

BEYOND EXPECTATIONS: A MOTHER'S JOURNEY WITH A CHILD WITH DOWN SYNDROME

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Abstract

This research aims to explore mothers' experiences in caring for children with Down syndrome by focusing on the challenges they face and the strategies used to overcome them. This research uses a qualitative phenomenological research type with an Interpretative Phenomenological Analysis (IPA) approach, with a focus on in-depth interviews involving two mothers who have Down syndrome children. The research results show that there are 4 ultimate themes from both subjects, namely (1) Child behavior, (2) Optimism, (3) Emotional turmoil, and (4) Social support. Social support from family and neighbors, and optimism play an important role in helping mothers to overcome the challenges faced in caring for children with Down syndrome. This research provides valuable insight into the importance of social support and optimism in helping individuals, especially mothers with children with Down syndrome, in facing the challenges of caring for children with Down syndrome.

Keywords: mother's experience, children, Down syndrome

Abstrak

Penelitian ini bertujuan untuk mengeksplorasi pengalaman ibu dalam merawat anak down syndrome, dengan berfokus pada tantangan yang dihadapi dan strategi yang digunakan dalam mengatasi hal tersebut. Penelitian ini menggunakan jenis penelitian kualitatif fenomenologis dengan pendekatan Interpretative Phenomenological Analysis (IPA), dengan fokus pada wawancara mendalam yang melibatkan dua orang ibu yang memiliki anak down syndrome. Dari hasil penelitian menunjukkan bahwa ada 4 tema induk dari kedua subject yaitu (1) Perilaku anak, (2) Optimis, (3) Gejala emosi, (4) Dukungan sosial. Dukungan sosial dari keluarga dan tetangga serta keoptimisan memainkan peran penting dalam membantu ibu untuk mengatasi tantangan yang dihadapi dalam merawat anak dengan down syndrome. Penelitian ini memberikan wawasan yang berharga akan pentingnya dukungan sosial dan keoptimisan yang membantu individu khususnya ibu dengan anak down syndrome dalam menghadapi tantangan dalam merawat anak down syndrome.

Kata Kunci: pengalaman ibu, anak, down syndrome

INTRODUCTION

Every married couple generally expects the presence of a healthy and normal child. However, reality does not always live up to expectations. Some couples are awarded

children with different developments, such as delays in their development, which is called a child with special needs. One example is a child who has *Down syndrome* (Dayana, 2023). *Down syndrome* is defined as a genetic disorder characterized by limitations in physical and mental development, stemming from abnormal chromosomal development (Ranti et al., 2022). This occurs due to the failure of a pair of chromosomes to separate properly during cell division, thus leading to the existence of three copies of chromosome 21, bringing the total to 47 chromosomes instead of the usual 46 (trisomy). This excess chromosome can disrupt cellular metabolism and cause abnormalities in brain development, resulting in impaired motor balance and eventually leading to *Down syndrome* (Nurzahra et al., 2024).

Children with *Down syndrome* have unique facial features such as creases in the corners of the eyes, narrow eyes that tend to point upwards, a flat nose, a face that resembles a Mongolian, and a small mouth with a flat palate so that the tongue sticks out a little. In addition, they usually have a more flexible body than normal children (Azalia et al., 2025). Several things cause children with *Down syndrome*, such as medications consumed or errors in intake during pregnancy, exposure to radiation, chromosomal abnormalities during conception, and mothers who give birth when they are over 30 years old (Haya & Fitri, 2024). However, in reality, 80% of children with *Down syndrome* are born to mothers who are less than 35 years old (Firdaus & Pradipta, 2019). Having a child with *Down syndrome* certainly provokes various kinds of responses from parents. The most common reaction when they first find out that their child has an abnormality is usually in the form of shock, inner shock, shock, and disbelief in the fact (Ayuningrum & Afif, 2020). In addition, parents, especially mothers, often experience prolonged stress. This is because mothers are with their children more often than fathers, so mothers need socio-emotional support and more information about their child's condition to care for and maintain them (Mardiah, 2022).

Mothers who have children with *Down syndrome* also face many other challenges, such as adjustments in work and daily life. Many mothers have to reduce working hours, change jobs, or even quit their jobs to take care of their children (Julianto & Umami, 2022). In addition, mothers must also manage the time between taking care of children, taking care of the household, and carrying out other obligations (Simahate & Munip, 2020). In many cases, mothers feel that they are the ones most responsible for their child's condition, so it can cause feelings of guilt and inferiority (Amanullah, 2022). The stress experienced by mothers is also often related to various adjustments that must be made in daily life. They may experience sleep disturbances, physical and emotional exhaustion, and constant worry about their child's future (Puspitasari et al., 2024). In some cases, the stress experienced by the mother can lead to physical and mental health problems, such as depression and anxiety (Rahmah & Ulfa, 2024).

