock, 2020). The issue can be further stigmatised by cultural factors. According to Alias et. al. (2015), in some Malay families, the decision-making power of the mothers depends on the opinions and perceptions of the elderly. On the other hand, in Chinese culture, sharing the shame of one's family is highly discouraged. Due to this, many mothers tend to keep their children's developmental problems a secret, as it is considered a shame for the family. With limited understanding within the community, people around the family often offer unsolicited suggestions and comments that are irrelevant to the family's situation. As a result, parents often feel frustrated and, at times, helpless (Bull, 2003).

2.2 Family Relational Challenges

Family tension would tend to arise when the behaviours of children with dyslexia become noticeable. Main caregivers' observations are even considered as overreacting. Due to a lack of knowledge, delaying professional advice and support is common (Alias et. al., 2015; Woodcock, 2020). This is even more challenging when the child's performance is inconsistent and physical signs of their symptoms are ambiguous (Carotenuto et al., 2017; Woodcock, 2020).

Due to limited support, knowledge and rampant cultural stigma, the experience of mothers and parental-child relations could become less satisfying (Bonifacci et al., 2013; Senarath, 2021; Carotenuto et al., 2017; Multhauf et al., 2016; Brock & Shute, 2009). Furthermore, mothers may neglect their relationships with their spouse or other children while focusing on the child with dyslexia (Thwala et al., 2015). Sibling rivalry is often observed when the other children in the family do not receive equal attention, and yet they are expected to show understanding (Al Lamki, 2012; Brock & Shute, 2009). Mothers tend to become emotionally overinvolved and may exhibit hostility toward their children (Abd Rauf et al., 2020).

The relationship with the spouse can deteriorate further when they hold differing views on parenting, particularly when cultural expectations for mothers to be capable of managing everything within the household single-handedly are imposed upon them (Brock & Shute, 2019; Chan & Mo, 2021). This leads to the pressure of juggling multiple roles and responsibilities, in which mothers are often bearing the burden without realizing the costs on their mental health (Chan & Mo, 2021).

Financial burden is unavoidable when families have children who require special care (Woodcock, 2020; Thwala et al., 2015; Alias & Dahlan, 2015; Griffiths et al., 2004). Woodcock (2020) further argued that the expenses might go beyond affordability. In other words, the financial burden has a direct bearing on the overall family tension.

2.2 Personal Challenges

While juggling with various demands of taking care of children who have special needs, parents' career development, and personal times for rest and recreation are often negatively affected (Alias & Dahlan, 2015; Chan & Mo, 2021; Multhauf et al., 2016; Thwala et al., 2015; Scherer et al., 2019; Senarath, 2021). Besides navigating multiple responsibilities, mothers also experience subtle emotional burdens that are often less understood by those around them. For instance, grieving for the loss of a "perfect child" when their child receives a diagnosis (Thwala et al., 2015), these mothers may be confused as to why this happened to them. They may even feel responsible for the child's condition and thus dive into the self-blame spiral (Senarath, 2021; Poon-McBrayer & McBrayer, 2014). They blame themselves for not identifying the signs earlier so that early intervention can be received (Abdullah @ Mohd. Nor & Johan, 2019; Alias et al., 2015). Their physical health is also affected due to insufficient rest. They were found to experience excessive fatigue and stress (Senarath, 2021). Their life patterns change drastically when the children are diagnosed with a disability (Griffiths et al., 2004). Self-blame, sense of loss, guilt, exhaustion, sense of inadequacy and loneliness are the common emotions mothers often have to bear silently.

In short, when families have children with special needs, the impact is far-reaching and has many implications. Although the burden of mothers is well documented, past studies have also shed light on how they adapt to the situation as the mothers journey through the high demands of caregiving to the children who require special care.

3.0 METHODOLOGY

This qualitative study aimed to explore and understand the experiences of mothers raising a child with dyslexia while their spouse is not physically present due to work commitments. It focuses on understanding the participants' world and the meanings they ascribe to a human problem and experience, whether individually or as a group (Creswell, 2020, p. 32). The inclusion criteria for the participants:

1. Mothers who are currently living in Johor Bahru, Malaysia.
2. Have at least one child who is diagnosed with Dyslexia by a Malaysian government hospital-based child psychiatrist or clinical psychologist based in a private centre.
3. Have a child with dyslexia between the ages of 2-18 years, who is currently receiving education in play school, kindergarten, primary school, secondary school or other special education learning centers.
4. Wives whose husbands are physically working in Singapore at least 5 days per week.

