Experiences of and Challenges Faced by Mothers Raising Children with Down Syndrome: A Qualitative Study

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ABSTRACT:

This qualitative study explored the experiences of and challenges faced by mothers raising a child with Down syndrome The study group consisted of mothers raising children with Down syndrome. The qualitative data were collected between July 30, 2025, and September 30, 2025. To identify these mothers' experiences and challenges, data were collected through a focus group interview with 15 participants using socio-demographic data collection and semi-structured interview forms. A descriptive thematic approach was used for data analysis, and coding and analysis were carried out using the MAXQDA qualitative data analysis program. Three main themes emerged from the analysis: emotional responsibility, social burden, and family responsibility. The findings suggest that mothers' experiences of and challenges in raising a child with Down syndrome affected their lives in several ways. Increasing the public awareness of the bio-psychosocial needs of mothers and their children and developing family-focused interventions and educational programs for children with Down syndrome could help reduce the difficulties these mothers face.

Keywords: Down syndrome, Mother, Children, Experiences-Challenges, Qualitative

1. Introduction

Down syndrome is a lifelong neurodevelopmental disability characterized by persistent and pervasive impairments in social understanding and communication, poor adaptive functioning, and restricted or repetitive behaviors and interests (Harm et al., 2013). Current epidemiological studies have revealed that the prevalence of Down syndrome has increased over the past two decades (Anderson et al., 2019).

Being the parent of a child with Down syndrome is a stressful and challenging experience (Çelik and Karauzun, 2013), particularly in countries where support services are limited. Caregivers of children with Down syndrome and autism often experience impaired mental health, including anxiety and depression (Cohrs and Leslie, 2017); lower quality of life and well-being; and higher levels of stress compared with caregivers of typically developing children (Hoffman, 2009) and children with other childhood disorders such as Down syndrome and/or attention deficit hyperactivity disorder (Hayes and Watson, 2013). Mothers of children with Down syndrome report higher psychological distress and caregiving burden (Estes et al., 2013); health problems (Fairthorne et al., 2015); lower levels of resilience (Van Riper, 2007); and difficulties in various areas of family life, including marital and sibling relationships and family socialization (Shin et al., 2009).

Stress factors for parents of children with autism include the severity of autism symptoms and the level of disability, such as the child's intelligence quotient (Craig et al., 2016). Therefore, having a child with lower levels of cognitive development and functional abilities may exacerbate parental stress owing to the child's long-term propensity for dependency. These problems have a direct and significant impact on mental fatigue among mothers and fathers (Cadman et al., 2012), which intensifies as children age. The difficulties children experience are often recognized by teachers and caregivers. In such cases, parents may experience increased stress as they face challenges in managing their child's comorbid deficits. Similarly, a perceived lack of social support among mothers of children with Down syndrome is a major predictor of mental health problems (Alon, 2019) and negatively affects parental stress and family socialization (Dias et al., 2022). Leeand et al. (2021) found that a lack of social support services contributes to parents experiencing greater difficulties with parenting skills related to the child's characteristics, further exacerbating parental stress and depressive symptoms. Children's characteristics often influence their mothers' decision to seek formal social support (e.g., professional help and respite services), which can assist parents in addressing their children's needs and reducing the social stigma experienced by their children (Lange et al., 2025).

This study conducted a qualitative investigation to explore the experiences of and challenges faced by mothers raising children with Down syndrome (Eskişehir sample).

2. Methodology

Research Design

The qualitative method of focus group interviews was used to identify the experiences of and challenges faced by mothers raising children with Down syndrome.

Participants

Data were collected face-to-face from mothers of children with Down syndrome living in Eskişehir between July 30, 2025, and September 30, 2025. Criterion sampling, a type of purposive sampling, was used to select participants. It involves examining individuals, situations, or events that meet specific criteria based on the purpose of the study (Yin, 2009). Participation in this study was subject to meeting the inclusion criteria. Mothers of children with Down syndrome living in Hakkari province who voluntarily agreed to participate and completed the informed consent form were included. Participants were recruited through social platforms (e.g., WhatsApp, Facebook, and Instagram) and invited to focus group interviews conducted in university faculty classrooms. Five sessions were held, each with 3

mothers, resulting in a total of 15 participants, as data saturation was reached.

