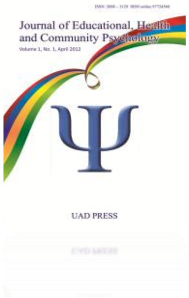


Journal of Educational, Health and Community Psychology
Vol 13, No 3, 2024 E-ISSN 2460-8467

Reframing Hope: The Process of Adapting Mothers to Children with Down Syndrome after Receiving a Diagnosis

Haerani Nur
Universitas Negeri Makassar
haerani.nur@unm.ac.id

Rohmah Rifani
Universitas Negeri Makassar
Rohmah.Rifani@unm.ac.id

Nurfitriany Fakhri
Universitas Negeri Makassar
Nurfitriany.fakhri@unm.ac.id

Abstract

This study aims to explore the experiences of mothers adapting after receiving a Down Syndrome (DS) diagnosis for their child. Utilizing a Heideggerian phenomenological approach, data was collected through in-depth interviews with 10 mothers of children with DS, focusing on their emotional responses, acceptance, and hopes. The analysis identified three main themes: initial reactions to the diagnosis and the resulting loss of hope, the process of acceptance, and managing hopes while adapting to the child's condition. The findings reveal the complex journey mothers undergo in restructuring their emotions and thoughts, underscoring the importance of diagnostic confirmation, social support, and spiritual beliefs in the acceptance process. This study contributes to a deeper understanding of mothers' experiences following a DS diagnosis and offers insights for health professionals and support systems to better assist families during this critical period. The theme of "reframing hopes" emerged as central, facilitating mothers' ability to adjust and maintain hope for their children's futures.

Keywords: Acceptance of diagnosis, arrangement of hope, down syndrome, maternal adaptation, phenomenological approach.

Received 21 July 2024/Accepted 30 August 2024 ©Author all rights reserved

Introduction

Down Syndrome (DS) is one of the most common genetic disorders, with an incidence of approximately 1 in 700 live births worldwide (Anil et al., 2016; Sarkar et al., 2022). Receiving a DS diagnosis for a child is often a life-altering experience for parents (Eray & Öpengin, 2023; Wardah Tariq et al., 2024). While fathers of children with special needs encounter significant challenges, they may experience milder impacts compared to mothers. Fathers often employ adaptive coping strategies to manage the stress associated with raising a child with special needs, which helps them reduce anxiety and maintain a positive outlook (Muzayyanah & Ersy Azheema Huda, 2023).

As primary caregivers, mothers face substantial adjustments in their lives. They may worry about their child's condition and future, encounter difficulties in caregiving, and potentially have to reduce working hours or even leave their jobs to focus on their child's needs. Consequently, the adaptation process, involving continuous emotional, physical, and financial struggles, is particularly challenging for mothers (Buyukavci et al., 2019; Suza et al., 2020).

Moreover, accepting a DS diagnosis often shatters parents' hopes, making the reality difficult to accept. This necessitates an adaptation process and a reorganization of their perspective on the condition (Skotko et al., 2011). The moment of diagnosis is often a critical juncture for families affected by DS, marking the start of a journey that not only involves coming to terms with the medical implications but also navigating complex dynamics related to emotions, social perceptions, and personal beliefs (Goff et al., 2013). Understanding this process is essential for healthcare providers, support systems, and the broader community to offer appropriate and timely support to parents, especially mothers, of children with DS.

Although there is a substantial body of literature on the experiences of parents receiving a DS diagnosis—covering topics such as initial reactions (Grane et al., 2023; Lehman et al., 2021; Rasendrakumar et al., 2021), stress experiences, coping strategies, and support needs (Celik & Kara Uzun, 2023; Fuca et al., 2022; Gashmard et al., 2020; Lee et al., 2021), and parenting a child with DS (Dias et al., 2022; Hippman et al., 2012)—the specific processes of maternal adaptation and the reconfiguration of maternal hopes after diagnosis have received less attention. This study aims to address this gap by exploring in depth the experiences of mothers after receiving their child's DS diagnosis.

The concept of "reframing hope" is central to this study. According to Snyder, hope is not merely wishful thinking but a cognitive process that involves setting a goal, identifying pathways to achieve that goal, and possessing the agency to pursue it (Snyder, 1991). In the context of a DS diagnosis, mothers often need to reconstruct their hopes for their children and families (Truitt et al., 2012). This restructuring process is not about diminishing hope but about reconceptualizing how mothers can adjust their hopes to align with the realities of raising a child with DS.

The purpose of this study is to provide a deeper understanding of how mothers adapt and rearrange their hopes after a DS diagnosis. Specifically, the research aims to answer the following questions:

1. How does the mother's hope look after receiving a DS diagnosis?
2. How does the mother process to accept the diagnosis?
3. How does the mother rearrange her hopes for the child's future?

