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Stigma and Mental Health Challenges of Caregivers of Children with Dyslexia

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Abstract

The prevalence of dyslexia cases has been increasing worldwide. Issues related to dyslexia have led to a more complex role and experience of caregivers in taking care of their children with dyslexia as compared to caregivers with normal children. Caregivers of children with dyslexia are often reported to have higher stress in parenting compared to parents with normal children. This study explored stigma and mental health challenges of caregivers of children with dyslexia. A small homogenous sample of six caregivers participated in an individual one-off, semi-structured interview. The thematic analysis identified the challenges faced by the caregivers of children with dyslexia, which are the aspects of stigma and mental health. Stigma has been extracted into two themes, which are lack of knowledge and judgement. While mental health challenges can also be categorized into two themes; distressful role and negative emotions. This study highlights that most of the caregivers experienced stigma and expressed psychological challenges in parenting a child with dyslexia. Future research, therefore, could expand these findings across wider demographic samples to further validate these findings and inform the development of relevant support services to assist caregivers in the long difficult journey of parenting a child with dyslexia in Malaysia.

Keywords: Dyslexia, Parenting, Stigma, Psychosocial Support, Mental Health Challenges

Introduction

Children with dyslexia can be described as children who have a specific learning disability. Specific learning difficulties or disabilities (SLD) refers to a group of mental disorders characterized by difficulties in learning basic academic skills that are not consistent with the person’s chronological age, educational opportunities or intellectual abilities. Dyslexia is a learning difficulty that primarily affects the skills involved in accurate and fluent word reading, spelling and writing skills. The word dyslexia are derived from the Greek word ‘dys’ meaning difficult while ‘lexis’ meaning words or language. Globally, it is estimated that one out of 10 people suffer from dyslexia, which is a condition where a person has difficulty reading, has a prevalence of 5-17%, worldwide. The child has problems mastering school tasks despite putting in good effort, having normal intelligence and adequate stimulation or learning instruction.

Worldwide statistics emphasise that one in ten people will have dyslexia. Expanding this on a much larger scale, in a world of approximately 7.8 billion people roughly at least 780 million could be dyslexic and it can occur in people of all backgrounds. The number of children with dyslexia is estimated to be continuously increased in Malaysia. In Malaysia, according to the latest statistics from the Education Ministry’s Special Education database, about 314,000 or 17% of students enrolled in primary schools in 2020 were dyslexic. Of those placed in special education for a learning disability, around 80% associated with dyslexia. There are groups support and association for individuals with learning disabilities, especially dyslexia, since 1995. *Persatuan Dyslexia Malaysia (PDM)* one of the earliest associations that promote a general awareness and understanding of the problems and needs of children and others with specific learning disabilities and to assist them to obtain specialized diagnosis and treatment according to their disabilities.

Despite a lot of support system for dyslexic children, there are still lack of understanding and support system for their caregiver. Raising children with dyslexia poses various challenges to caregivers especially parents, as a primary caregiver. Having dyslexic children to be taken care may give dramatic life experiences compared to caregivers who take care for normal children. They may face more challenges tasks and they have to be prepared mentally and physically to cope with those challenges (Bonifacci et al., 2019). Many research on dyslexia has generally focused more on the children with dyslexia, thereby paying less attention to the caregivers of children with dyslexia, and most of the existing research on dyslexia has tended to focus on supporting the children.

Failure of coping with all the challenges and lack of support system not only affects the caregiver’ life, but also to their dyslexic children. In addition, learning disability stigma is commonly held negative beliefs about people with learning disabilities, dyslexia are also no exception. Dyslexic children often labelled as lazy, stupid, and problematic. Some of parents often may feel shame and guilt to have a child with dyslexia. The 'stigma' makes things even more difficult for children and caregivers in coping with their difficulty. Social isolation and psychological distress can be further exacerbated by stigma, exclusion, and inequitable policies (Maridal et al., 2021).