Data Collection Methods

In the qualitative research process, the data and tools collected from various sources and settings are crucial for understanding the phenomenon under study (Bogdan and Biklen, 2007). In this study, data were collected using semi-structured interviews, document review, and a reflective researcher's journal to examine the situation comprehensively within its context (DeWalt and DeWalt, 2001; Merriam, 2009). The data collection techniques were developed based on the research questions. The research team used the literature to guide data collection with a sociodemographic data form, which included six questions regarding mothers' age, marital status, education level, and number of children as well as the gender of the child with Down syndrome and their age. A semi-structured interview form with three questions was used to identify the experiences of and challenges faced by mothers raising children with Down syndrome, including questions such as "Tell me about your experiences as a mother raising a child with Down syndrome. How has your child's Down syndrome impacted your life the most?" and "Can you tell me about your relationship with your child and family members? What concerns do you have about your child's future?" Prior to the study, the questions were reviewed for clarity and appropriateness by three experts in the field. Participants were coded as K1, K2, K3, and so on.

Data Analysis

In qualitative research, the data analysis process involves organizing and preparing the data. This includes several closely interconnected steps, such as coding data; organizing themes; and organizing, reporting, and interpreting data (Creswell, 2015). First, the recorded interviews were listened to multiple times and transcribed verbatim. The transcripts of the interviews conducted with 15 mothers of children with Down syndrome who were studying nursing were combined into a single text. The texts were read and reread in their entirety to identify and explore the participants' main ideas. Second, the documents obtained during data collection were examined. The semi-structured interviews and the researcher's diary were analyzed, and the results were recorded in the diary. After being transcribed and compiled by the researchers, the data from semi-structured interviews and document review reports were uploaded to MAXQDA version 2024. The researchers analyzed all data codes. During the coding phase, participants' opinions were reviewed, analyzed, and assigned codes to represent their views (Miles et al., 2014). The data analysis process is shown in **Figure 1**.

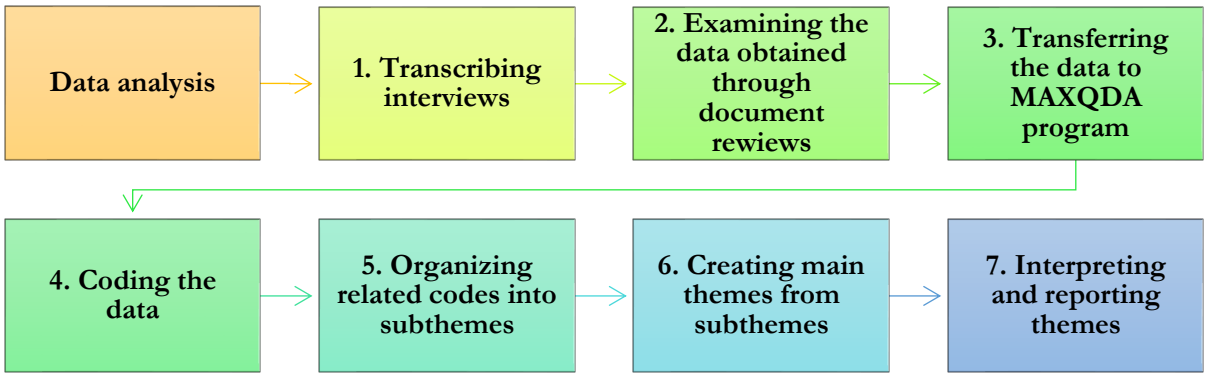

Figure 1. Data Analysis Process

Reliability

Certain measures can ensure reliability and credibility in case studies, including internal, external, and construct validity (Glesne, 2014). In this study, these measures included semi-structured interviews, document reviews, and a reflective researcher's journal during data collection. The researcher's journal documented challenges encountered in the field, experiences, and suggestions for research. The researchers regularly

reviewed the consistency of the data obtained from various sources. Video recordings, transcripts, and potential dialogues and documents from the semi-structured interviews were securely stored in virtual environments. Permission for the research was obtained from the Ethics Committee of Cyprus Aydın University (Date: 29/05/2025–IRB 2025/05.002). To avoid ethical violations, informed consent was obtained from the mothers of children with Down syndrome. The study was concluded to be ethically appropriate, and the research process ensured that the findings were valid and reliable.

