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A Lifelong Responsibility: A Transcendental Phenomenological Study of Mothers of Children with Disabilities

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Research Article

Keywords: Children with disabilities, parental experience, motherhood, future concerns, phenomenology

Posted Date: November 10th, 2026

DOI: https://doi.org/10.21203/rs.3.rs-11659615/v1

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Additional Declarations: No competing interests reported.

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Abstract

Raising a child with a disability is a complex and enduring experience that can reshape mothers' psychological, social, relational, and future-oriented lives. Although qualitative research on maternal caregiving is growing, less is known about how mothers' concerns about their children's futures are intertwined with their own life course and how culturally grounded meaning-making shapes this experience. This study aimed to explore the lived experiences of mothers of children with disabilities and the meanings they attribute to motherhood and their children's futures. A qualitative study guided by Moustakas's transcendental phenomenological approach was conducted with six mothers of children with disabilities. Participants were selected through criterion sampling. Data were generated through an online focus group and analyzed by distinguishing individual experiential accounts from interactional contributions, followed by phenomenological synthesis across participants. Four interrelated dimensions emerged: finding new meaning in life, motherhood at the center of life, living with uncertainty, and the need to be seen and understood. Mothers described motherhood as an enduring responsibility involving personal transformation, self-deprioritization, emotional demands, and continuous adaptation. Major concerns involved education, independent living, and life after parents. Understanding, acceptance, and peer support were also emphasized. The findings highlight the need for family-centered psychosocial services that address mothers' well-being alongside their children's developmental needs, including peer support and future-oriented planning.

Keywords: Children with disabilities; parental experience; motherhood; future concerns; phenomenology

A Lifelong Responsibility: A Transcendental Phenomenological Study of Mothers of Children with Disabilities

Children with disabilities (in Türkiye commonly referred to as children with special needs [özel gereksinimli çocuklar]) are individuals who require ongoing or temporary support in education, health, and social services due to intellectual, physical, sensory, behavioral, or developmental differences (Aktan, 2021). The World Health Organization (2023) conceptualizes disability in relation to limitations in functioning and participation that emerge through the interaction between health conditions and environmental and personal factors. Thus, having a child with a disability affects not only the child's developmental trajectory but also parents' psychosocial adjustment, family roles, social participation, and expectations for the future (Yüksel & Tanrıverdi, 2019). Parents may need to reorganize substantial aspects of their lives around caregiving responsibilities. This process can affect social life, career goals, and personal development plans (Çetrez İşcan & Malkoç, 2017), while the intensive demands of caregiving may also create considerable economic pressures and, in some cases, lead mothers to withdraw from employment (Karadağ, 2014). The presence of a child with a disability may further reshape family roles and influence parents' life satisfaction (Hassamancıoğlu et al., 2020). In particular, when caregiving responsibilities are disproportionately assumed by mothers, they may experience increased psychological distress and difficulties in maintaining their own well-being (Avşaroğlu & Gilik, 2017). Beyond these individual-level challenges, social and relational factors also play an important role in parents' adaptation. Social support and societal attitudes toward disability can influence parents' coping processes and perceptions of their experiences (Bayraklı & Kaner, 2012). Limited social support may contribute to feelings of isolation and hopelessness, whereas supportive family and social environments can strengthen family resilience (Karadağ, 2009; Özbay & Aydoğan, 2013). Accordingly, supporting families of children with disabilities requires approaches that address not only children's developmental needs but also parents' psychosocial well-being and family functioning. Family-centered approaches emphasize the involvement and needs of family members in intervention processes and may contribute to parental well-being and children's development. Social awareness and inclusive practices are similarly important for reducing exclusion and facilitating families' participation in social life (Altuntaş & Atasü-Topçuoğlu, 2016; Sucuoğlu, 1995).

