Voices of Motherhood: A Narrative Exploration of Raising Children with Down Syndrome

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ABSTRACT

This study aims to understand the parenting experiences of mothers of children with Down syndrome in Malaysia. Through in-depth interviews with five mothers, four themes emerged: financial difficulties, managing time, coping with emotional distress, and facing a lack of acceptance from the community. The findings of this study shed light on the significant sacrifices and efforts made by mothers of children with Down syndrome as they work to provide their children with the best possible care and support. Additionally, the importance of inclusive education for children with Down syndrome is highlighted, as it can play a crucial role in helping these children reach their full potential and be included in society. This study's findings are vital for professionals working with families of children with Down syndrome, as it provides valuable insight into the experiences and needs of these mothers. By understanding the specific challenges and triumphs these mothers face, professionals can better support and empower them as they raise their children and advocate for their needs.

Keywords: Down syndrome, Mothers, Motherhood, Inclusive Education, Parenting, Family

1. Background of study

Raising a child with Down syndrome can significantly affect the entire family's way of life. Regardless of any context, families of children with down syndrome will constantly face unique challenge associated with Down syndrome. It can be challenging for families to recognise and accept challenges that come with this diagnosis and to adapt their lifestyles to best support their child's development. Many have reported that the diagnosis and the immediate aftermath are the two factors that are the most difficult. The success of these adaptations depends on the characteristics of each family member and the strength of the family's relationships and support for one another. Being a mother is one of the most challenging responsibilities a woman can have because it requires the continuous development and adaptation of the mother-child relationship. It has been found that mothers who are caring for children with disability have a significantly increased risk of experiencing mental health issues themselves (Benson, 2018; Padden & James, 2017). Several studies on children with varying types of disabilities found that the parents of children with disabilities struggled with a variety of negative emotions, including anxiety, depression, denial, and shock (Huiracocha et al., 2017; Phillips et al., 2017). Most of the research studies on the experiences of families with a child with disability indicate that while there may be commonalities in parenting experiences, the impact varies greatly between families. The role of family in encouraging the participation of children with disabilities across all activities are very crucial where the emphasis should be focused in all areas such as information resources, network, and community supports (Arakelyan et al., 2019).

2. Children with Down Syndrome

Down syndrome, a chromosomal disorder characterised by distinctive facial features and mental retardation, records for about 8% of all congenital abnormalities in Malaysia. Down Syndrome, also known as Trisomy 21, is a chromosomal condition caused by the presence of an extra copy of chromosome 21. The National Down Syndrome Society estimates that there are around 6,000 babies born with Down Syndrome in the US each year (NDSS, 2020) while the World Health Organization (WHO, 2020) estimates that about 1 in every 1,000 live births globally is a child with Down Syndrome. It is believed that Down syndrome occurs at similar rates across racial and ethnic groups, even though its incidence varies by population. Malaysia's prevalence of Down syndrome is not significantly different from that of other countries. Due to underdiagnosis and underreporting, the actual incidence rate may be slightly higher. It is estimated to affect between 1 in 700 and 1 in 1,000 live births in Malaysia. Down syndrome is equally prevalent in males and females of all races and ethnicities. It is a genetic condition that is not caused by anything the parents did or did not do during pregnancy. Most children with Down syndrome reach developmental milestones later than other children, such as walking, eating, and talking. They often have mild to moderate intellectual disability and may have specific challenges with attention span, verbal memory, and expressive communication.

3. Literature Review

Multiple studies conducted in diverse cultural contexts have shown that parents (particularly mothers) of children with disabilities tend to have lower levels of psychological well-being and physical health compared to parents of children without disabilities or who have typical development. This was the case regardless of the context in which the studies were conducted (Emerson& Hatton, 2009) Itsuggested that the absence of adequate financial or material resources within a family is strongly linked to feelings of dissatisfaction with one's life, increased levels of psychological stress, and a lower overall level of well-being among mothers who are caring for children who have special needs. There is a significant connection between mothers' jobs, levels of education, ethnicity, and the stress that mothers experience.