There are several other impacts of the challenges of mothers who have *children with Down syndrome*. Some mothers feel overwhelmed and experience prolonged stress due to the heavy responsibility for childcare and parenting. Mothers are the first to feel pressure because they feel worthless and fail to give birth to a child in a normal state.

They may feel disappointed, sad, and ashamed because they feel responsible for their child's condition (Metavia & Widyana, 2022). In addition, it was also found that mothers who have *children with Down syndrome* do not feel burdened over time. This is based on the gratitude he has. These mothers felt a feeling of sincerity, resignation, and finally accepted the condition of their children (Nurhidayah, 2020). On the other hand, some mothers can overcome these challenges with a more positive attitude. They learn to accept their child's condition sincerely and feel grateful for their child's presence. Some mothers even find happiness in caring for children with *Down syndrome* because their children have fun traits, such as good social skills, being easy to manage, and being funny (Situmeang et al., 2023). Based on the above explanation, research on the experience of having a child with *Down syndrome* for parents, especially mothers, is important to conduct. The focus of this research is to understand the challenges they face, the impact of those challenges, and how they cope with and accept their child's condition. This research is expected to provide better insight into the needs and support needed by mothers in caring for children with *Down syndrome*, as well as provide insight into what can help them in facing this challenge.

METHOD

This research is qualitative research with *an interpretative phenomenological analysis* approach. According to Jonathan A. Smith, phenomenology is a philosophical approach to experiential research. The basic principle of phenomenological research is that experiences should be analyzed by paying attention to how the experience occurred in a person's life and talked about in terms that are not separate from the experience (Jaya, 2020). The research report will contain direct quotes that provide an overview of data sources such as interviews, field notes, personal documents, memos, and other official documents (Moleong;, 2017).

The data of this study were collected through semi-structured interviews that focused on the mothers' experience in parenting children with *Down syndrome*. The selection of informants uses the purposive sampling technique, which is a sampling method in which the researcher sets certain criteria in selecting informants. Informants are selected based on certain considerations that are in accordance with specific relevant characteristics (Hernawati, 2017). The criteria are as follows: (1) The participant is a mother who has *a child with Down syndrome*, (2) resides in West Sumatra, and (3) is Willing to be interviewed regarding the life experience of having a child *with Down syndrome*. With these criteria, the researchers then found 2 participants with demographic characteristics:

Table 1. Demographic Characteristics

Name (pseudonym)	Age (When the child is born)	Age (When interviewed)	Religion	Status in the family

Y	32	42	Islam	Mother of one child with Down syndrome and two daughters
I	22	40	Islam	Mother of one child with Down syndrome, one son, and two daughters

RESULTS AND DISCUSSION

The researchers identified several key themes that reflected the life experiences of mothers who had children with Down syndrome, according to the research objectives. This main theme is a combination of the superordinate themes found in both subjects. The main themes identified by the researcher are feelings of sadness over what others say to their children, believing in God's destiny, believing that children are the bearers of sustenance, forms of support by those around them, and mothers' experiences with children with Down syndrome.

The following is a table that summarizes the overall results of the research with the scientific approach:

Table 2. Summary of the overall results of the research

MASTER THEME	SUPERORDINATE THEME
CHILD BEHAVIOR	<ul style="list-style-type: none"> • PROVIDING UNDERSTANDING • SENSITIVE TO CHILDREN'S CHANGES • AWARE OF CHANGE
EMOTIONAL TURMOIL	<ul style="list-style-type: none"> • ANGER • FEELINGS OF SADNESS
OPTIMISTIC	<ul style="list-style-type: none"> • GRATITUDE • BEING AWARE OF THE CIRCUMSTANCES • BELIEF • SUBMISSION • TRY SINCERE
SOCIAL SUPPORT	<ul style="list-style-type: none"> • BACKING • THE EXISTENCE OF SOCIAL SUPPORT • GET SUPPORT

This study explores the experiences of two parents who have children with *Down syndrome*. Although the two subjects in this study had different backgrounds and life situations, there were some similarities between them in parenting children with *Down syndrome*. This can be seen from the challenges or problems they face. Mother Y and Mother I both have a problem where their child often goes berserk if the subject refuses to give what their child wants.