Parents' experiences may become particularly complex following the diagnosis of a child with a disability. This process involves not only emotional reactions but also cognitive, social, relational, and economic adaptation (Patterson, 1988). Parents may experience intense and fluctuating emotional responses while simultaneously attempting to understand their child's needs and develop strategies for providing appropriate care (Kurt et al., 2008).

Adaptation to this new situation unfolds over time and has been conceptualized as involving different stages through which parents gradually reorganize their understanding of their child, their family roles, and their expectations for the future (Drotar et al., 1975). Following diagnosis, parents may initially experience shock, uncertainty, and emotional turmoil. They may subsequently seek information and professional support to understand the child's condition and identify appropriate educational and therapeutic resources. Over time, parents may develop new routines and reorganize family life around their child's needs. A further stage involves developing longer-term perspectives concerning the child's participation, independence, and future care. Within this process, uncertainty and perceived demands interact with existing family resources and coping capacities, influencing family adjustment and adaptation (McCubbin & Patterson, 2014; Patterson, 1988).

These experiences do not occur in isolation; rather, they are shaped by interactions between the family and the broader social, educational, health, and institutional environments (Bronfenbrenner, 1979; Navarro & Tudge, 2023). Bronfenbrenner's (2000) Ecological Systems Theory provides a complementary framework for understanding these experiences. At the microsystem level, parent–child relationships and family interactions are central; at the mesosystem level, relationships among family, school, health services, and other support systems become important. Broader societal attitudes, cultural expectations, and social policies constitute part of the macrosystem and may either facilitate or constrain family adaptation. From this perspective, mothers' experiences of raising a child with a disability are shaped by the interaction of individual, family, institutional, and societal conditions rather than by the child's characteristics alone. Consistent with this perspective, the availability of social support and opportunities for psychological adaptation may influence how mothers experience and manage caregiving responsibilities (Özdemir, 2025).

One particularly important dimension of this experience concerns mothers' perceptions of the future. Questions about how children's educational, vocational, social, independent-living, and care needs will

be met may generate persistent uncertainty and anxiety (Çiftçi, 2021). Future anxiety refers to worry and unease concerning uncertain or potentially adverse future circumstances (Zaleski, 1996). For parents of children with disabilities, future-oriented concerns may involve who will provide care, whether the child will achieve an adequate level of independence, what educational and vocational opportunities will be available, and how financial and social resources will be sustained over time (Cengiz et al., 2021). Such concerns may also be associated with psychological burden and reduced quality of life. Internationally, the question of what will happen when parents are no longer able to provide care has been documented among ageing family carers (Brennan et al., 2018), and a systematic review has shown that, despite such concerns, many families of individuals with intellectual and developmental disabilities have not engaged in concrete future planning (Lee & Burke, 2020). In Türkiye, a Parental Future Anxiety Scale has recently been developed specifically for parents of children with intellectual disabilities (Yıldız, 2024).

Although these quantitative scales make important contributions to measuring anxiety numerically, they may remain limited in terms of depth. Despite the growing literature on families of children with disabilities, many studies have focused on psychological adjustment, stress, social support, and related variables through quantitative designs; for example, a meta-analysis has shown elevated parenting stress among parents of children with autism compared with parents of typically developing children (Hayes & Watson, 2013). Such approaches provide valuable information about the prevalence and correlates of parental difficulties but offer more limited insight into how mothers themselves experience, interpret, and give meaning to motherhood in the context of raising a child with a disability. Internationally, qualitative research has shown that mothering a child with a disability can involve benefits as well as burdens (Green, 2007), that parents may come to experience family life as a world of their own (Woodgate et al., 2008), and that caregiving experiences are shaped by cultural and contextual conditions (Mkabile et al., 2021). Recent qualitative studies in Türkiye have also begun to address mothers' perceptions of motherhood, caregiving difficulties, and support needs (Alataş et al., 2026; Gökçek & Boyacıoğlu, 2025; Işık-Uslu & Çetin, 2024; Özsavran et al., 2025). These studies have documented caregiving burden, changes in maternal roles, and support needs, but have generally treated concerns about the future as concerns about the child alone and have given limited attention to the cultural and spiritual frames through which mothers interpret their experiences. Nevertheless, less is known about how future-

oriented concerns are experienced in everyday life, how they influence maternal roles and priorities, and how mothers make sense of these experiences over time.