3. Results

Table 1 presents the sociodemographic data of mothers of children with Down syndrome, including information about mothers and their children. Fifteen mothers participated in the study, with their ages ranging from 23 to 44. They had up to four children each, and the ages of the children with Down syndrome ranged from 3 to 13 years.

Table 1. Results of the Sociodemographic Data

Mothers' participation codes	What is your age?	What is your marital status?	What is your educational background?	How many children do you have?	What is the gender of your child with Down syndrome?	What is the age of your child with Down syndrome?
K1	27	Married	High school	3	Girl	7
K2	33	Married	Primary school	3	Boy	13
K3	29	Married	High school	2	Boy	3
K4	23	Married	High school	2	Girl	7
K5	26	Married	High school	4	Girl	8
K6	35	Married	High school	3	Boy	6
K7	30	Single	Primary school	2	Boy	10
K8	31	Married	High school	3	Girl	7
K9	26	Married	Middle school	1	Girl	6
K10	29	Married	Middle school	2	Girl	4
K11	41	Single	High school	1	Boy	12
K12	24	Married	University	1	Boy	9
K13	44	Single	University	2	Girl	11
K14	29	Married	High school	2	Boy	8
K15	36	Single	University	3	Boy	3

Table 2 presents the main themes and subthemes derived from the mothers' statements. The first main theme, *emotional responsibility*, includes *hopelessness, disappointment, and concerns about the child's future owing to their special circumstances*. The second main theme, *social burden*, encompasses the *fear of stigma and isolation*. The third main theme, *family responsibility*, covers aspects related to the *spouse, family struggles, and financial difficulties*.

Table 2. Main Themes and Subthemes

Main themes	Subthemes
Emotional responsibility	• Hopelessness due to their child's unique situation • Disappointment

Social burden	• Concerns about their child's future • Fear of stigma • Isolation
Family responsibility	• Conflicts with spouse • Family struggles and financial difficulties

1. Emotional Responsibility

When asked about their experiences of and challenges in raising a child with Down syndrome, all participants generally expressed a strong sense of emotional responsibility. Mothers reported feeling deeply upset about their child's condition and noted that they sometimes experienced periods of intense depression.

1.1. Hopelessness due to their child's unique situation: Some mothers stated that after their child was diagnosed with Down syndrome, they struggled to accept the diagnosis, exhibited aggressive behavior, and felt deeply saddened.

K8: "Since my child's diagnosis, I've never been able to accept it. I cried until dawn and was very upset."

K11: "I constantly questioned myself about my child's condition, wondering if it was my fault."

K10: "I feel so ashamed of myself; I caused everything."

K4: "Maybe I made so many mistakes. God is punishing me with my child's condition."

1.2. Disappointment: The majority of mothers expressed feelings of inadequacy in raising a child with Down syndrome and difficulty meeting their child's care needs.

K2: "My son needs intense attention and focus 24 hours a day to manage his behavioral difficulties. You know, having to meet his needs every day is very frustrating. Sometimes I feel like I don't love him enough, and this thought creates feelings of guilt."

K3: "I generally feel very lonely, and it makes me very tired."

K11: "I feel exhausted in every way. I'm physically exhausted, I can't keep up. I'm so tired of all the responsibility."

1.3. Concerns about their child's future: Mothers expressed worries about their child's future owing to their condition, feeling unable to invest in their child's education, job opportunities, and preparation for adulthood.

K4: "Even now, I don't know what to do, but I constantly think about what I can do for this child."

K2: "I keep thinking, 'Will my child be able to support himself in the future because of his condition? What will this child do if something happens to the family?'"

K9: "Will he be able to find a job in the future? Or who will care for this child in the future? I'm the one worrying the most about the family, and I can't figure this out."

2. Social Burden

2.1. Fear of stigma: Most mothers reported feeling stigmatized because of their children's Down syndrome, which restricted them from leaving the house.

K1: "Every time I go out, everyone's always looking at me and my child."