3.1 Procedure for Data Collection

Data was collected through qualitative in-depth exploration of participants' personal experiences. Johor Bahru was selected as the target location for recruitment due to the pseudo-single parenting phenomenon happening frequently for fathers who would cross over the international border to the neighbouring country, Singapore, for better work opportunities. Firstly, adopting purposive sampling, the researcher surveyed and contacted some of the special education centres, early childhood centres, psychiatrists and child therapists in Johor Bahru. Recruitment advertisements were posted on several mothers' groups and special needs groups on Facebook as well. Mothers who are interested in participating were required to fill out an online Google Form. The Google Form included multiple-choice and open-ended questions designed to gather essential background details to confirm the suitability of the participants. The demographic data collected were name, age, race, contact number, preferred language, employment status, physical and medical condition, current address- state and city, emergency contact person and number, significant others in the family, number of children, number of children diagnosed with dyslexia and any coexisting conditions, partner's location and reason for not staying at home for at least 5 days per week, frequency of partner's return home, and total household income per month. The household income category was set based on the Household Income and Basic Amenities Survey Report 2019 by the Department of Statistics, Malaysia (Ministry of Economy, 2020). These data points provided a comprehensive understanding of the participants' context, in which each mother's story is embedded, and the factors contributing to their experiences raising a child with dyslexia. For example, socioeconomic circumstances may impact access to resources, caregiver stress levels, and stigma (De Leeuw et al., 2024). Comorbid conditions were included as dyslexia often coexists with other disorders and often adds a layer of complexity to the challenges faced by both the child and the mother (Stephenson et al., 2024).

A screening process was conducted prior to the commencement of the data collection to ensure that the self-volunteered participants fulfilled all four inclusion criteria. The researcher contacted the registered mothers to thank them for giving attention to the research. Possible risks and confidentiality issues were explained and discussed, too. Participants were informed that they had the right to withdraw from the project at any time without needing to provide any explanation or fear any repercussions.

Both the interviewer and interviewee signed the informed consent form before the interview. Participants were reminded of the safety measurements that are available if they experienced triggers and either the interviewer or the interviewee themselves felt the need to seek help from a mental health professional, throughout their participation in the study. The participants were involved in 1.5- to 2.5-hour individual in-depth semi-structured interview sessions. The participants were invited to attend a subsequent follow-up meeting for clarification and further exploration of the necessary aspects for a better understanding of what had been shared during the interview session to collect information that would enhance the meaning or quality of the research result. Data collected through WhatsApp from the participants after the interview session were included in the results as well, with the consent of the participants. They were assured that the interview recording would only be accessible to the research team, for transcription purposes and any identifying data in the transcription would be replaced by a symbol or random letter before passing or showing to another member for cross-checking or translation.

Being mindful that the sharing of their experiences of raising kids with dyslexia could have been overwhelming, the researcher discussed and shared community resources with the mothers as part of the research debriefing process.

3.2 Formulating Interview Questions

Before setting the interview questions, the researchers referred to relevant literature (Hsu et al., 2021; Ramli et al., 2019) and listed out possible relevant areas for exploration in this underexplored topic. The final set of interview questions was then discussed with the research supervisor and refined further, based on the relevancy and neutrality of the questions, while ruling out possible personal bias which might affect how the interview questions were set and how it might affect the facilitation of the interview session (E.g. How did you come to learn about dyslexia? Do you still remember the experience of taking your child for an assessment?). The interview questions deck was tested a few times with peers through role-play to make sure that the aspects explored and the dialogue flow stayed on track. After that, the researcher translated the interview questions into Chinese, Malay, and Tamil versions, in preparation for an interview with any of the Malaysian multiethnic community members. The translated interview questions were also cross-checked by another peer. The interview question sheet was sent to the participants a day before the interview so that the participants were more prepared on what to expect and had the option of preparing what to share beforehand. This is to promote autonomy of the participants and respect their decision in deciding the content and the extent of their self-disclosure on the topic.