The mother's role in child raising generally is more significant than the fathers. The challenges of caring for a child with Down syndrome tend to increase as the number of children in a family increases. Caring for any child can place a financial strain on a family but raising a child with developmental delays typically requires even more resources. Various studies have determined that families of children with developmental delays need outside financial assistance.

Additionally, several studies have demonstrated that economic difficulties can result in elevated stress levels and strained family relationships. Parents from a high socio-economy status family who have better privilege advantage in terms of time, energy, and educational knowledge are able to promote warmth and affection in building parent-child relationship (Dixson et al., 2017). Therefore, families with low socio-economic status have higher tendency to experience various familial stressors and unfavorable life events which can overwhelm the family with extreme family burden (Bøe et al., 2017). The concerns are even more prevalent in nations such as Malaysia, where the early intervention programme is not yet provided for free as part of the public education system.

Nelson Goff et al. (2013) discovered that both mothers and fathers experienced a "violation of expectations" after learning that their child has Down syndrome. Such devastating news usually result in grief, stress, and shock. In a narrative study of nine mothers, Lalvani (2008) discovered that upon diagnosis, the mothers experienced shock, distress, and depression. In another study, Lalvani (2011) conducted a similar narrative inquiry and found similar experiences, including expanded descriptions of anger, fear, guilt, rage, and devastation. According to Gabel and Kotel (2015) and Isgro (2016), mothers experience similar levels of shock, sadness, stress, and grief.

Parenting a child with Down syndrome can be a challenging and rewarding experience. Many parents of children with Down syndrome report feeling a range of emotions, including fear, uncertainty, sadness, joy, pride, and love. Both mothers and fathers may find it challenging to inform family and friends that their child (or foetus) has Down syndrome. In their findings, Gabel and Kotel (2015) described mothers' difficulty concerning how family, friends, and strangers viewed their children and their decision to continue carrying a foetus with Down syndrome. Humphreys et al. (2008) discovered that their partners' support alleviated mothers' emotional strain. Another study by Carpenter (2015) discovered that informal social support from family, friends, religious leaders, neighbours, and proper social support from medical personnel, social workers, and interventionists significantly altered the nature of their initial diagnosis experiences, typically for the better. Most research studies on families' experiences with a child with a disability indicate that, while there may be commonalities in parenting, the impact varies considerably between families (Muscott, 2001). Considerable research suggests that mothers of children with Down syndrome bear enormous burdens due to the limited family and community support they receive (Aldersey, 2012). While most of the supports received mostly were from the mothers or families who have children with down syndrome, more public awareness is required to gain support and broaden coverage.

4. Methodology

Research Design

A narrative inquiry into identity and experience frames our research design. A "deeply relational type of inquiry" is narrative inquiry (Clandinin, 2007). It is "sensitive to...subtle textures of thought and feeling" (Webster & Mertova, 2007) at work in a narrative account of lived experiences, allowing the most significant events to emerge in the stories participants tell. According to Clandinin & Rosiek, (2007) narrative inquiry "…portrays not only on individuals' experiences, but also on the social, cultural, and institutional narratives that comprise, shape, express, and enact individuals' experiences,". The narrative inquiry method was chosen so that participants could share their experiences about raising a child with Down syndrome without being overly directed by the researchers. The impact of experiences is frequently overlooked in quantitative research, whereas narrative inquiry allows researchers to understand those experiences. Converting field texts to research texts serves as a bridge between data collection and data analysis in narrative inquiry.

Recruitment

This study involved mothers from Klang Valley, Malaysia with Down syndrome children ages 12 to 16 years old. The mothers were recruited through email invitations to discuss the challenges and impacts of raising a child with Down syndrome on the family dynamic. To be eligible to participate in the study, the mothers needed to have a child diagnosed with Down syndrome according to The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) criteria.