Because there is relatively insufficient literature regarding the issues on life experiences and stigma of caregivers who have children with dyslexia. Recognizing its significance, this study intends to provide information not only to have deeper understanding about caregiver’s life experiences on stigma and psychosocial support, but also to explore the complex interplay between these experiences and mental health status that caregivers of dyslexic children faced. The resources, family support, and overall functioning of the family are important factors for achieving a satisfying life for children with disabilities (Maridal et al., 2021). Therefore, this study aims to explore the stigma that are being experienced by caregivers and their mental health challenges in raising children with dyslexia. By exploring these issues, we can empower caregiver of children with dyslexia to overcome their obstacles and provide them with comprehensive support system and appropriate interventions.

Literature Review

Caregivers of children with dyslexia often face a multitude of challenges in their caregiving role. We used to say that caregivers of children with dyslexia must have a clear plan and knowledge of these children's needs, but have we ever understand the hard work of this caregivers in meeting those needs, especially in terms of psychosocial support and the stigma they faced that eventually affecting their mental health. While the academic and educational difficulties of dyslexic children have been extensively studied, there is a notable gap in understanding the psychosocial support, the stigma experienced by caregivers, and the it's impact on the mental health of the caregivers. This knowledge gap and lack of understanding raises concerns about the well-being of caregivers and their ability to provide effective support for their children with dyslexia.

Mental Health Challenges

Dyslexia represents significant challenges not just for the children but can also be traumatic for their parents or caregivers. Psychological stress reactions following a diagnosis of childhood learning disability involve the risk of long-term psychological impact for caregivers and families because dyslexic child needs special attention (Bonifacci et al., 2019). Caregivers with dyslexic children show increased levels of emotional difficulties than non-dyslexic. Caregiver stress is a strong predictor and can be a mediator of caregivers' psychological well-being. There are cumulative evidence suggests that caregivers of children with dyslexia may be at elevated risk of experiencing parenting stress and distress such as isolation and unhappiness in the parenting role and risk for mental health concerns such as anxiety (Brehaut, 2011).

Caregivers of children with learning disabilities have been shown to experience increased stress and greater negative caregiving consequences than those with typically developing children (Isa et al., 2017). It is very important that the emotional environment of dyslexic children is good and positive, especially from caregivers because these children need the best support from the closest people. Ongoing chronic stress can lead to negative parenting practices and adversely affect the parent–child relationships and outcomes (Delany, 2017).

Psychosocial Support

Psychosocial support in caregiving is vital to all caregivers especially to those having neurodevelopmental disability children. Children with this disorder might often manifest disturbing behaviours such as agitation and temper tantrums, and these disturbances significantly interfere with their activities of daily living, as well as to caregivers. Many caregivers of children with special needs say they feel so much stress because they are their child's manager, tutor, supporter, motivator and all wrapped into one. With all of the other demands of work and other commitments, these roles can be overwhelming. How effective children receive an intervention they need largely depends on their caregiver.

Therefore, good knowledge and awareness about dyslexia accompanied by a goodsupport system from surrounding including health, financial, and educational system may provide a positive impact on the caregivers in raising these children (Chien & Lee , 2013). For example, dyslexic children need treatment and continuous therapy that may require high costs especially by private therapy centers. Smythe et al. (2003) suggested that educational or clinical treatment of SLD without considering familial contexts and needs significantly reduces the chances of successful intervention outcomes.

Stigma

Stigma is commonly experienced by caregivers of patients with learning difficulty around the world, including Malaysia. Little research has been undertaken to study dyslexia and stigma. Among the challenges experienced by parents are psychological stress resulting from the difficulty of accepting their child and the worry about stigma from family members and neighbors. Caregivers who have children with disabilities have problems with stigma, rejection, discrimination and labeling from the social environment due to having children who have disability (Multhauf et al., 2016). Society may discriminate children with disabilities. They may hold misconception about dyslexia, leading to stigma and criticize caregivers for their child's learning difficulty, leading to feelings of embarrassment or isolation. Dyslexics and their parents commonly have issues over labelling, which rooted from the denial of difference (Alexander-Passe, 2015).