K5: "My child never interacts with other children at school; he's always in the classroom and doesn't leave."

K7: "Some families immediately discourage their children because they think they'll be socially ostracized just for hanging out with my child."

K12: "Some families think my child is crazy."

2.2. Isolation: Mothers indicated that their social ties and relationships have diminished. They often isolated themselves owing to their

child's condition and expressed concerns about maintaining previous relationships.

> *K15: "My old social life is practically gone because of my child's condition. I can't leave the house or form new relationships because of the constant fear of being stigmatized."*
>
> *K13: "Of course, I avoid going to social events (e.g., birthdays, parties, and weddings); these events are not for a family with a child with autism. When the child gets nervous, the risk of social judgment is high."*

3. Family Responsibilities

3.1. Conflicts with spouse: Families with children with Down syndrome are affected in multiple ways. Mothers reported experiencing numerous problems with their spouses, including anxiety, disagreements, arguments, and even divorce.

> *K6: "Because I constantly care for my child, there's a disconnect between us. The child's needs come first, which inevitably means I neglect my spouse, and then we start arguing."*
>
> *K14: "I have a huge responsibility. I'm so tired at the end of the day that I can't spend time with my spouse in the evenings."*
>
> *K13: "My spouse and I couldn't find common ground regarding my child's condition. We were constantly arguing about whether we should do this or that. Eventually, he said he would no longer take responsibility for my child's care and divorced me, which made me very upset."*

3.2. Family struggles and financial difficulties: Mothers reported that the constant effort to care for their child was exhausting. In addition, their child's Down syndrome led to significant healthcare expenses (e.g., speech and occupational therapy and psychotherapy), causing financial stress. Some treatments were abandoned due to a lack of additional financial resources.

> *K10: "Although I struggle with everything, we are financially exhausted because we pay so much for my child's private healthcare. Insurance doesn't even cover it, and we're at a loss."*
>
> *K9: "Although we struggle financially as a family, we can't keep up. I work extra jobs in my spare time, like cleaning."*
>
> *K5: "I had to quit my job because we couldn't keep up with my child's treatment. I have to take care of both, and I'm even trying to work two jobs at once."*

4. Discussion

This study used semi-structured interviews to directly examine the experiences of and challenges faced by mothers raising children with Down syndrome. The findings revealed three main themes and related subthemes based on the mothers' statements.

The first theme was emotional responsibility, encompassing hopelessness, disappointment, and concerns about their child's future owing to their unique situation. Mothers generally perceived responsibility as fulfilling their fundamental roles for their children and the family. Pillay et al. (2012) concluded that mothers of children with Down syndrome are emotionally burdened, sometimes experiencing diminished hope for the future due to their children's condition. Rahimi and Khazir (2019) examined parents' perceived life experiences of raising a child with Down syndrome and identified three main themes: "continuing a difficult life that is not suitable for accepting a child with Down syndrome," "social environment," and "perceived future concerns." These themes demonstrated that parents share significant worries about their children's care. Çelik and Karauzun (2023) explored the stressful experiences and coping strategies of parents of young children with Down syndrome. Their qualitative study revealed that the families experienced emotional burdens; caregiving stress; coping with stigma and discrimination; concerns about the future; and difficulties related to health, education, and finances. Other studies indicate that raising a child with autism, compared with Down syndrome, can lead to an increased emotional burden among mothers, including heightened parenting stress, anxiety, guilt, and feelings of being overwhelmed (Nealy et al., 2012; Smith et al., 2010). Papadopoulos (2021) examined

the experiences of and difficulties faced by mothers raising a child with autism spectrum disorder, and Suza et al. (2020) studied mothers of children with Down syndrome. Both studies offered findings similar to ours, showing that mothers often feel inadequate under their heavy responsibilities, struggle to provide psychological support to their children, and experience hopelessness.