3.3 Data Analysis

The present study adopted Braun and Clarke's (2013) six-step thematic analysis approach in the recommended order to identify the relevant themes. Upon completion of the interview sessions, which were audio-recorded with participants' consent, the researchers listened to the recordings while transcribing the interviews. After that, the researcher read and reread the interview transcripts several times. The initial codes were identified, followed by emergent themes that were derived from the transcripts, observation notes and initial patterns were organised and arranged into clusters. A summary table was prepared to match the cluster labels together with their subordinate theme labels, with the quotations and references to where the relevant excerpts may be found in the transcript. The emergent themes were cross-checked with peers, the research supervisor and another third-party member checking and finalised only upon mutual agreement.

It is noteworthy that personal biases of the researcher would be inevitable, as she has about a decade's working experience with children who have dyslexia. As such, measures were taken to ensure the trustworthiness of the data by remaining open to personal biases and blind spots during research supervision instead of denying their presence, being wary of personal emotional reactions towards the support system and keeping triggered feelings in check.

4.0 RESULTS

Despite various efforts and attempts for active participant recruitment over four months, only two mothers eventually agreed to participate in the study. The research team observed that this could have been due to fear and stigma prevailed in some mothers' willingness to participate in the interview. The in-depth interviews were conducted virtually, at the convenience of the mothers. Table 1 summarizes the demographics of the mothers who participated in the interview sessions. To protect their privacy and ensure anonymity, R1 and R2 were assigned to represent the mothers, as shown in Table 1. ￼

The two mothers who volunteered to participate were aged 40-50 years, residing in Johor Bahru, Malaysia, and each has at least one child formally diagnosed with dyslexia. Both mothers were employed and belonged to the M40 socioeconomic category of household income families. Each participant participated in two interviews.

Table 1 Participants Demographic Data

R1	R2
Age range: 40-50 years old	
Household income: RM4,851-RM10,970 (M40)	
Spoken languages: Mandarin & English	
Religion: Christian	
3 children (Ages 12, 8, 6)	3 children (Ages 22, 18, 14)
Employed (PT) + Self-employed	Employed (FT)
Husband's availability: Weekends with exception	Husband's Availability: Weekday Nights + Weekends
Spouses were not at home for 2 years (During the COVID-19 pandemic)	

4.1 Findings based on the Mothers' Experiences

The challenges of the mothers will be presented in the findings. Figure 1 depicts the summary of the findings. Three themes emerged from the challenging experiences of the mothers, which are anchored at the environmental, familial, and personal levels. The interview excerpts were translated from Mandarin to English and back-translated from English to Mandarin. The excerpts were tidied up for the sake of readability and clarity.