By addressing these questions, we aim to contribute to the literature on parents' experiences with DS and offer insights that can inform more effective support strategies for families navigating this challenging period.

Method

Design

This study employs a qualitative methodology using a Heideggerian phenomenological approach to explore in depth the experiences of mothers following a diagnosis of Down Syndrome (DS) in their children. The Heideggerian phenomenological approach, also known as hermeneutic or interpretive phenomenology, was selected because it allows researchers to understand and interpret mothers' experiences within the context of their broader lives (Horrigan-Kelly et al., 2016).

Participants

The study involved ten mothers of children with DS, recruited through purposive sampling from communities and schools for children with special needs. The ages of the mothers ranged from 28 to 45 years, and their children with DS were aged between 2 and 13 years at the time of the study. All participants had received a postnatal DS diagnosis for their child. The informed consent process was thorough, including both written and oral explanations of the research objectives, procedures, risks, and benefits of participation. Participants were assured of data confidentiality, their right to withdraw from the study at any time, and were given the opportunity to ask questions. Written consent was obtained only after ensuring participants' full understanding, with an emphasis on ongoing consent throughout the research process.

Data Collection

Data was collected through semi-structured in-depth interviews with each participant. These interviews, lasting between 45 and 60 minutes, were conducted in a private setting chosen by the participants. The interview guide included questions about the diagnosis experience, initial reactions, coping strategies, changes in perspective over time, and current views of their child's future. All interviews were audio-recorded and transcribed verbatim. Examples of interview questions used in this study include:

1. Can you tell me about your experience when you received the DS diagnosis for your child?
2. What are the mother's hopes for her child after receiving a DS diagnosis? Tell us how the mother's hopes have changed.
3. How did you adjust to yourself and your hopes for your child after receiving a DS diagnosis?

Trustworthiness

To ensure the trustworthiness of this research, the member checking technique, as recommended by Creswell (2016), was implemented. This process involved verifying the findings with participants to ensure the accuracy and credibility of the researcher's interpretations. After the initial analysis, a summary of individual findings was compiled and presented back to each participant. They were given the opportunity to review, provide feedback, clarify misunderstandings, and add any additional information if necessary. Based on this feedback, the researcher made the necessary revisions to the interpretation and findings. This process aims to enhance the validity of the research and ensure that participants are actively involved in the research process, thereby ensuring that their voices are accurately represented.

Data Analysis

Data analysis in this phenomenological research followed a data-driven approach, adhering to the stages of phenomenological analysis outlined by Moustakas (Creswell, 2016). The process involved several key stages.

In the data analysis process, the researcher first engaged in epoche, seeking to set aside personal biases and experiences to fully concentrate on the participants' experiences. Following this, the researcher undertook horizonalization, identifying important statements from the interview transcripts. These statements were then grouped into themes or units of meaning through the process of clustering meaning. Subsequently, textual descriptions were developed to capture what the participants experienced, while structural descriptions were created to explain how the phenomenon was experienced. Finally, the analysis culminated in the synthesis of meaning and essence, where the textual and structural descriptions were integrated to uncover the core essence of the participants' experiences. Throughout this process, the researcher iteratively read and reflected on the data, using open coding to identify and connect emerging themes.

Limitations

This study has several limitations that should be considered. The small sample size and limited geographic focus may constrain the transferability of the findings. Despite efforts to minimize bias, the interpretation of the data may still be influenced by the researcher's perspective. Additionally, the study focuses solely on mothers' experiences, excluding the perspectives of other family members. The reliance on participants' retrospective memory may also affect the accuracy of the data. While the phenomenological approach allows for an in-depth exploration of the participants' experiences, it may not fully capture broader contextual factors. These limitations highlight the need for further research with larger and more diverse samples, as well as more comprehensive methodologies.