Participants

The following were the requirements for potential participants in this study - the mothers. (1) they needed to be the primary carer of a child who was 16 years old or younger. (2) their children are diagnosed with Down syndrome (according to DSM-5 criteria). First of all, the mothers were invited to participate in a talk about the challenges of parenting a child with down syndrome and its effect on the family dynamic. The invitation was sent out via email to initiate the process of participant recruitment. The participants in this study were mothers between the ages of 35 to 50 years old. All the mothers had either a tertiary or post-secondary education, employed, and married. The participants in the study were identified as Parent A, Parent B, Parent C, Parent D, and Parent E. Tables 1 and 2 provide a descriptive summary of the participants' and their children.

Table 1

Summary of the Participants

Participants	**Age Range**	**Mother's level of education**	**Employment**	**Marital Status**
Parent A	35-40	Tertiary	Yes	Married
Parent B	40-45	Tertiary	Yes	Married
Parent C	40-45	Tertiary	Yes	Married
Parent D	45-50	Post-Secondary	Yes	Married
Parent E	35-40	Tertiary	Yes	Married

Table 2

Summary of the Children

Child	**Age**	**Diagnosis**	**Other Diagnoses**	**Gender**	**Attending school?**
A	14	Down syndrome	No	Male	Yes
B	13	Down syndrome	No	Male	Yes
C	15	Down syndrome	No	Female	Yes
D	14	Down syndrome	No	Male	Yes
E	16	Down syndrome	No	Male	Yes

Ethical Consideration

In this study, all recruitment and research procedures adhered to the ethical standards of the institutional and national research committee (SEGi University). All the participants provided informed consent for recruitment, data collection, transcription, data storytelling, data analysis, and report writing.

All the names used to describe the participants in this article are fictitious. Additionally, some characteristics of the participant have been altered to protect their identity further.

Collecting and Recording of the Data

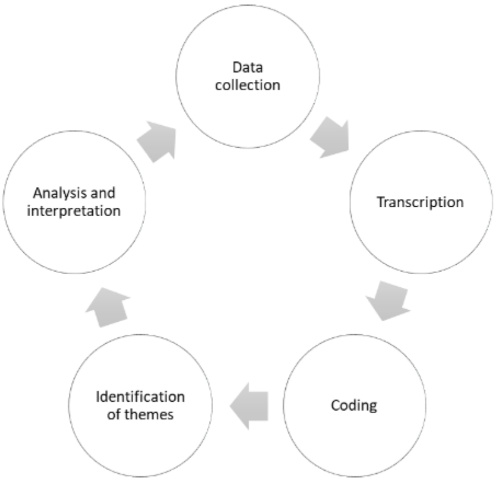

Figure 1. Data Collection Activities adapted from Creswell's (2014)

In this study, we applied the narrative thematic analysis within the text as the primary focus. The narrative thematic analysis analyses the data collected from interviews with the participants. This process included five stages: organising and preparing the data, getting a general sense of the information, coding, identifying themes, and interpreting the data. In the first stage, the audio tapes from the interviews were transcribed and any initial themes or patterns were noted. The transcripts were then compiled and edited to remove non-narrative lines, assign fictitious names to the participants, and remove any identifying information. The next stage involved coding the data manually and identifying themes based on existing literature. This study identified four major themes related to the challenges faced by parents raising a child with Down syndrome: financial, time management, emotional distress, and lack of acceptance from the community. These themes were identified through narrative thematic analysis, a tool used to understand the underlying meanings and themes within a text or group of texts. This method can help identify patterns and trends within the data and shedding light on complex issues.

5.0 Findings and Discussions

Challenges Faced by Parents in Handling Children with Down syndrome.

Theme 1: Financial

Financial difficulties are seen as one of the main challenges faced by parents who have children with Down syndrome. All five parents reported their financial difficulty in managing the cost of living of children with Down syndrome. This could be evidenced in the following dialogues:

Parent A: I am a super worried mummy. She cannot get a fever because she already has brain damage if fever I will be very ganjiong… I spend a lot on medical. Maybe I am too much, maybe she got nothing. I only trust the specialist, I don't trust the normal clinic, until now.