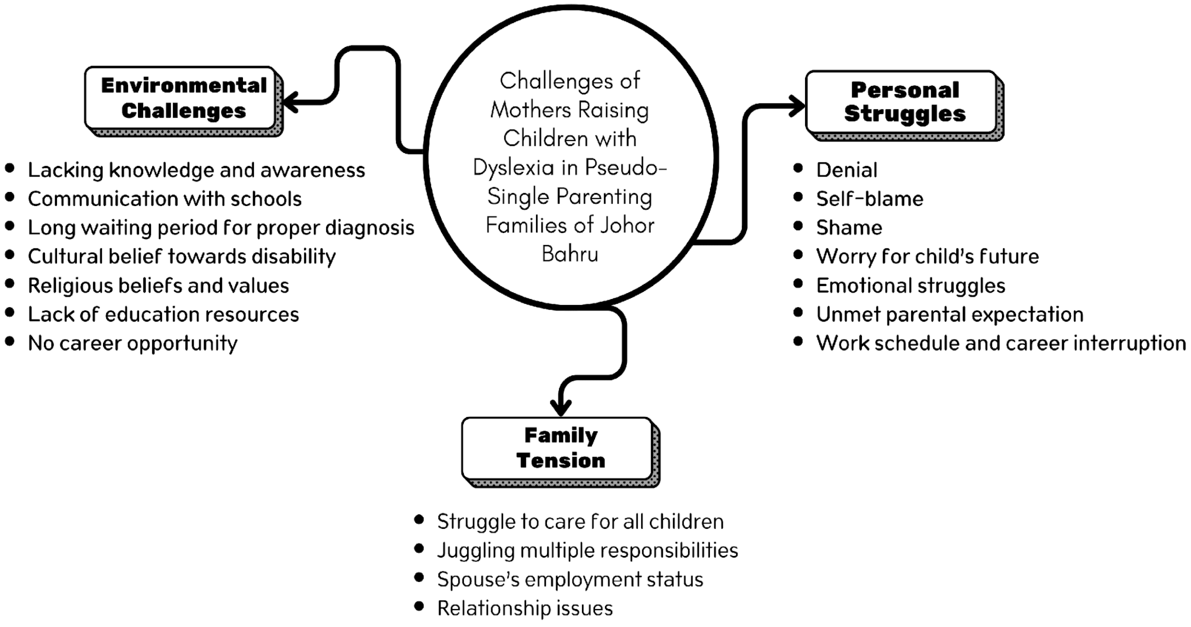

Figure 1 Challenges of the Mothers at Different Levels

4.1 Findings based on the Mothers' Experiences

4.1.1 Environmental Challenges

a. Lacking Knowledge and Awareness - Teachers in the school were found to show a lack of understanding of dyslexia and are not equipped to support children with dyslexia in class.

"Teachers do not have that kind of knowledge about children's lacking, so many of them do not understand. If I transfer him out (from the current school), we may face the same problem. That's it… For example, what the English teacher said about my son, eyes floating around, eyes not focusing… I keep telling her, she still cannot understand, she still punishes him every time! It's the same!" (R1)

Another mother also shared her experience in communicating with the teachers that they often have a misperception on dyslexia and hence not able to understand the child's needs:

"The school teachers have a very very fixed mindset, very very strong fixed mindset. When they see a child like that, they will tell you, there's nothing wrong with him, he is just lazy, let him go for tuition and he will be okay. I don't talk to the teacher every time I go to the school, I scold the teacher. I am very frustrated with school teachers." (R2)

According to the mother, some teachers suggested strict and stern teaching strategies that mothers could not relate to:

"I will communicate more with the form teacher. She told me that if a child needs to be trained, he needs to be whipped. This is her philosophy… I told her, "I have tried and there is no effect." (R1)

Misdiagnosis is also a possibility as not every clinician is familiar with different types of learning difficulties. Therefore, the signs of dyslexia are easily overlooked due to a lack of professional knowledge.

"I went to the clinic and told the doctor my child has a problem. Initially, the doctor diagnosed him as a slow learner, but I said he is not a slow learner because a slow learner can still pick up a lot of things. His problems are memory, recognition, concentration, and struggle with direction. He struggles with reading, writing, and comprehension, so these are all not signs of a slow learner, so I insisted that the doctor refer me to the hospital." (R2)

Lack of knowledge and awareness in the public domain and in the professional training for healthcare providers and teachers can delay the process to seek diagnosis and implement the needed support.

b. Communication with Schools - A mother also disclosed feeling frustrated when the school did not give them feedback, even as they noticed the child was struggling to keep up with academic expectations. It appears the school personnel had no idea that the student's condition needed special attention. It inevitably caused delays in identification and treatment.

"Before I brought him to the small clinic, I went back to his preschool to look for his teacher. I checked with his teacher, as he was at kindergarten for 2 years. His exams were all 100%, so he did not have problems in kindergarten. But why does he face a lot of problems when he goes to standard 1? Then, when I went back to find out the reason. Do you know what the teacher told me? All the things that he did, he did with teachers' help… I was very shocked! 2 years! When she had a meeting with me, she did not even mention any problem. Any problem! Did not mention it! So, I took 1.5 years to find out what the problem is." (R2)

c. *Long Waiting Period for Proper Diagnosis* - The issue of seeking diagnosis can be exacerbated by the long waiting queue at government hospitals. The mother also mentioned the waiting time after the doctor from the general clinic referred her son to see the psychologist doctor in the government hospital:

"I insist that the doctor put me in the hospital. Then, the next step was, I went to the children's pakar (English means "expert"). It took 3-6 months [to get the diagnosis]." (R2)

***d. Cultural Beliefs towards Disability* -** How disability is perceived in the local culture could have an impact on mothers' seeking help behaviour. A mother shared her experiences below:

"Especially in our Chinese culture, many parents do not want to face the fact that their kids have such a problem. Then people tend to gesticulate, due to that, parents also tend to conceal their children's problems, which is not encouraged." (R2)

e. Religious Belief and Values

"My siblings like to label me, saying that, I must have done a lot of bad things in my previous life, so this life, I have this special son to crack your head." (R2)