Result

The study involved 10 mothers who received a DS diagnosis for their child shortly after birth or within a few months thereafter. Mrs. LS, whose first child was diagnosed with DS, initially struggled but eventually became confident in focusing on fostering her child's independence and potential. Mrs. JM, who received the diagnosis for her youngest child, came to accept her child's condition as a gift from God. Similarly, Mrs. RF, who also received a diagnosis for her youngest child, initially had difficulty accepting it but ultimately surrendered to God's will. Mrs. NY, whose first child was diagnosed with DS, was initially very worried about her child's future. Mrs. FT initially did not believe the diagnosis, but with her family's support, she gradually began to accept it. Mrs. BG, whose first child was suspected of having DS shortly after birth, sought confirmation and, upon receiving it, started to build new hope. Mrs. AG, who had a child with DS later in life, felt devastated at first but eventually adjusted to her child's presence. Mrs. FN felt deep sadness but tried not to dwell on her grief after receiving the diagnosis for her only daughter. Mrs. IH was initially shocked and saddened, but she ultimately accepted her child as a gift from Allah. Finally, Mrs. TT, who received the diagnosis for her youngest daughter, was shocked and depressed but, with her husband's support and a willingness to learn, began to adapt and build new hopes. The thematic analysis identified three main themes related to the mothers' adaptation process after the DS diagnosis: the initial reaction to the diagnosis and the resulting loss of hope, the process of acceptance enabling adaptation to the child's condition, and the restructuring of hopes and the building of new hopes. These themes are discussed in detail, supported by illustrative quotes from the participants.

Early reaction to the diagnosis and loss of hope of the mother

Mothers of children with DS typically receive the diagnosis shortly after birth, which often becomes a life-changing moment for them. When receiving a DS diagnosis for their newborn, mothers commonly experience a range of negative emotions, including shock, sadness, disbelief, and disappointment. These initial reactions are often accompanied by grief over the loss of the "normal" child they had envisioned and the future they had imagined. Many mothers describe how the hopes and dreams they nurtured during pregnancy are suddenly shattered, replaced by worries and uncertainty about their child's future. This sentiment is poignantly expressed by Mrs. TT, FN, and FT in the following interview excerpt.

> *"When I found out I was pregnant with a girl. We are a family, especially I am very happy because both of my brothers are boys. It was already expected that there would be a cute girl. There are so many hopes for him, he has imagined that when he grows up, there will be someone to accompany him to cook, accompany shopping, travel and others. It is already imagined that later he will be able to do many things, cooking, sewing and others. But as*

> *soon as he knew he was DS, that hope seemed to disappear and replaced with doubt, could he or could not... I had a slump 2 to 3 months after giving birth. There was so much anxiety in me from day to day that I suffered from anxiety disorders." (TT) "Of course I feel very sad after finding out that my son, who is the only woman, was declared DS" (FN). "We received the diagnosis after giving birth, and when we got home crying a lot... what is in my mind and my husband's mistake, what mistakes did we make until KMI should be given a child like this... Moreover, he is the boy we were expecting because his two older brothers are girls." (FT)*

The position of a child holds significant meaning for a mother, making their birth highly anticipated. For example, the birth of a daughter after having several sons is often eagerly awaited, just as mothers with daughters may eagerly anticipate the birth of a son. In these situations, mothers often dream of having an ideal child that matches their hopes. This anticipation is especially strong for mothers expecting their first child, as expressed by Mrs. NY and BG in the following interview excerpt.

> *"I found out about the condition of my child DS two days after giving birth, based on the prediction and information from the pediatrician who conducted a visitation after I gave birth. There was a feeling of shock, this was the first child and never imagined before because during pregnancy it went normal and was not detected during pregnancy" (NY). "Giving birth to my first child at a young age at that time, I had very high hopes, I had imagined having a daughter who was funny, chatty, could go to school and go to a well-known university, it turned out that I could get a diagnosis of DS, my hopes collapsed instantly.." (BG)*

Based on the interview data, it can be concluded that receiving a postpartum diagnosis of DS for their child profoundly affects mothers, triggering deep emotional reactions that often lead to a loss of hope for their children's future. The impact is even more pronounced when the child holds a special significance for the mother, such as being a long-awaited daughter, the first child, or when the mother is older at the time of receiving the diagnosis.

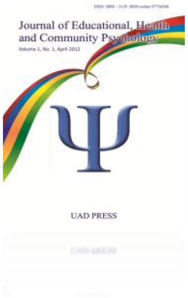
> *"When I found out that my son DS was of course devastated because honestly there were no descendants or families from me or my husband like that. Especially with this old age,*

> *how can I focus on taking care of children who many people say are idiots" (AG)*

The age of the mother is also a significant factor influencing her reaction to the diagnosis. Young mothers, who often have high hopes for their first child, may experience intense emotional distress upon receiving a DS diagnosis. On the other hand, older mothers who give birth to a child diagnosed with DS may feel overwhelmed by the challenges of caring for a child with special needs, believing they may not have the energy or resources to meet those demands. Additionally, the interview data revealed that a lack of a family history of DS can add to the emotional burden. Many mothers struggle to accept the diagnosis because it seems unexpected or unwarranted in the absence of a hereditary link.