Parent B: We attended classes to learn about how to take care of disabled children.

Parent C: I did not do many therapies with her apart from Kiwanis, because we don't have the budget to do it. It is expensive. I did not do it.

Parent D: "I do need financial support to buy books for her, hmm because the teacher asks her to train in the house. Where it cost more than what I can't effort to buy."

Parent E: "The doctor asks to bring Sabrina to the speech therapist three days a week, but I bring her to therapist centres once a week which is affordable to pay."

The results of the findings are supported by previous research that highlighted the need for extra expenditure in raising a child with special needs in managing the essential resources of the child in daily life (Bahry et al., 2019). Besides that, another research stated that parents with children with special needs are handling the cost of the treatment, which exceeds the family's budget (Hasan, 2021). Medical costs for a child with Down syndrome can be 12 to 13 times higher than for a child without the syndrome. Extra expenses are required to manage living with disabilities, and there is a lack of affordability in obtaining necessary resources for disabled children. (Surianti et al., 2017). Besides that, the economic burden of a family increases as one of the parents especially mother is required to do some adjustment in working her hours or give up her job to provide proper care and welfare for the child with Down Syndrome (Fridman et al., 2017). If the child suffers from additional conditions in addition to Down syndrome, these costs may escalate. The cost of raising a child with a disability can vary widely depending on the severity of the child's disability, the specific needs, and the availability of resources within the community. Some estimates suggest that the additional expenses associated with raising a child with a disability can reach a few thousand ringgits more per year, which is several times higher than the cost of raising a physically or mentally normal developing child. It is also found that that families of children with disabilities were more likely to experience financial hardship and have lower household incomes than families of typically developing children. (Parish, S. L., Rose, R. A., & Kilany, M, 2016).

Theme 2: Balancing Work and Family

Parents with a child with Down syndrome experience some struggles in managing time in their daily life. Balancing work and family become a crucial element for those parents who are raising children with Down syndrome. Parents are required to spend extra time and energy in handling children with Down syndrome. Two parents indicated that taking care of children with special needs leads to the inability of the parent in managing their time in daily life.

***Parent 1**: Working mom, you have to take care of your work, you have to take care of your transportation, especially if you are sending your child to some school, like an early intervention* *programme. The transport, the timing you have to report to your work, you have to have an understanding employee…. You have to rush back, maybe you don't have extra time to spare with her if you are a working mom.*

Parent 3*: I changed my role, from the front end, I became the back end. I have become a data collector. When she was young, I have to go to the clinic, at least one or two times every week. In a way, I was lucky. I got a job. I deal with international; I deal with U.S, Europe and Asia. I kind of like to have a bit flexible. I don't have to work like nine to five, in the office.*

It is very crucial for working parents to maintain a job and taking care of a child with disability. (Shirley et. al., 2017). Parents' failure in having adequate time to play their roles in the workplace and home can lead to parental stress. Parents are required to allocate most of their time in fulfilling the special needs of children with Down Syndrome. Hence, parents with Down Syndrome basically struggle in balancing personal and professional life due to the requirement conflict between work and caregiving for the child (Shirley, et. al., 2017).

Theme 3: Life with Emotional Distress

Parents who are raising children with disabilities suffer from numerous physical and mental stress (Ganjiwale et al,. 2016), and parents who give birth to a child with Down syndrome struggle with a wide range of ~~emotional~~ distressful emotions. This situation can be caused by a number of factors such as denying the disability condition of the child, receiving unsympathetic form of comments from others, blaming oneself for having this child, failure in giving proper care for the child, and inappropriate sympathetic feelings by the people around them. Interestingly, all the participants reported the emotional distress experienced after the birth of a child with Down syndrome. It was unanimously reported that mothers of children diagnosed with Down syndrome express feelings of sadness, worry about the child's future, and stress related to the experience of raising a child with Down syndrome.