Methodology

Research Design

The research study is a qualitative research approach. According to Rozmi Ismail (2012), qualitative research is a research approach that emphasizes descriptive, inductive and theoretical studies on how people give meaning to their lives. Qualitative methods are the right choice to obtain and deepen information in more detail than quantitative methods because they are more in-depth and comprehensive than quantitative studies that emphasize numerical data.

In this study, primary caregivers of dyslexic children are the samples for the study. A qualitative method was used by interviewing primary caregivers of dyslexic children who had been diagnosed by experts, to find out their experiences dealing with her mental wellbeing, psychosocial support receives and stigma along the journey in upbringing their dyslexic children. This qualitative study employed the phenomenology approach as it sought to elicit an in depth understanding about the caregivers' life experiences. Using a phenomenological approach allows the researcher to derive meanings within the context of the participant's surroundings and environment in raising children with dyslexia.

Potential participants were invited to contact the authors, who mailed them an information pack containing a Participant Information Sheet, a copy of the interview guide. This convenience sampling method was selected to ensure participants' voluntary participation in a discussion involving potentially sensitive issues. The interview was conducted in Bahasa either through online or face to face. Informed consent also be mention in the email before caregivers proceed with the interview. Confidentiality is strongly emphasized. They were reassured of confidentiality and anonymity of the data to be collected from them.

A phenomenological approach was used to explore the subjective experiences of the participants as well as their perceptions of those experiences. Phenomenology can be defined as the study of the structuring of experience or consciousness. Relationships between implicit pre-understandings and more-explicit understandings emerge, as the researcher is actively involved in this dynamic process influencing the extent to which each participant's experience can be accessed.

Sample and Sampling Method

The sample involved a total of 6 participants who had children with dyslexia between the ages of 6 to 12 years old were recruited through purposive sampling. This sampling strategy can provide an in-depth understanding, and focus on people with a related phenomenon of interest. Purposive sampling refers to a group of non-probability sampling techniques in which units are selected because they have characteristics that you need in your sample. They are all primary caregivers. The primary caregiver will be taken as a participant, will be defined as the person responsible for the day-to-day decision-making and care of the child. All of children diagnosed with dyslexia without others comorbidity.

The age range of the participants was between 25 to 50 years old. All of the participants are married and living together with their spouse. The participant was participated in semi-structured interviews, which were conducted at a time and location of their choice either via online or face to face. The interviews took place throughout February and March 2024. All of their children had been diagnosed dyslexic in either private or government center in Selangor, specifically Hulu Langat District. Three participants are working mothers, 2 of them are working in government sector while 1 working in private sector. Another three participants are full time housewife.

Data Collection

The semi - structured interviews were conducted to all participants. The interview only prepared the main questions and follow-up questions are based on the participants' answers (Refer Appendix A). The length of the recorded interviews ranged from approximately 45 minutes to one hour. Before interview occur, both the Depression Anxiety Stress Scale 21 (DASS-21), the Affiliate Stigma Scale (ASS) and the Multidimensional Scale of Perceived Social Support (MSPPS) assessments were used in assessing each participant in the study upon interview via google form. Guided by previous literature and pre-assessment result, the interviews took an exploratory approach to understanding how their experiences and challenges of raising their dyslexic children, related to psychosocial support, stigma and mental well-being of themselves.

Data Analysis

Transcripts interviews were then collectively analysed using a thematic approach to identify domains of common experience between participants, and how these related to challenges they faced as caregivers to dyslexic children. Themes were derived from salient statements made by participants. According to Braun and Clarke (2006), thematic analysis is very flexible, easy and suitable for researchers who do not have experience in qualitative research and the results of the analysis can provide information to the community. The researcher was immersed in reading and re-reading the original written transcript (All the participants are interviewed in WhatsApp and Telegram Aps conversation). Relevant comments regarding participants' challenging experiences emphasized and organize similar statements into overarching themes and subsequently developed a framework of common domains to guide the interpretation of data.