> *"When the doctor told me that my child might be DS, maybe hypothyroid, or maybe both, I wasn't really clear what and how it was DS and hypothyroid, but it felt like I was going to faint. The point is that this must be bad news. I went back to the treatment room and browsed, because my son also lacked physical signs such as his pinky knuckles, the lines of his hands, the distance between his eyes, so we filled our days with rejection. Plus other tests such as the heart, hypothyroid, everything is normal, so the reason for refusal is complete." (BG) "It's really difficult, ma'am... Sometimes we get out of control. Constantly with the question of why I was given my child like this is not perfect like other people's children? Meanwhile, I have also tried my best". (LS)*

The delivery of unclear diagnoses and the lack of sufficient information can further intensify a mother's rejection of reality. Even if the mother is not fully aware of her child's condition, she may sense that something is wrong, leading to increased anxiety and fear. When mothers compare their children to those born without complications, the disparity often deepens their sense of disbelief and rejection of the situation. The hopes and dreams they had built are suddenly replaced by feelings of denial. This loss of hope can have profound effects, as the expectations of having an ideal child are replaced by fear and uncertainty about the child's future. For many mothers, this is an incredibly challenging experience, one that can lead to deep negative emotions and ongoing emotional distress.



The process of the mother accepting the child's condition

The process of mothers coping with a DS diagnosis in their children is a dynamic and challenging journey. Each mother's experience is unique, shaped by her individual circumstances, which means the time required to adapt varies widely. Generally, several stages are identified in the adaptation process. The first stage is the shock and loss of hope, where mothers experience intense negative emotions such as sadness, disbelief, and denial of reality. This reaction is often exacerbated if the diagnosis is communicated unclearly or with minimal information, and is further influenced by factors such as the child's position in the family, the mother's age, and family history.

The second stage is acceptance, where mothers begin to come to terms with their child's condition and start to build new hopes. This acceptance is often facilitated by several factors, including the establishment of an accurate diagnosis, social support from husbands, families, and medical professionals, and strong spiritual beliefs. Once acceptance is achieved, mothers typically enter a phase of hope restructuring and empowerment. During this phase, they begin to see new potential and possibilities in their children, becoming more proactive in parenting, exploring and nurturing their child's special interests, and setting more realistic and higher hopes. At this stage, mothers are better able to adjust both themselves and their hopes to align with their child's condition.

Several factors have been identified that facilitate a mother's acceptance of having a child with DS, including the accurate enforcement of the diagnosis, social support, and spiritual beliefs. Establishing a clear and accurate diagnosis is crucial for mothers to plan the necessary interventions and treatments to ensure their child's optimal development. Many mothers, like BG, continue to seek information, consult multiple specialists, and undergo various examinations to obtain a diagnosis they trust is accurate, as illustrated in the following story.

> *"If I was personally at that time, I needed a certain diagnosis, because otherwise, I would continue to deny it. After the diagnosis was upright, I was able to rebuild my hopes. Start being realistic too. I started to believe that I must go on no matter what the conditions". (BG)*

The confirmation of a definitive diagnosis is a crucial stage for mothers in the process of accepting a child with DS. The uncertainty surrounding a diagnosis can be a significant psychological burden, often leading mothers to remain in a phase of denial as a self-defense mechanism. The journey to obtaining an accurate diagnosis is frequently complex, involving multiple medical examinations and consultations with specialists, which can result in confusion and heightened anxiety. However, once the diagnosis is firmly established, it often serves as a psychological turning point for the mother. The certainty of the diagnosis enables mothers to begin rebuilding hope, adopting a more realistic outlook, and developing a positive attitude towards the challenges ahead. The enforcement of a diagnosis does more than just provide a medical label; it also initiates the psychological adjustment process, helping mothers find the internal strength to accept their new reality and move forward in caring for a child with DS. In addition to the importance of diagnosis confirmation, social support plays a critical role for mothers. This support system is vital for helping them navigate the emotional and practical challenges of raising a child with DS, as illustrated by Mrs. TT and FT in the following interview excerpt.

> *"I know that my son DS, during an examination before being discharged from the hospital by a pediatrician. Shocked, sad, shocked. Everything mixed into one, I cried as much as I could. My husband hugged and encouraged me, he said that he would raise wonder women together, that's what our child is called" (TT). "At first, I couldn't accept it, I just cried and cried every day. Every time I breastfeed my child, my tears keep falling.., but with the support of my husband and family as well as the doctors we went to for consultation everything was positive. Finally I began to be confident in my daughter's condition". (FT)*

Social support plays a crucial role in a mother's process of accepting her child's condition. Support from husbands, family, and medical personnel serves as a significant source of strength in coping with the emotional challenges that arise from the child's diagnosis. The various forms of support and care provided by a husband, in particular, can help a mother recover from emotional lows. This support not only offers emotional comfort but also motivates mothers to learn more about their child's condition, ultimately building their confidence to care for and educate a child with DS. Additionally, positive responses from the community when mothers take their children to public places help reduce stigma and boost their confidence. This comprehensive social support aids mothers in moving through the phases of grief and denial, guiding them towards acceptance and a renewed determination to provide the best care for their child.