Parent 1*: Especially for the first 3 months, it is very difficult for me to go through these stages. I will keep on asking myself, why me? Why me?*

Parent 2: *"I feel depressed towards accepting my daughter when she was born."*

Parent 3: *"I feel frustration after she was born."*

Parent 4*: I felt so depressed when I could not balance my work and the care invested on my child.*

Parent 5*: I, myself, have experienced depression before, and I had suicidal thoughts. At one point, when my maid ran away since it was too overwhelming for her. my pillar of support was my maid, my helper. She was gone, and I had to spend so much money on therapies. I was very* depressed.

Parents of disabled children are proven to experience a higher level of stress in parenting compared to parents of neurotypical children such as autism (Muhamad & Alfa, 2016). Some of the challenges include the stress of handling sibling issues, financial struggles, and future and education concerns (Shirley et al., 2017). Mothers of children with Down syndrome struggle with the extreme level of stress and frequently face difficulty in terms of adjusting their careers, finances, and lifestyles after the birth of a child with Down syndrome (Khan et al., 2018). In the long run, the continuous emotional distress feeling that the parent faces may lead to chronic mental problems for parents (Tahereh Rahimi & Zahra Khazir, 2019).

Theme 4: Lack of Acceptance from the Community

One of the most common challenges that parents who have children with Down syndrome face are a lack of community acceptance. Family members, friends, neighbours, and others in society are often unaccepting of children with Down syndrome. People in the community who live near children with Down syndrome may exhibit intolerance. Inadequate reactions and interactions with children with Down syndrome resulted from a lack of awareness about the special needs component. Most parents reported community rejection as a result of raising a child with Down syndrome. Throughout the interviews, all mothers reported that having a child with Down syndrome was a transition into a new and often unwelcome identity in society. Mothers demonstrated their awareness of societal attitudes that stigmatised and isolated them. This is demonstrated in the following stories by various mothers:

Parent 1: *"My son doesn't have any deep bonding with his sister and always says why always gives attention to her"*

Parent 2*: Grandparents feel that Megan is a burden.*

Parent 3: *"My mother told me that my daughter is cursed by the ancestors when she was born, and then they told me she is a burden to the family.*"

Lack of acceptance from the community towards families of children with disability lead to stigmatisation. A qualitative study by Ng & Ng (2022) indicated that parents of children with disability experienced unfair treatment by others in the forms of social degradation that that includes being avoided, treated poorly, and being stared at. Families with disabled children who are in the struggle of managing challenges of their children’s disability are in the need of coping with insult, hostility, and rude remarks from the community (Kayama et al., 2017). Hence, parents of children with disability tend to limit their social interaction due to adverse attitudes of the society towards people with disability (Duran & Ergün, 2017).

Discussion

This study was designed to explore mothers' experiences raising children with Down syndrome. The findings revealed diverse experiences among mothers of children with Down syndrome. This study revealed that caring for children with Down syndrome depicts mothers with significant challenges. These challenges were associated with their emotional reactions upon learning of their child's condition, caregiving challenges, societal reactions, perceived cause of disability, and the coping strategies they employ to deal with their current situation. To successfully raise children, mothers in this study were concerned about the need for strong support from family and society. Better psychological health was reported by mothers who received strong support from their spouses, siblings, grandparents, and children's schools. Social support is essential in facilitating children with Down Syndrome, reduce family stress, and cultivate positivity and hope (Gashmard et al., 2020)

Nevertheless, it was evident that some mothers were unhappy with the support they received from family, friends, and society. Researchers observed that nearly all the mothers have a deep affection for and strong bonds with their Down syndrome child. They show them more tolerance and affection than their other children. In addition to economic support, families require various forms of social support, such as financial aid to provide their child with an early intervention programme and to help them develop their skills as quickly as possible. A large amount of support is required to empower a family with children with Down syndrome, given that raising a child with Down syndrome could alter the family's dynamic capacity.