The second theme was social burden, with the subthemes of the fear of stigma and isolation. Mothers reported experiencing social anxiety during and after their children's upbringing, social distancing, and social disapproval. They also noted a significant social impact, including increased isolation from friends and extended family. Gobriel (2018) studied the lived experiences of mothers of children with autism spectrum disorder in Egypt and found that mothers tended to keep their children at home to avoid stigma, which led to social isolation. Aruwajoye (2024) examined mothers raising children with Down syndrome in Western Nigeria and observed that children faced stigma, isolation, and social pressure. Furthermore, Currie and Szabo (2020) reported that parents caring for children with rare neurodevelopmental disorders experienced social taboos and stigma, reflecting challenges similar to our findings. Amorim and Shimizu (2022) conducted a bioethical analysis of stigma among caregivers of children with Down syndrome and concluded that societal stigma fosters feelings of inferiority, social disadvantage, unemployment, reduced financial resources, lack of acceptance, intolerance, social invisibility, limited healthcare access, and poor quality of life. Tekola et al. (2020) reported that parents of children with developmental disabilities in Ethiopia often isolated themselves and their children from social life (shared stigma), which parallels our findings. Additionally, Deakin and Jahoda (2020) found that mothers were highly sensitive to the stigma surrounding Down syndrome and took measures to prevent their children from becoming aware of it and being socially isolated. Similarly, Luetke Lanfer et al. (2025) reported comparable stigma experiences among caregivers of children with disabilities in Freetown, aligning with the social burden described by our participants.

The third main theme was family responsibility, with subthemes of conflicts with spouse, family struggles, and financial difficulties. Mothers often prioritized the needs of their children with autism spectrum disorder, focusing on coping with increasing childcare challenges, which led to changes in family dynamics. Studies have reported deterioration in family members' relationships, mothers' inability to spend time with their spouses, ongoing struggles, and financial difficulties. Fucà et al. (2022) studied parenting stress in mothers of children and adolescents with Down syndrome and concluded that parents' work and economic situations affected the family structure, resulting in insufficient family care and related problems. Brobst et al. (2009) found that the divorce rate was higher among parents of children with autism spectrum disorder compared with families of children without disabilities. Even among parents who remained married, raising a child with autism was associated with lower marital satisfaction compared with parents of typically developing children (Gau et al., 2012). Alam El-Deen et al. (2021) reported that the burden on family caregivers of children with Down syndrome increased alongside financial pressures, leading to deterioration in family relationships. Darla and Bhat (2021) studied the health-related quality of life and coping strategies of families with children with Down syndrome in South India. They found that children's increasing life expectancy further amplified the economic burden due to healthcare costs. Ou et al. (2015) reported that in urban China, the financial impact of a preschool child with autism on families was 16 times greater than that for a typically developing child, reflecting similar financial burdens described by our participants. Moreover, in a qualitative study in Istanbul on parenting challenges of children with autism spectrum disorder, Rfat et al. (2023) found that parents expressed concerns about financial burden, family conflict, mental health issues, and community challenges, echoing our findings. Hayden et al. (2023) reported that the behavioral adjustment of children with intellectual disabilities

and their siblings is closely related to sibling relationship quality and that mothers face significant struggles in managing this process.

5. Conclusion

This study provides valuable insights into the experiences of and challenges faced by mothers raising a child with Down syndrome. Mothers encountered a range of difficulties, including emotional and social burdens, family-related challenges, and financial pressures. They identified their children's behavior and family struggles as primary sources of caregiving burden, stress, and financial strain while perceiving significant stigma from their communities. These challenges had a substantial and far-reaching impact on their lives. To broaden the applicability of these findings, further research with larger, more representative samples including fathers and, where possible, other family members would be beneficial.

Limitations: While this study provides evidence on the experiences and challenges of mothers raising a child with Down syndrome, several important limitations should be considered. First, the nature of qualitative research limits generalizability. Recruiting participants from a broader and larger population could help future studies capture a wider variety of mothering experiences. Second, this study does not reflect the lived experiences of fathers raising a child with Down syndrome. This is particularly important as fathers' involvement has consistently been shown to contribute significantly to positive child development. Future research should examine the role and experiences of fathers in caring for a child with Down syndrome. Additionally, studies that integrate perspectives from the entire family could provide insights into shared feelings and experiences, as interactions among family members often yield unique and meaningful findings, contributing to the development of effective family-based interventions. Third, future research should explore mothers' experiences and challenges related to their children with Down syndrome not only during childhood but also at different developmental stages, including adolescence and young adulthood.

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