Spiritual beliefs are also identified as a powerful factor that helps mothers in the acceptance process after receiving a DS diagnosis. The belief in God's omnipotence, and the understanding that only God can provide true strength, leads many mothers to find solace in surrendering to God's will. This spiritual strength is particularly evident in the experiences shared by Mrs. AG, RF, JM, and IH in the following interview excerpts.

> *"I tried to surrender and every night prayed according to my religion, praise God I began to have a big heart to take care of and take care of my child". (AG). "Just give up, maybe God is testing me through my child. Maybe it's a test of patience. So I thought "this is okay, God help me" if I let my guard down, I'm sure someone helped" (RF). "Yes. I have accepted the condition, this is maybe God's gift, this is how the child is taught". (JM). "God had another will, after our child was born, the doctor told us that our child had Mongolism. one type of DS. Oh Allah... too heavy, but we have to be strong to accept reality" (IH)*

Spiritual belief plays a crucial role as a source of strength and acceptance for mothers who have children with DS. The interview data reveals that many mothers lean on a higher power to face the challenges of raising a child with DS. They interpret the presence of their child as part of God's plan, viewing it as a test of patience, a special gift, or a divine will that must be embraced. Prayer serves as a vital pathway for these mothers, helping them find inner peace and strength.

Surrendering to God's will is not seen as passive resignation but rather as a form of positive acceptance. This mindset encourages mothers to continue striving to provide the best care for their children. The belief that God will provide help, even through others, instills a sense of security and optimism, helping them face various difficulties. Through their spiritual beliefs, mothers are able to cultivate a "big heart" to care for their children with DS, transforming their perspective from viewing the situation as a burden to seeing it as a grace. This spiritual strength empowers them to move from initial grief to a deeper acceptance and compassion for their children with special needs.

Reframing and mother's adaptation to child's condition

Acceptance of children with DS generally enables mothers to better understand their children and recognize their potential. This understanding, in turn, helps mothers build new hopes for their children's futures, as expressed by BG and TT.

> *"When I started to accept his condition, there was another hope I had for him... Now seeing my child at the age of 4 years, I am starting to think that this DS child is not a child who can't do anything, the proof is that many DS children are accomplished. And if I look at my child, it seems that the tendency is the same in all DS children, they are excellent imitators, and they can remember for a long time what they see, and because of that, there is a higher expectation (BG) again. "… Finally, in my heart I was determined that my son could and should be able to. I will try my best to give my best... Seeing that he was already able to lie on his stomach, sit down and walk. My enthusiasm and hope appeared. I started to be able to teach him." (TT)*

The process of reframing hope experienced by mothers of children with DS after the acceptance phase is a transformative journey that reflects a profound change in how they view their child. Once the initial acceptance of the child's condition is achieved, mothers begin to build new hopes, which often start modestly, focusing on the child's basic independence in daily activities. Over time, as they closely observe their child's development and explore their child's potential, their perspective begins to evolve. Mothers start to identify unique characteristics and strengths in their child, such as strong imitation skills and excellent long-term memory. This deeper understanding facilitates the formation of higher hopes.

These newly formed hopes motivate mothers to continuously strive to support their child's development, including providing the best nutrition, attention, and activities that promote growth. Every achievement, no matter how small, acts as a catalyst for new hope and renewed enthusiasm. Simultaneously, the mothers' confidence as caregivers grows, reflected in their determination to provide the best care and their belief in their child's potential. This process of adjusting hopes marks a significant shift in focus—from the child's limitations to their potential—demonstrating the mothers' ability to adapt and grow alongside their child, despite the unique challenges of raising a child with DS.

It was identified that mothers undergo a process of adjusting their hopes in a realistic and positive manner, in line with their acceptance of their child's condition. The support mothers receive, particularly from those closest to them, along with their spiritual beliefs, are key factors that continuously strengthen them, enabling them to eventually change their perspectives on their DS child. This growing confidence is further bolstered as the child's developmental progress becomes more apparent and as mothers discover their child's potential, as expressed by LS and TT in the following interview excerpts.