Lived experiences are also connected to the environment. Although raising a child with a disability involves challenges that may be shared across contexts, the way these challenges are experienced and interpreted is also shaped by cultural and social conditions. Gender roles, family structures, societal attitudes toward disability, and the availability of social support may influence mothers' responsibilities and expectations. In Türkiye, where family relationships and family-based caregiving remain important sources of support, caregiving responsibilities may be particularly concentrated within the family and, in many cases, on mothers. Examining mothers' experiences within this socio-cultural context can therefore contribute to a more contextualized understanding of motherhood, caregiving, uncertainty, and meaning-making among mothers of children with disabilities.

This gap is particularly important because the experience of raising a child with a disability is not solely a matter of burden or difficulty; it may also involve changes in meaning, identity, priorities, relationships, and perceptions of life. Understanding these dimensions requires attention to mothers' lived experiences and the meanings they attribute to them. Therefore, the present study adopts a transcendental phenomenological perspective to explore the lived experiences of mothers of children with disabilities and the meanings they attribute to motherhood and their children's futures. By focusing on mothers' experiential accounts, the study aims to illuminate how this experience is lived and interpreted and to provide knowledge that may inform psychosocial support for families. In doing so, it seeks to contribute to the literature in two ways: first, by examining how mothers' concerns about their children's futures are intertwined with their own aging, vulnerability, and life course, rather than treating future anxiety solely as a child-focused concern; and second, by illuminating how culturally and spiritually grounded meaning-making in the Turkish context shapes the lived experience of motherhood.

Method

Research Model

This study adopted Moustakas's (1994) transcendental phenomenological approach, which emphasizes describing lived experience and identifying its underlying essence through the meanings participants attribute to the phenomenon, to explore how mothers of children with disabilities experience and make sense of raising their children, particularly in relation to motherhood, everyday life, and concerns about

the future. The study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ; Tong et al., 2007; see Online Resource 1).

An online focus group, rather than a series of individual interviews, was selected primarily due to practical constraints in coordinating separate sessions with mothers who were simultaneously managing ongoing caregiving responsibilities, as reflected in the scheduling difficulties reported in the Study group section below. Consistent with Bradbury-Jones et al. (2009), focus groups can be compatible with phenomenological inquiry when participants' individual lived experiences are analytically preserved and the influence of group interaction is explicitly and critically considered, an approach adopted throughout the present study (see also Limitations and Directions for Future Research). Although data were generated through an online focus group rather than individual interviews, the focus group was used as an interactional context for eliciting, elaborating, and clarifying participants' experiential accounts. The group itself was not treated as the unit of analysis; rather, the phenomenon of interest remained the mothers' individual lived experiences. Interaction among participants provided opportunities for mothers to recall experiences, elaborate on their accounts, and reconsider aspects of their experiences in response to the accounts of other participants.

Study Group

The participants were six mothers of children with disabilities, recruited through criterion sampling. The inclusion criteria were having at least one child with a disability who was receiving special education support, having direct and ongoing experience of raising this child, and being able to participate in, and reflect on, an online focus group discussion. Potential participants were reached through announcements at rehabilitation centers that included information about the study. Initially, eight mothers expressed interest in participating; however, two were unable to participate because of scheduling constraints, resulting in a final group of six participants.

The participants shared the common experience of raising a child with a disability, although their individual experiences and perspectives varied. The demographic and child-related characteristics of the six participants are presented in Table 1.