"If he goes berserk, it is usually because of a fight over his cellphone with his younger brother," (Y, 282-286)

"If you don't want to be loved, it will rage on him....." (I, 118-1234)

This is in line with Mulya (2017), who said that children with *Down syndrome* can behave aggressively, such as tantrums or tantrums. In addition, the problems faced are that each of them shows feelings of sadness, hurt, and anger when their child becomes a victim of ridicule by others. Y's mother felt sad and offended by the old parents who called *children with Down syndrome* idiots. Meanwhile, Mrs. I felt sad and upset when her child was called disabled by others.

"..... their parents call him an idiot, yes, sad ante," (Y, 59-61)

"Sometimes it's sad that this person, we say... If you are disabled, angry, you must be angry, right..."(I, 45-55)

Bad words or verbal violence are harsh words, such as mocking, prejudiced, intimidating, and threatening, that can hurt the feelings of others (Chalisyah et al., 2024). The impact of verbal violence on a person's psychology is feelings of anger, sadness, disappointment, fear, anxiety, eating problems, sleep problems, self-harm, and *suicide threats* ((Setiawan & Muttaqin, 2023). (Rahmatunnisa et al., 2020) support the above statement through their previous research, which says that negative words from the community or neighbors about children with *Down syndrome* are defective and different from other children, which makes mothers feel sad and hurt. According to Adhiyaman et al., (2007), the *coping positive reappraisal* strategy is a way for a person to cope with stress and pressure by trying to think positively and take lessons from what he is currently experiencing. It can be concluded that, in addition to feeling sadness due to their child being insulted by others, Mrs. Y and Mrs. I interpreted this situation as a sign of strength and confidence. Both subjects reported that they tried to think positively and take wisdom by believing that if God gave them a child with *Down syndrome*, it would mean that God would also give them the ability to take good care of and raise the child. Faith in God's destiny helps them overcome problems such as the sadness they are experiencing, as a source of motivation to give the best for their child and face challenges in the future.

"Ante believes that God gave a child like this to Ante, a sign that Ante is capable" (Y, 29-33)

".... sometimes they come to give sustenance" (Y, 229-237).

"If Allah gives us such a child, it means that we are able..." (I, 206-225)

"Yes, that's the term, the term increases the sustenance like that, right," (I, 69-71)

Andriana et al., (2024) support the above statement through their previous research, which says that positive thinking by viewing their child with Down syndrome as a gift from God encourages parents to accept their child's situation. In addition to thinking positively by accepting God's destiny, both subjects also overcome their grief through the support they get from the people around them. Mrs. Y and Mrs. I both received support from their families and neighbors. Both parents take part in caring for their children who have *Down syndrome*. Mrs. Y's siblings and parents also took care of her *child with Down syndrome*, even while she was working. The form of guarding is in the form of holding her child when she is fussy and difficult to manage. The neighbors of the two subjects assisted by notifying them when the children ran away. Neighbors and people around Mrs. I provided information about the whereabouts of her *child with Down syndrome* when she ran away. In addition, the two also received words of encouragement from those closest to them. Mrs. Y also received a monetary donation for her child because of his status as an orphan.

"... Ante's siblings who seem to give support as if they come to their house with a carry, then if the Ante family is supported. ... the Ante's parents accompany the Ante," (Y, 388-404)

"Sometimes I go to Lakaik, I don't bring any money, give to people." (Y, 686-688)

"If the people around you are just as strong as words" (I, 249-252)

"There are from parents sometimes parents also help with their education," (I, 254-256)

The theory of social support from Chen & Guo, (2020), which is related to the above, is emotional support and instrumental support. Emotional support is the act of showing empathy, care, and care for someone, so that they feel comfortable, loved, and cared for when facing stress or problems in life. Examples of emotional support can be seen from the words of encouragement received by both subjects and the concern of the neighbor who informs them of the whereabouts of their runaway child. Meanwhile, instrumental support is direct assistance provided in the form of practical or financial services that help meet a person's needs. This is evident in the physical assistance that Mrs. Y receives from her family, such as carrying her fussy child and taking care of him while Mrs. Y works, as well as the monetary donations she receives. Ghoniyah and Savira (2015) support the above statement through their previous research, which says that family support can encourage parents with children with *Down syndrome* to be able to accept their child's situation, take care of their child well, and overcome existing problems.

CONCLUSION

This study found 4 main themes of both subjects, among the main themes are child behavior, emotional turmoil, optimism, and social support. This research shows that mothers who have children with Down syndrome face many emotional and social challenges. However, with strong social support, religious beliefs, and positive thinking, they can overcome those challenges and care for their children with compassion.

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