Some of the mothers who participated in this study reported that the experience of having children with Down syndrome made them feel like outsiders in both their families and society. The presence of a child with Down syndrome in the family was associated with a decrease in the quality of life of the parents because of an increase in the number of problems and disruptions in the functioning of the family (Tahereh Rahimi & Zahra Khazir, 2019). One of the most significant concerns that were voiced by parents of individuals who have disabilities was a concern for their children's future, specifically concerning the limited opportunities for employment and financial independence, as well as the pervasive stigmatisation and discrimination that would continue to restrict their integration and participation in society. Mothers have reported feeling sad after receiving a diagnosis from a medical or psychological source, as well as after learning about regarding their children's condition from teachers and personal information. This may have occurred after the mothers learned about their children's situation.

Raising a child with Down syndrome can be a long-term, ongoing challenge for mothers, as they must support their child's various needs throughout their life. The unexpected diagnosis can be emotionally overwhelming and stressful for some families and may lead to increased risk for stress, exhaustion, and adverse health effects. Many mothers in this study emphasised the importance of solid support from family, friends, and the broader community in helping them successfully raise their children and reported improved psychological health when they had this support. Support group for parent who is raising children with Down Syndrome play a dominant role in terms of supporting and giving information and essential resources (Abdul Wahab & Md. Monoto, 2018). Nonetheless, it was evident that some mothers were dissatisfied with the support they received from family, friends, and society. According to some mothers who participated in this study, the fact that they had children with Down syndrome made them social outcasts.

Study Limitations

This study had some limitations. Firstly, the findings of this study cannot be applied to all Malaysian mothers of children with Down syndrome. Because the current study focused on mothers in urban areas, it is unknown whether mothers in rural Malaysia undergo similar experiences as mothers in the urban areas. Secondly, because their children attend special schools, the participants in this study were relatively homogeneous. As a result, the findings cannot be applied to mothers whose children do not attend special schools. Thirdly, while this study focuses on the experiences of mothers, it does not minimise the role and experiences of fathers in the lives of their children. Future research into fathers' experiences may provide a deeper understanding of the dynamics of raising a child with Down syndrome. Nonetheless, the findings of this study can be used to guide future research ~~into~~ on the experiences of parents, potentially leading to an improvement in their well-being.

Policy and Intervention Implications

The focus should be on providing families with coping strategies tailored to their specific requirements to assist them in navigating the challenges of raising children with Down syndrome. Early intervention services, including speech therapy, physical therapy, occupational therapy, coordination therapy, fine motoric therapy, and life skills training would be beneficial for children with Down syndrome to reach their full potential. The multidisciplinary team, particularly the mental health professionals, should assist mothers in finding meaning in the experience of having a child with Down syndrome by assisting them in considering the positive aspects of their experiences, offering them hope, assisting them in making efforts to reframe their situation, and supporting them in finding meaning in the experience of having a child with Down syndrome. The results of this study could provide helpful information for developing policies and programmes that consider the cultural needs of children with Down syndrome.

Moreover, inclusive disability policies that require the appropriate agencies to provide mental health assessments to families of children with Down syndrome should be implemented. Advocacy and support groups should be involved in anti-stigma programmes to educate the public about the causes of Down syndrome, the experiences of family members, and the importance of showing love and concern for families of children with Down syndrome. Individuals with Down syndrome and their families need to have advocates who can work to ensure that their rights are protected and that they have access to the resources and support they need. Parents and caregivers of children with Down syndrome may need support in areas such as financial assistance, respite care, and access to information and resources. Government and other corporate organisations should provide financial assistance to the family to give them the opportunity to educate their children and support themselves. Continued research into Down syndrome can help improve our understanding of the condition and lead to new treatments and interventions that can benefit individuals with Down syndrome.

6. Conclusions

The findings of this study are vital for professionals working with families of children with Down syndrome. According to this study, mothers of children with Down syndrome face significant social, physical, economic, and emotional challenges in Malaysia and elsewhere. The children face difficulties in their daily lives and the future. Educators and policymakers must collaborate to create a welcoming and supportive educational environment for all children, including those with Down syndrome. Further research is needed to better understand the experiences and needs of parents raising children with Down syndrome and to identify ways to support and empower these families.

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