The sample size was determined with reference to methodological recommendations for phenomenological and focus group research rather than to a predefined saturation criterion. Phenomenological studies typically involve small samples of individuals who have all directly

experienced the phenomenon, commonly ranging from three to fifteen participants (Creswell & Poth, 2018), and focus groups addressing sensitive and personally meaningful topics are recommended to include smaller groups of about five to eight participants so that each person has sufficient opportunity to speak (Krueger & Casey, 2015). In addition, the concept of information power suggests that a smaller sample can be adequate when the study aim is narrow, participants hold highly specific experiences relevant to that aim, the study is supported by an established methodological framework, and the quality of dialogue is strong (Malterud et al., 2016). These conditions applied to the present study: all six mothers had direct and ongoing experience of the phenomenon, the aim was focused, and the 104-minute session yielded an average of approximately 14 minutes of speaking time per participant. Consistent with critiques of data saturation as a universal criterion for qualitative sample size (Braun & Clarke, 2021), the adequacy of the data was therefore evaluated in terms of the richness and depth of the individual experiential accounts.

To maintain confidentiality during the group discussion, participants were identified by code names based on emotion words, as listed in Table 1.

Table 1

Characteristics of the participants and their children

Code name (emotions)	**Age**	**Educational background**	**Marital status**	**Number of children**	**Age of child with a disability**	**Type of disability**
Joy (P1)	43	High school	Married	4	9	Intellectual disability
Love (P2)	52	High school	Divorced	3	7	Visual impairment
Compassion (P3)	38	Undergraduate	Married	1	8	Language and speech difficulties
Hope (P4)	33	Two-year degree	Divorced	2	10	ADHD

Happiness (P5)	41	Middle school	Married	4	8	Hearing impairment
Longing (P6)	30	Undergraduate	Married	1	7	Autism

Note. P = participant. ADHD = attention-deficit/hyperactivity disorder. Code names were assigned by the researchers to protect participants' confidentiality.

Interview Form

A semi-structured focus group interview form was developed by the researchers to explore mothers' lived experiences of raising a child with a disability and their concerns regarding their children's futures. The form consisted of three main questions and 11 follow-up questions designed to elicit participants' experiences, feelings, perceptions, expectations, and the meanings they attributed to these experiences without directing them toward predetermined themes.

The questions were developed based on the relevant literature and reviewed by three experts, two with expertise in special education and one in guidance and psychological counseling. Their feedback was considered in revising the clarity, wording, and scope of the questions. The form was not pilot tested prior to data collection.

The questions were open-ended and used flexibly during the focus group discussion. Follow-up questions were used to encourage participants to elaborate on their experiences and meanings or to clarify statements requiring further explanation.

The main questions and examples of probing questions were as follows (translated from Turkish; the original questions used the term özel gereksinimli [special needs], which is the term commonly used in Türkiye):

If you were asked to describe what it is like to have a child with special needs using just one or a few words, what would you compare it to? (Metaphor question)

Probes: *"What experiences of yours does this metaphor reflect?" "What emotion in this metaphor resonates with you the most?"*

What are the challenges of raising a child with special needs? What are the areas where you struggle the most?

Probes: *"How did this process affect your life?" "Who supported you during this process?"*

What are your concerns about the future of your child with special needs?

Probes: *"What is the first thing that comes to mind when you think about your child's future?" "What kind of support do you need to cope with these concerns?"*

The metaphor question was included to encourage participants to express the meanings they attributed to their experiences at both symbolic and experiential levels.

Data Collection

The focus group session was conducted via Zoom, and participants joined the session from their own homes. At the beginning of the session, participants were informed about the purpose and procedures of the study, and voluntary informed consent was obtained for participation and audio recording. The interview was audio-recorded with participants' permission, and the researcher kept field notes throughout the session to document relevant contextual and interactional observations. No individuals other than the participants and the researcher were present during the interview. The session was conducted in Turkish, and the recording was transcribed verbatim for analysis. The analysis was carried out on the Turkish transcript, and the quotations reported in this article were translated into English by the authors, with attention to preserving their original meaning. Conducting the analysis in the original language and translating only the reported quotations was intended to minimize the loss of meaning that can occur in cross-language qualitative research (van Nes et al., 2010). Across the 104-minute transcript, individual participants' speaking turns amounted to an average of approximately 14 minutes (approximately 1,900 words) each (range: 11–16 minutes), providing a substantive basis for constructing individual experiential accounts despite the group format.