These cultural and religious beliefs may further perpetuate the shame mothers have been experiencing because they are not easily verifiable as well.

f. *Lack of Education Resources* - Most of the tutoring centres only cater to children who do not have dyslexia. It creates difficulty for mothers when they are looking for extra support to help their child with academic learning:

"Like I want my child to take the exam for Form 5, it is impossible for him to do self-study, so I went to the tuition centres to find a teacher, here and there, no one wants to take him. So, he is not like other children, like Form 5 students, they want to go for tuition, many centres want to take them, but not for special children (heavy). This is the problem that we have. They can succeed, they can learn, but no place is willing to accept them, no teachers are willing to teach them." (R2)

Another mother has a similar experience when looking for a tutor who understands Dyslexia to support the child's learning. The mother expressed feeling hurt when her son was punished by teachers:

"She hit my second child, I was listening outside and it really hurts my heart… It's hard to find a teacher who is willing to teach, and I myself do not know how to teach." (R1)

g. No Career Opportunity - One of the mothers expressed concern for her child's career opportunity in the future.

"Yes, feeling hopeless. Even many educated parents face the same problems, which school should their children go to. They are already grown-ups. Why doesn't our government create opportunities for them to progress, let them develop? Like my child, he is 18 years old. I am frustrated that why he can't go to college. Why can't he have the opportunity to go into society like normal people? How to link them to society, how to make them plan for their dream, which I placed a lot of trust in. Even if my child studied in a special education class, the government should assist them so they can obtain a certificate for the future. They can use it as an official document for them to enter the workforce, but in the end, after graduating, there is nothing! NOTHING (exclaimed) that the school gave the proof that he has the knowledge. You can imagine how frustrated the parents are." (R2)

4.1.2 Family Tension

a. Struggles to care for all children - Mothers with more than one child at home need extra effort and attention to ensure all children are cared for. Sometimes, mothers might not be able to focus on the child with dyslexia only:

"The youngest one [without Dyslexia] is affected. He is willing to do homework. I let them do their homework. The second one (with Dyslexia) kept running and hiding, but I did not chase him back, because I was taking care of one child.already… I want to focus on the young one. If I walked away, he would start playing, and in the end, both did not get to complete the work. So, I was thinking of getting his [homework] done first. (R1)

When the mother reinforces good behaviours by praising one of her children, the other child might get upset. Mothers tend to blame themselves for not being able to attend to the needs of all children.

"The youngest one, he folded his clothes and tidied up his bag by himself that day. I just thought that it's good behaviour and I told my second child. But then the second child went to beat him, you know. Why so? … Then I wondered, did I use the wrong method?" (R1)

b. Juggling Multiple Responsibilities - Both mothers shared how their daily life is occupied with different responsibilities while raising a child with dyslexia, and their husbands were away from home working in Singapore. It may cause physical, mental, and emotional tiredness:

"Mom still has to work! You have to discipline the children. You need to educate them. You still need to be the breadwinner. You will be schizophrenic…" (R1)

c. Spouse's Employment Status - The husbands' unpleasant experiences at the workplace and their career development can be another factor of concern, particularly so when the husband is the main breadwinner of the family. A mother's concern was expressed below:

"I see that he is also working very hard in the company. He is 47 years old, others are 20, 30 years old. All who are younger than him are his bosses, so he will be very stressed, because people will look down on him. He told me that day. So, when I heard him say this, I was puzzled again. I was afraid that he would tender his resignation letter again, and I would work alone if he resigned." (R1)

d. *Relationship issues* - These mothers are often the academic tutors at home and have to go through challenging homework situations with the child. This could lead to conflicts whenever the child displays aggressive behaviours, and further affect the parent-child relationship:

"Why did God give me such a bad child!' Um, I will scold him like this. Then, one night, he told me, 'Mum, you have been telling me this since I was in Year 3. In fact, I started to understand recently, I did not understand it before.' He told me this, crying while talking… Then he said, 'Don't say it anymore, I don't want to hear it anymore. You keep telling me that I am a slow learner, I know, I already know.' He got mad that night and ran downstairs." (R1)

Besides, there might be conflicts between the parents when they have different views and expectations toward the child's learning progress:

"I prefer to educate my child without [my husband]. I will choose the time when he is working, then I will send my child to those centres where he needs to learn. Because he will nag when the child cannot. Just like learning piano, he thought that it is easy for the child to play Canon, the famous song. When the child played for him in the C key, he said, 'This is not the original one.' So, he has higher expectations, which I do not really agree with, so we will always quarrel." (R2)

The lack of understanding of dyslexia among neighbours, friends, and relatives has an impact on their interaction with the child and how they perceive the parents or family of a special needs child. Some comments that they make can hurt both the child and the parents. There might be relationships that the mother or the parents would rather avoid out of the intention to protect the child. It is viewed as a necessary action:

"Actually, I have left my siblings for more than 10 years. I just do not want them to hurt [my child]. Because it is very difficult to build his self-confidence, but it is very easy to destroy his confidence. So anyone who has [negative] impact on him, whether it's me or my husband, we will try to avoid it." (R2)

Whenever the child with dyslexia displays behaviours that are different from others, they would then be teased by others. For example, the child with Dyslexia was trying to learn to cycle and he was teased:

"[My child with Dyslexia] placed one foot on the pedal, so he dared not sit on that saddle. Every evening he does this kind of movement. All my neighbours' kids who come out for cycling would tease him when they passed by." (R2)

Relational tensions with various parties are real to the mothers and the child with dyslexia. Increased public awareness on dyslexia is not only needed, but skills to manage differences, societal expectations, and even public ridicule are needed in family and social relationships.

4.1.3 Personal Struggles

a. Denial - After receiving the diagnosis, mothers dipped into emotional struggles, which might hinder them from seeking support.

"Still do not, do not really know, maybe should say could not accept it! Do not feel like wanting to understand further. Although… I should [seek further help]." (R1)

b. Self-blame - Mothers tend to blame themselves for not recognising the condition earlier:

"We regret that we did not catch it sooner, and is it going to hurt him?" (R2)

"Well, I will blame myself. Arh, if it had been earlier, maybe now… it might be the same, but it might be better, yes?" (R1)

c. Shame - Mothers also felt shameful about their child's condition. Mother disclosed feeling stressed about sending their child(ren) with dyslexia to social events or enrichment classes, as they might not behave in a way that others expected them to, and that would make her feel embarrassed:

"Yes, at first, I did feel shameful, I blamed myself, why I have this type of son." (R2)

"Even if it won't cause trouble to others, I will tell my children strictly, 'Do not embarrass me!' They have always been scolded by others, and then I will have to say 'sorry, sorry, teacher', I felt… er… ha-ha… It's embarrassing! No one ever tells me my child is excellent." (R1)

d. Worry for child's future - Their child's future development appeared to be one of the major concerns of the mothers towards their children:

"As parents, we could not see their future. Yes, I do not know how he can make a living." (R2)

"I went to the special needs centre, the teachers feel that this condition is very common, very common. This is a very small matter, but to me it is a big matter… It is very hard to plan ahead. With this condition, you do not know which high school he can attend, and do not know where to go... Sigh…" (R1)

e. Emotional struggle - The mothers tended to feel emotionally overwhelmed with their child's diagnosis, as it often led them to think about the child's possible future, which seemed to be uncertain:

"I get emotional sometimes, my teaching principle is 'emotional' (laugh), emotional venting. I feel that I am venting my emotions, I will say things like 'Why do you know nothing? (laugh) What are you going to do?' There was one time, he sat for an exam and he got zero. Wow, I kept crying…. I couldn't help it, I was like 'what to do, what to do, this is happening now'." (R1)

f. Unmet Parental Expectation - A mother shared that she found it hard to adjust her expectations, which could be due to her past experiences and her aspirations for her children:

"[When I was] at school, I was very envious of those who could go on stage and win awards, so I hope my children can do this. So, I think my child should master English well when they are young, then they can end up in Singapore, Australia, or the UK. My heart still hopes for this."
"When he was younger, he wrote his ambition right… He said he wanted to be a doctor. So, I set my mind on him being a doctor. Yes, but he is not, he was not made to be a doctor… I hope he can be a professional." (R1)

g. Work schedule and Career Interruption - When mothers volunteered or were designated to take up the role of primary caregiver, they chose to give up their job or intentionally adjust their work schedule to better support the child:

"Gave up. I gave up (my job) for 9 years already. My child got diagnosed at 9 years old, I resigned the moment I received the report." (R2)

A mother also disclosed how taking care of the child with dyslexia affected her work schedule:

"I took a week off and did [homework] with him. I said, let's do it together" (R1)

The mothers' emotional experiences also took a toll on their personal development as a person, especially when help and support were not easily available or accessible.