> *"Because initially I hoped to have a normal child. Right now, only we can see... what can he do... in the race... what will he have... leaning where he has a desire. Who knows if it could be his future. He could be a national swimmer". (LS). "Alhamdulillah, as time goes by with prayer and effort. My son has made a lot of progress and is starting to be independent. Seeing the development of a child who is always lively and cheerful, I am stronger, more patient and more affectionate for him. If anyone looks at it with a strange look, I will explain without hesitation that my son is DS. There are still many things that I have to work on for him. God willing, hopefully he can become a proud child for the family". (TT)*

After mothers are able to find new hope regarding their child with DS and their future, a significant shift in perspective occurs. The focus moves from the child's limitations to the potential and possibilities that can be nurtured. Mothers begin to actively observe and identify the natural tendencies and talents of their DS children, no longer fixated on typical developmental milestones. This new outlook encourages mothers to take a more proactive role in raising and supporting their children. They start to explore and cultivate their children's special interests, seeking out activities and areas where their child shows promise, with the aim of developing these skills for the future.

As children make developmental progress, even small achievements are met with great appreciation. These milestones are not only seen as signs of growth but also as indicators of future potential. This motivates mothers to continue providing targeted support and stimulation tailored to their child's unique needs. The shift in perspective also transforms how mothers view their own roles. They no longer see themselves merely as caregivers for children with special needs but as active supporters and advocates, dedicated to optimizing their child's potential. This newfound confidence empowers mothers to face societal perceptions with resilience, ready to explain their child's condition and even promote greater awareness and understanding of DS in their communities.

Overall, this change in perspective reflects the evolution from passive acceptance to an empowered approach, where mothers channel their energy into maximizing their child's potential. They don't just accept their child's condition; they actively seek ways to enhance it. The view of DS shifts from being seen as a limitation to being recognized as a unique characteristic that carries its own potential. Through this renewed perspective, mothers find deeper meaning in their roles, joy in their child's achievements, and greater confidence in their child's future, all while maintaining hope. By continuously developing their hopes and striving to optimize their child's potential, mothers demonstrate that they have navigated a complex process of adaptation to the presence of a DS child in their lives. They adjust their hopes, roles, and views, leading to a more meaningful and fulfilling life.

Discussion

The results of this study reveal three main themes in the journey of mothers who have children with Down Syndrome (DS): the loss of hope after diagnosis, the acceptance process facilitated by social support and spiritual beliefs, and the development of new hopes leading to a positive perspective.

The loss of hope following a DS diagnosis is a common reaction among mothers, often characterized by shock, deep sadness, and disbelief. This phenomenon can be understood through the concept of "ambiguous loss" as described by Jeter & Turns (2022), where parents grieve the loss of the "normal" child they had envisioned. The impact of this loss is exacerbated when the diagnosis is not communicated effectively, leading to prolonged emotional difficulties in caring for a child with DS (Gashmard et al., 2020; Rasendrakumar et al., 2021; Buyukavci et al., 2019; Suza et al., 2020).

The process of accepting a child with DS is complex and highly individual. This study identifies social support and spiritual beliefs as key factors that facilitate maternal acceptance. Darla & Bhat (2021) highlight instrumental social support as a primary coping strategy for families with children with DS. Support from husbands, families, and healthcare professionals provides significant emotional strength

to mothers as they navigate the challenges associated with the diagnosis.

Spiritual beliefs also play a crucial role in the acceptance process. Rodrigues et al. (2023) found that parents often rely on spiritual coping strategies to handle the challenges of raising a child with DS. These beliefs help mothers perceive the presence of a child with DS as part of a divine plan, aiding in their acceptance and adaptation. This acceptance process reflects the "Gaining Meaning" phase, where mothers begin to interpret their experiences through the lens of spirituality and social support (Lalor et al., 2009).

Following the acceptance phase, mothers begin to build new, more realistic hopes for their children (Nur et al., 2018). This shift in perspective is crucial for both the mother's and child's adjustment. The process involves reconstructing hopes, as mothers start to recognize and nurture the unique potentials and possibilities within their children (Korkow-Moradi et al., 2017; Lalor et al., 2009).

The difference in mothers' perspectives about their children with DS and their future after developing these new hopes is profound. Initially, mothers may view a DS diagnosis as an insurmountable limitation. However, after undergoing the adaptation process, their perspective shifts dramatically (Subu et al., 2024).

The implications of these findings are significant for clinical practice and family support. It is crucial for professionals to build trusting relationships with parents, communicating with respect, understanding, and empathy. Additionally, these findings support the development of interventions focused on strengthening social support and facilitating effective coping strategies, including those rooted in spirituality, to aid mothers in their adaptation journey.