During the discussion, the researcher used the main questions and follow-up probes to encourage participants to describe concrete experiences and the meanings they attributed to them. Participants were also given opportunities to elaborate on, differentiate, or reflect on their experiences in relation to the accounts of other mothers. Toward the end of the discussion, participants were invited to reflect on the meaning of their experiences and whether hearing other mothers' accounts had prompted them to reconsider or recognize aspects of their own experiences.

Data Analysis

Data analysis followed Moustakas's (1994) transcendental phenomenological approach. Before and throughout the analysis, the researchers engaged in epoche by reflecting on and consciously bracketing their preconceptions regarding mothers' experiences of raising children with disabilities. Reflexive notes were maintained to document this process and increase awareness of potential interpretive influences. Epoche was understood as an ongoing reflexive process of identifying, reflecting on, and consciously bracketing preconceptions rather than as the complete elimination of prior knowledge or assumptions. Because the data were generated through a focus group, the analysis explicitly distinguished individually articulated experiential accounts from interactional contributions. Statements in which participants described their own experiences, feelings, perceptions, or meanings were treated as individual experiential accounts. Statements that primarily expressed agreement, affirmation, clarification, or extension of another participant's account were interpreted in relation to the preceding interaction and were not automatically treated as independent experiential statements. This distinction ensured that the focus group was not analyzed as a collective experience and that participants' individual lived experiences remained the primary basis of the phenomenological analysis.

Following epoche, the transcript was read repeatedly to achieve familiarity with the dataset. During horizontalization (i.e., initially treating every relevant statement as having equal value), statements directly expressing participants' experiences and meanings related to the phenomenon were identified as significant experiential statements. These were examined at the participant level to develop individual experiential accounts that preserved each participant's distinctive perspective. The individual accounts were then compared across participants to identify recurrent experiential meanings and the relationships among them. These patterns were synthesized into composite textural and structural descriptions, from which the phenomenological essence was derived. This approach aimed to preserve the distinctiveness of each mother's lived experience while also identifying the common experiential structure of the phenomenon.

The data were analyzed manually without qualitative data analysis software. Consistent with the interpretive aims of phenomenological inquiry, agreement between coders was pursued through investigator triangulation and consensus rather than through a statistical index of coding reliability. Two researchers first independently identified significant statements and developed preliminary meaning units and individual experiential accounts. They then met to compare their interpretations line by line,

examining each point of divergence against the relevant transcript segments and the surrounding interactional context of the focus group. Divergent interpretations were not resolved by majority or by default to either researcher's view; rather, they were discussed until a shared understanding grounded in participants' own words was reached, and the resulting decisions, including the merging, renaming, or redefinition of meanings, were recorded in the reflexive notes as part of an audit trail. The emerging themes and composite descriptions were subsequently reviewed by the full research team.

Trustworthiness

The quality of the qualitative research process was considered in terms of credibility, transferability, dependability, and confirmability, following Lincoln and Guba (1985).

Credibility: The researchers repeatedly reviewed the complete transcript, distinguished individual experiential accounts from interactional statements as described above, compared individual meanings across participants rather than treating the focus group as a single collective narrative, and used direct quotations to demonstrate the connection between participants' accounts and the findings.

Dependability: The analysis followed the systematic sequence described above, from epoche to the composite descriptions; two researchers coded the data independently and resolved differences through discussion until consensus was reached, and analytic decisions were documented throughout the process.