Findings

Backgrounds of Participants

Participant 1

The participant (1) is a housewife and the biological mother to a dyslexic daughter who is 12 years old and she is her youngest child. The participant stated that she was knowing the child's development was not normal from the beginning by said that “I have an eldest child who suffers from dyslexia too, therefore the youngest child was also expected earlier because she was delayed in speech and other milestone”. Later, her youngest was diagnosed with dyslexia in Biodyslexic Centre Sungai Buloh at aged of 10 years old. In addition, the participant has total 4 children, 2 of them are dyslexic children, 1 child having chronic kidney disease and 1 other child is normal.

Participant 2

The participant (2) is a housewife, bachelor degree holder in business management. She is the biological mother to a twin daughters aged of 12 years old. Both of them diagnosed with dyslexia at aged of 8 years old at PDM Ampang. The participant stated that the initial trigger that led to the diagnosis was from their teacher. “The twin’s classroom teacher told the child that she noticed my children having problem in learning and asked me to make an appointment with the special education service center in Putrajaya for screening”. Later, they were both diagnosed with dyslexia at aged of 8 years old at PDM Ampang.

Participant 3

The participant (3) is a housewife and a biological mother to a dyslexic daughter who is 8 years old and she is her eldest child. The participant had Bachelor Degree in Accounting. The participant stated that she was able to identify learning difficulty of her daughter due to a remark from her relative who suggested she see a doctor as stated by the participant “Early signs were detected by a relative who has knowledge in the field of psychology who heard my daughter spell 'mama' as a+m+a+m. After a brief assessment by her, she suggested me to take my child to undergo a proper and comprehensive dyslexia assessment”. Later, her daughter was diagnosed with dyslexia at PDM Ampang at aged of 6 years old.

Participant 4

The participant (4) is a working mother at private sector, had Bachelor Degree in Science and Technology. She is a biological mother to a 7 years old daughter that been diagnosed with dyslexia in PDM Bangi. She had been noticed the differences in her daughter character after start schooling, which then lead to the diagnosis. “We sent her to kindergarten at aged of 5, the first month she enjoyed going to school. After that, she refused to go to school and always give an excuse to skip school. She changed from a cheerful person to a child who preferred to play alone, unwilling to talk and shy”. She added, “During parental review day with the teacher, teacher complain that my daughter did not want to follow teacher instruction, she prefer to do her own work”. Later, her daughter was diagnosed with dyslexia at aged of 6 years old and currently still in PDM Bangi for full intervention course.

Participant 5

The participant (5) is a teacher in government school and the biological mothers to a dyslexic son who is 11 years old and her eldest child. The participant informed that she was able to identify his son's difficulty by stating “My son started with speech delay, he spoke gibberish when he was 5 years old. After a year of speech therapy, progress was still slow and therapists recommend taking him to PDM for a dyslexia screening”. Later, her son was diagnosed with dyslexia at PDM Bangi at aged of 6 years old.

Participant 6
The participant (6) is a government servant and the biological mother of a dyslexic daughter who is 11 years old and eldest child. The participant also has 2 other children. The daughter was diagnosed with dyslexia at 6 years old. The participant informed that she could identify the difference in her daughter due to his different development compared to her brother sister by stating "The teacher always told me that my younger's results was better than my eldest child" when they were in same preschool. "From there I noticed something wrong. When I tell my younger daughter to read the alphabet, she can however her sister is in a daze and does not know and remember". Later, her daughter was diagnosed with dyslexia at PDM Bangi.