Overall, this study provides valuable insights into the emotional and cognitive journey of mothers with children with DS, from the initial loss of hopes to the development of new, more realistic and positive hopes. The findings emphasize the importance of providing ongoing and comprehensive support for mothers and their children with DS, from the sensitive delivery of the diagnosis to the facilitation of the adaptation process and the cultivation of new, positive perspectives. Further research is needed to explore these experiences across diverse demographics to enhance the

transferability of the findings.

Conclusion

This study successfully explored the adaptation experiences of mothers after receiving a Down Syndrome (DS) diagnosis for their child. Using a Heideggerian phenomenological approach, the study revealed three main themes in the adaptation process: initial reactions to the diagnosis and the loss of hope, the acceptance process, and the restructuring of hope and adaptation to the child's condition. These findings provide a deep understanding of the complex journey mothers undergo in accepting and adapting to their child's condition, highlighting the importance of social support, spiritual beliefs, and adequate information in facilitating this process.

References

Anil, V., Chaitanya, M., & Sasidhar, R. (2016). Review on down syndrome in newly born babies. *Research & Reviews : Journal of Medical and Health Sciences Review on Sex Hormones*, *5*(3), 1–9.

Braga, P. P., da Silva, J. B., Guimaraes, B. R., van Riper, M., & Duarte, E. D. (2021). Problem-solving and coping in family adaptation of children with down syndrome. *Revista Da Escola de Enfermagem*, *55*, 1–9. doi: 10.1590/S1980-220X2020001803708

Buyukavci, M. A., Dogan, D. G., Canaloglu, S. K., & Kivilcim, M. (2019). Experience of mothers with down syndrome children at the time of diagnosis. *Archivos Argentinos de Pediatria*, *117*(2), 114–119. doi: 10.5546/AAP.2019.114

Celik, P., & Kara Uzun, A. (2023). Stressful experiences and coping strategies of parents of young children with Down syndrome: A qualitative study. *Journal of Applied Research in Intellectual Disabilities*, *36*(4), 881–894. doi: 10.1111/jar.13108

Creswell, J. W. (2016). *Qualitative Inquiry and research design choosing amoung five approach* (L. Habib (ed.); 3rd ed., Vol. 19, Issue 5). Vicki Knight.

Darla, S., & Bhat, D. (2021). Health-related quality of life and coping strategies among families with Down syndrome children in South India. *Medical Journal Armed Forces India*, *77*(2), 187–193. doi: 10.1016/j.mjafi.2020.07.010

Dias, C., Schwertner, C., Grando, D., Bidinotto, A. B., Hilgert, J. B., Schuch, J. B., de Azeredo, L. A., Bauer, M. E., & Hashizume, L. N. (2022). Caregiving of children with Down syndrome: impact on quality of life, stress, mental and oral health. *Special Care in Dentistry*, *42*(4), 398–403. doi: 10.1111/scd.12694

Eray, F., & Öpengin, E. (2023). Exploring the impact of special learning disability diagnosis on family

dynamics: A parental perspective. *International Journal of Educational Research Review*, *8*(4), 981–990. doi: 10.24331/ijere.1344731

Fuca, E., Costanzo, F., Ursumando, L., & Vicari, S. (2022). Parenting stress in mothers of children with autistic disorder, children with down syndrome and deaf children. *Journal of Clinical Medicine*, *11*(5), 15. doi: 10.3390/jcm11051188

Gashmard, R., Ahmadi, F., & Kermanshahi, S. M. K. (2020). Coping strategies adopted by Iranian families of children with down syndrome: A qualitative study. *Medicine (United States)*, *99*(28), E20753. doi: 10.1097/MD.0000000000020753

Goff, B. S. N., Springer, N., Foote, L. C., Frantz, C., Peak, M., Tracy, C., Veh, T., Bentley, G. E., & Cross, K. A. (2013). Receiving the initial down syndrome Diagnosis: A comparison of prenatal and postnatal parent group experiences. *Intellectual and Developmental Disabilities*, *51*(6), 446–457. doi: 10.1352/1934-9556-51.6.446

Grane, F. M., Lynn, F., Balfe, J., Molloy, E., & Marsh, L. (2023). Down syndrome: Parental experiences of a postnatal diagnosis. *Journal of Intellectual Disabilities*, *27*(4), 1032–1044. doi: 10.1177/17446295221106151

Hippman, C., Inglis, A., & Austin, J. (2012). What is a "balanced" description? Insight from parents of individuals with Down syndrome. *Journal of Genetic Counseling*, *21*(1), 35–44. doi: 10.1007/s10897-011-9417-2

Horrigan-Kelly, M., Millar, M., & Dowling, M. (2016). Understanding the key tenets of heidegger's philosophy for interpretive phenomenological research. *International Journal of Qualitative Methods*, *15*(1), 1–8. Doi: 10.1177/1609406916680634