In summary, environmental, familial, and personal factors can become significant sources of struggles, particularly when support is direly needed.

5.0 DISCUSSION

The findings have confirmed previous studies that challenges of the mothers can stem from environmental impacts such as lack of knowledge and awareness among teachers and health professionals (Ramli et al., 2019; Suffiah & Cheng, 2022; Woodcock, 2020); cultural stigma and the difficulties to recognise the symptoms and subsequently, getting appropriate interventions (Dzulkifli, 2023; Hart, n. d.). Due to this, delayed intervention is rampant. The results also confirmed that family stresses can be triggered by financial strain, disagreement between husband and wife, sibling rivalry, and multiple responsibilities. These can take a toll on the physical, psychological, and emotional development of the mothers (Greaves et al., 2017; Carotenuto et al., 2017).

This study confirmed the importance of religious faith (Senarath, 2021; Alias et al., 2015), familial support and community resources (Griffiths et al., 2004), which helped the mothers to stay positive. These findings are in alignment with Bronfenbrenner's (2005) theory of ecological development, children with dyslexia would need ample support at the various levels of ecosystems - microsystem (interactions and interpersonal relationships with parents, teachers), mesosystem (environment), exosystem (formal institutions) and eventually the macrosystem (society, traditions) - to predict optimal outcomes when the child eventually grows into a young adult (Hassan, 2023).

This study also highlighted how cultural belief plays a role (Chan & Mo, 2021) in hindering the help-seeking process, particularly mothers' feelings of shame and self-blame can be amplified by the inherent cultural expectation. Meanwhile, the behaviours of children with dyslexia are often not attributed as symptoms of delayed development, but as bad children. It is common that when something goes wrong, the attribution of the issue is often based on the person's qualities. This can deter the development of the children as well as the parents' decision to seek help.

Besides, in Chinese culture, parents' happiness is often based on the achievements of their children. Making parents feel proud is an important cultural value. Thus, when the children have special needs that hinder their abilities, the parents' sense of loss reigns (Thwala et al., 2015). The grief process might be compounded by a lack of knowledge and support. This might negatively affect the mental health of the parents and the children if appropriate intervention is not put in place. In other words, heightened awareness and knowledge are pivotal to help parents to have the right mentality so that the children's developmental issues can be addressed.

In other words, this study has underscored the significance of inherent cultural factors that could perpetuate the struggles of mothers, especially in the context when the resources are scarce. Fathers' involvement should be promoted. Nevertheless, to reinforce the cultural value of attributing the quality of children based on academic achievement should be critically re-evaluated.

6.0 CONCLUSION

Raising children with dyslexia in pseudo-single families has been challenging and occasionally isolating. As such, it is recommended that the government and various private entities in society work together to forge more effective partnerships in identifying those in need, to be able to accurately assess, diagnose and subsequently treat these children in a timely manner. Additional support structures need to be in place to better support parents who deal with the daily struggles of raising a child with special needs in the mainstream neurotypical society. Support groups for mothers who are facing burnout, feeling alone, and too overwhelmed to cope would also help in their journey of caring, especially if they learn that they are not alone in this journey. It is crucial that the above lead to the development and implementation of guidelines and treatment protocols so that more essential training on the ground can be developed to effectively help teachers, schools, and clinicians have a unified and systematic approach in supporting children with dyslexia and their families. This study has underscored the significant impact of cultural factors on the help-seeking process. Education and help-seeking are crucial to reducing the stigma in society. Though the mothers' sharing has shed light on the challenges in raising children with dyslexia, the findings cannot be generalized to all mothers who have children with dyslexia, as variations in geographical contexts, resources, and educational level need to be accounted for. Future research could further explore mothers' similar experiences across various geographical locations in Malaysia to increase understanding of the variations as well as the uniqueness of mothers' experiences.

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Conflicts of Interest

The author(s) declare(s) that there is no conflict of interest regarding the publication of this paper

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