Table 1
Caregiver Background Summary

Background Variable	**Number of Caregiver**	**Frequency (%)**
Sex		
Female	6	100
Male	0	0
Age		
20-29	1	16.7
30-39	4	66.6
40-49	1	16.7
Race		
Malay	6	100
Chinese	0	0
India	0	0
Others	0	0
Status		
Married	6	100
Divorced	0	0
Non-Married	0	0
Occupation		
Government	2	33.3
Private	1	16.7
Not working	3	50
Education		
SPM	0	0
Diploma	1	16.7
Degree Bachelor	5	83
	0	0

Table 2
Child Diagnostic Details

Background Variable	Number of Children	Frequency (%)
Dyslexia		
ADHD/ASD	0	0
with others comorbid	0	0
no additional diagnosis	6	100
Place of Dyslexia Assessment		
Private Sector	6	100
Government Sector	0	0
Age of Diagnosis		
3-6 years old (Preschool)	4	60
7-12 years old (Primary School)	2	40

Thematic Analysis

Analysis of the interview identified the challenges faced by caregiver of dyslexic children. The themes of stigma and mental health challenges of mothers who raised children with dyslexia are summarized in Diagram 2:

Diagram 2
Summary of the Findings

Stigma

Themes:

- Lack of Knowledge
- Judgement

Mental Health Challenges

Themes:

- Distressful Role
- Negative emotions

Mental Health Challenges

The results of the thematic analysis found that mental health of the caregiver always been affected due to many issues either before diagnosis and after diagnosis of their children. The hardship as well as challenges of them need to be addressed and given attention. There are two main themes in mental health challenges:

a) *Distressful role*

Along with the realisation of disability comes the need for greater involvement of caregivers especially the mother. They need to give extra attention, do extra task, spend energy and time in teaching. The high demand of the role as a primary caregiver to dyslexia children and require changes in life pattern. One of participant had given up her career to help her children who need her more and become a priority at that time.

> *"... 2 children in need, I had to quit my job to cater for children with learning difficulties, ... Being a full-time housewife is also a struggle"*
>
> (Participant 1)

As the caregivers took on additional roles of parenting to dyslexic children, they found that they had to take on more responsibilities and they expressed some difficulties in adjusting to their new responsibilities with little understanding or assistance from others. Many working mothers have a struggling daily schedule and have to put an extra time to provide education to their children, most of their free time was spent assisting their dyslexic children, and also to send them to extra classes including to the dyslexia centre. One of the working mothers shared:

> *"When the child starts intervention, the pressure increases. I live in Cheras, I drive to the centre early in the morning, wait her in the public library until the child finishes class and rush to send back her to the nanny's house again and then rush to the office"*
>
> (Participant 4)

b) Negative emotions

Most of the caregivers in this study expressed various negative emotions. The negative emotions towards the child's condition are worry, denial, guilt, self-blaming, disappointment and sadness. The initial reaction by most caregivers is shock. All caregivers had known for many years that something was not right but could not put their finger on what or why. For example, one of the mothers expressed that she was the one that should be blamed for not alert about her child:

> *"After my daughter was diagnosed with dyslexia, I felt disappointed and blamed myself. Every day I help her to complete the school work given by the teacher, but I fail to recognize that the difficulty in reading and writing is one of the characteristics of dyslexia"*
>
> (Participant 3)

She also added that:

> *"As a fulltime housewife, I should be more sensitive to identify children's problems in learning"*
>
> (Participant 3)

Participant who is working mother also had experienced feeling of guilt. One of participant of working mother said:

> *"…. I blame myself because I was too focused on work. Every day I come back home late. If I can detect it earlier, it's better, and the sooner we can intervene"*
>
> (Participant 4)

Upon further asked regarding her feeling of frustration, she added:

> *"… had to be brave. Crying has become a habit"*
>
> (Participant 4)

Caregivers in the study also feel guilty when they see that their children are struggling in learning which subsequently warrant the children to attend extra classes. The children have to attend extra classes to ensure that they are able to achieve academic learning like other normal children. One of the participants shared her exhaustion:

> *"It always been triggering a negative emotion when I see my child stressed and tired when learning, especially in the early stages of intervention. This is because we always do revision at home and she get tired…. To be honest, I will give myself and my child time to rest from studying"*
>
> (Participant 3)

Furthermore, most of the caregivers in this study shared that they were worried about their child's condition and the child's future life. The anxiety was shared one of the participants:

> "I'm worried she cannot learn. That is what worries me the most ... She is getting less interested in reading because she does not know how…"
>
> (Participant 6)

However, most of the mothers were finally accepting the child's condition. It is because most of them believed that they were chosen to have a 'gifted' child. Most of the mothers were able to control and overcome negative feelings since they knew that dyslexia are not as severe as other disability.

> *"I have a friend who has a child with down syndrome. So, I always think positively that I think it's okay that my daughter is just a dyslexic"*
>
> (Participant 6)

> *"Initially my husband thought that our child was autistic, after it was confirmed that she was not autistic, we were very relieved because hearing other people's experiences of handling autistic children is much more challenging"*
>
> (Participant 4)

Stigma

There are 2 themes revealed under the domains of the stigma found in the analysis of the research study that has been conducted. Most of participants do not have stigma against their children (affiliate stigma).

> *"… Give time and space for the child to learn, slowly she will overcome the learning problem and be able to master it"*
>
> (Participant 3)

> *"I myself told them that the child has dyslexia. my friends in the office know the status of my child having an OKU card"*
>
> (Participant 6)

a) *Lack of Knowledge*

However, they go through a lot of challenges due to stigma from people around them. Most of the issues that arise are due to the lack of understanding of the family member and the community towards dyslexic children. The public does not know the difference between children with dyslexia and normal children because physically they look normal children, which causes them not to understand the conditions and difficulties experienced by the participants, causing any action taken by the pparticipant lead to misunderstandings.

> *"My friends say they do not even see that my daughter has special needs because everything is normal physically…. I think many people do not know what dyslexia is, so for me there is 'no' negative stigma for dyslexia"*
>
> (Participant 6)

At a more personal level, participants also reflected on a lack of knowledge within their own family and making comments such as:

> *"My husband said it is normal for little girl to be slow, there is nothing wrong with her. My husband never joined the dyslexia check-up"*
>
> (Participant 6)

> *"At that time, we didn't know what dyslexia was, take time to accept it. I did own research to understand about dyslexia... after own research, there is no conclusive evidence for the cause of dyslexia. I slowly forgive myself. Even though I had understood but I still worry about the acceptance of people around me"*
>
> (Participant 5)

In this sense, a lack of awareness about dyslexia was perceived through seemingly unfair treatment from schools, both for the carers and their children. Not all teachers understand and able to teach dyslexic students. One of participant shared her experience;

> *"The teacher once called my twins lazy, their Mathematic teacher once discriminated against the student in this remedial class, I spoke up and took my twins to transfer another school"*
>
> (Participant 2)

She also added regarding a lack of knowledge about dyslexia among teachers:

> *"… In that school no one knows what is dyslexia because the school is a mainstream school. After that incident, the headmaster sent the remedial teacher to a special education and dyslexia course"*
>
> (Participant 2)

There is also participant stated the same thing regarding the lack of knowledge and understanding about dyslexia among teachers and they tend to stigmatize.

> *"Previous school, a teacher put my daughter at the back of the class because she is slow to catch up and does not focus... At current school, the teacher recognizes the dyslexic child, the teacher encourages my child and she enjoys going to school because there is a teacher who understands her difficulty"*
>
> (Participant 6)

b) Judgement

Participants also reflected on experience where they had personally felt judged by others because of their child. Judgement was an extension of lack of knowledge due to misunderstanding of the nature of dyslexia. Others viewed dyslexia through a lens of what they considered as 'normal'.