Jeter, K., & Turns, B. (2022). Grieving the child that never was: Treatment of ambiguous loss in parents of children with down syndrome. *Australian and New Zealand Journal of Family Therapy*, *43*(2), 243–256. doi: 10.1002/anzf.1488

Korkow-Moradi, H., Kim, H. J., & Springer, N. P. (2017). Common factors contributing to the adjustment process of mothers of children diagnosed with down syndrome: A qualitative study. *Journal of Family Psychotherapy*, *28*(3), 193–204. doi: 10.1080/08975353.2017.1291238

Lalor, J., Begley, C. M., & Galavan, E. (2009). Recasting Hope: A process of adaptation following fetal anomaly diagnosis. *Social Science and Medicine*, *68*(3), 462–472. doi: 10.1016/j.socscimed.2008.09.069

Lee, E. Y., Neil, N., & Friesen, D. C. (2021). Support needs, coping, and stress among parents and caregivers of people with Down syndrome. *Research in Developmental Disabilities*, *119*(1). doi: 10.1016/j.ridd.2021.104113

Lehman, A., Leach, M., & Santoro, S. L. (2021). Delivering a new diagnosis of Down syndrome: Parent experience. *American Journal of Medical Genetics, Part A*, *185*(12), 3615–3622. doi: 10.1002/ajmg.a.62408

Sarkar, M., Biswas, S., & Rai, A. K. (2022). Molecular cytogenetic study of Down syndrome and it's health care experience. *World Journal of Advanced Research and Reviews*, *16*(2), 1093–1102. doi: 10.30574/wjarr.2022.16.2.1262

Muzayyanah, N., & Ersy Azheema Huda. (2023). The special parents for special children: A qualitative study. *Psychological Journal: Science and Practice*, *3*(2), 191–198. doi: 10.22219/pjsp.v3i2.27985

Nur, H., Wagey Tairas, M. M., & Hendriani, W. (2018). The Experience of hope for mother with speech delay children. *Journal of Educational, Health and Community Psychology*, *7*(2), 104. doi: 10.12928/jehcp.v7i2.8936

Rasendrakumar, A., Prabaharan, K., Ramanan, P. V., & Rasendrakumar, N. (2021). Parents' experience of receiving their child's diagnosis of Down's syndrome. *Karnataka Pediatric Journal*, *35*, 110–114. doi: 10.25259/kpj_23_2020

Rodrigues, S. de A., de Carvalho, E. Z. N., Campos, C. A., Fontanella, B. J. B., & Melo, D. G. (2023). Exploring spiritual/religious coping strategies among mothers of children with severe or profound intellectual disability during genetic counseling in Brazil. *Journal of Genetic Counseling*, *1*. doi: 10.1002/jgc4.1783

Skotko, B., Levine, S. P., & Goldstein, R. (2011). NIH Public Access. *American Journal of Medical Genetics, Part A*, *155*(10), 2360–2369. doi: 10.1002/ajmg.a.34235

Snyder C., et all. (1991). the Will and the Ways. *Journal of Personality and Social Psychology*, *60*(4), 570–585. doi: 10.1037/0022-3514.60.4.570

Subu, M. A., Lubis, E., Mustikowati, T., Marianna, S., Dewi, A., Dewi, S. H., Waluyo, I., Sutandi, A., Mottershead, R., Ahmed, F. R., Dias, J. M., & Al Yateem, N. (2024). Listening to the voices of mothers in Indonesia: Qualitative content analysis of experiences in parenting children with down syndrome. *Journal of Pediatric Nursing*, *77*(August), e8–e15. doi: 10.1016/j.pedn.2024.02.028

Suza, D. E., Napitupulu, M. A., & Hariati, H. (2020). Experiences of mothers of children with down syndrome. *Family Medicine and Primary Care Review*, *22*(4), 338–342. doi: 10.5114/fmpcr.2020.100445

Truitt, M., Biesecker, B., Capone, G., Bailey, T., & Erby, L. (2012). The role of hope in adaptation to uncertainty: The experience of caregivers of children with Down syndrome. *Patient Education and Counseling*, *87*(2), 233–238. doi: 10.1016/j.pec.2011.08.015

Wardah Tariq, Dawood Tahir, Shawana Kamran, & Tatheer Zahra. (2024). Insights into The Prenatal and Postnatal Knowledge & Critical Observations of Parents with Children who Have Down Syndrome: A Single Center Study. *Proceedings*, *38*(2), 122–127. doi: 10.47489/szmc.v38i2.507