> *"Most of Malaysians think dyslexia is normal, stubborn children who don't want to listen"*
>
> (Participant 6)

Caregivers in this study alo experienced stigma when family and friends questioned their parenting abilities. The perception of being judged as a bad parent was described by participants as being particularly painful:

> *"I am quite traumatized by my husband's family because for me they are quite judgmental. When my daughter was baby, she often cried, I was accused of not giving her enough to eat.... they often comparing my daughter with other grandchildren"*
>
> (Participant 4)

> *"Even among the family likes to comment comparing her with cousins of the same age, I will slow talk with my child and tell him that she is not stupid, she had dyslexia"*
>
> (Participant 5)

The judgement theme clearly demonstrates caregivers' experiences of felt stigma, reflecting their emotional reactions and frustrations as a result of other people's lack of knowledge.

> *"Stigma does exist, especially regarding the OKU card. Viral issues regarding the problems caused by OKU card holders… Stigma comes because people don't understand and don't know"*
>
> (Participant 5)

These are the challenges experienced by caregivers causing psychological stress resulting from the difficulty of others accepting their child and the worry about judgement from family members and neighbors. The caregivers who are being stigmatized by the community may experience psychological issues.

Discussion

This study highlights that most of the caregivers expressed psychological implications in parenting a child with dyslexia. These difficulties among caregivers were described under mental health domain. This finding revealed how these mothers who had dyslexic children faced with psychological challenges such as their distressful role as caregiver and having negative feelings, and these challenges needs help and support from others. Caregivers of children with dyslexia need the support of the extended family, from their siblings and immediate family. They will be stronger to face this test if they can lean on the extended family.

Consistent with literature, the findings indicate that some of the health needs were similar to those of family carers of children with other developmental disorders, including psychological impacts such as high stress and hardship in the caring process, limited knowledge of the illness and unrealistic expectations of overcoming the abnormality (Chien & Lee , 2013). Furthermore, these dyslexic children need a lot of attention especially in terms of education. Caregivers need to be more prepared for future possibilities, they need to sacrifice time and energy to ensure that the needs of dyslexic children are met, such as sending them to a special school whose schedule and requirements are also different from the usual school.

Parenthood is an enriching experience, both from social and psychological perspectives, but it also constitutes a crucial transition due to the specific demand that an individual needs to manage in a sufficiently adequate manner (Bonifacci et al., 2019). It is even worse if there is a drastic transition or a change in the role of the caregiver especially to a mother because some of them decide to quit their jobs and become full-time housewives to take care of dyslexic children. Many mothers choose to quit their jobs to focus their energy and time attending to their child (Poon-McBrayer & McBrayer, 2014). It is not an easy task; it takes a lot of time to adapt. Dyslexia represents significant challenges not just for the student but can also be traumatic for their parents (Elliott & Nicolson, 2016).

It also was found that the caregivers who had distressful role had highly expressed negative feelings towards their children' condition. Most of the caregivers are burdened with feelings of regret and guilt. They feel that everything that happens is due to lack of attention to the child's problems at the beginning due to their busyness or lack of knowledge about dyslexia. Moreover, there are caregivers who think that being slow in reading or writing is 'normal', not something serious (Gibbs & Elliott, 2020). Other reactions that arise are anxiety due to not knowing what will happen, fear of the future. Mothers become emotionally and physically drained as they become heavily involved in their child's remedial education and worry for the child's future (Delany, 2017).

Conclusion

This study contributes to broader understandings of social experiences among these caregivers. Particularly, experiences that are interpreted as stigmatising can be seen to exist along a journey of raising their dyslexic children. Through identifying this journey experiences, we are able to provide support to caregivers of children with dyslexia and thus provide appropriate intervention for the relevant stage of this journey because stigma significantly causing psychological stress and emotional disturbance to caregivers.

Both stigma and lack of psychosocial support added psychological impact on caregiver. Feelings of being overwhelmed were worse in caregivers whose families discriminated against dyslexic children and the caregiver. Caregiving was found to be exhausting, frustrating, anxiety provoking, stressful, and nerve-wracking. The needs of their loved ones may outweigh their capacity as caregivers and often trump their own needs.

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