Confirmability: Reflexive notes were maintained throughout data collection and analysis, and interpretations were grounded in participants' experiential accounts rather than predetermined conceptual expectations.

Transferability: Detailed information about the participants, research context, data-generation process, and analytic procedures was provided to enable readers to assess the applicability of the findings to other contexts.

Member checking was not conducted. Accordingly, credibility was supported through repeated engagement with the data, reflexivity, independent examination, direct quotations, systematic comparison of individual experiential accounts, and transparent documentation of the analytic process.

Researcher Characteristics

The focus group interview was conducted by one of the authors, an Associate Professor with a PhD in Guidance and Psychological Counseling. The researcher has academic and professional experience in

qualitative research, counseling, special education, and family-related research, as well as extensive experience in facilitating group processes, including group guidance, group counseling, and group supervision. Participants were informed about the purpose of the study and the researcher's role in the research. No prior personal or professional relationship existed between the researcher and the participants.

The researchers recognized that their academic and professional backgrounds could influence the interpretation of participants' experiences. Accordingly, reflexivity was maintained throughout data collection and analysis (Berger, 2015; Finlay, 2002). Because the focus group was facilitated by a researcher who was also involved in the analysis, particular attention was paid to this dual role. The facilitator's background in psychological counseling and group processes supported rapport and the elaboration of experiences, but it also carried the risk of steering the discussion toward familiar clinical concepts, such as burden, stress, or coping, or of responding to participants in a counseling rather than a research capacity. To address this, the facilitator used open-ended questions, checked reflective summaries with participants during the session by asking whether they accurately captured what had been said, and did not offer advice or interpretations to participants. With regard to insider–outsider positioning (Dwyer & Buckle, 2009), the facilitator's professional familiarity with families of children with disabilities, combined with the absence of shared lived experience as a mother, positioned him partly as an insider and partly as an outsider to the phenomenon. During analysis, the facilitator's interpretations were examined alongside those of a second researcher who independently coded the data and was not present during the focus group; differences were discussed with reference to the transcript, which helped to identify and question interpretations shaped by prior professional assumptions. The emerging themes were then reviewed by the full research team, whose members represent psychological counseling and child development.

Ethical Considerations and Data Protection

The study was approved by the [blinded for review] Social and Human Sciences Ethics Committee (Approval No. [blinded for review]) prior to data collection, and all procedures were conducted in accordance with the 1964 Declaration of Helsinki and its later amendments. Participants were informed about the purpose of the study, the voluntary nature of their participation, and the audio recording of the session, and informed consent was obtained from all participants. Participants were informed that the

audio recording would not be shared outside the research team, and that anonymized direct quotations from the transcript, without their names or any identifying information, could be included in scientific publications.

Particular attention was paid to protecting the privacy of participants and their children. Because the study involved a small number of mothers recruited through local rehabilitation centers, and because the transcript contains detailed information about the children's diagnoses, educational settings, and family circumstances, participants could potentially be re-identified from the full dataset even after names are removed. To minimize this risk, participants were addressed by emotion-word code names during the session and in reporting, identifying details were removed from the reported quotations, and access to the audio recording and transcript was restricted to the research team. For the same reasons, and in line with the conditions of the ethics approval and the consent obtained, the audio recording will not be shared and the dataset is not publicly available; however, anonymized Turkish transcripts and their English translations can be made available by the corresponding author upon reasonable request.

Results

The phenomenological analysis first examined the individual experiential accounts of the six mothers, distinguished from interactional statements within the focus group, and subsequently identified recurrent meanings across participants; thus, the focus group was not treated as a single collective narrative.

At the individual level, mothers described raising a child with a disability in distinctive but partially overlapping ways. Joy emphasized changes in her perspective on life and a strong sense of responsibility for her child's education. Love described acceptance as an ongoing process while experiencing exhaustion and the pressure to remain strong. Compassion highlighted patience, personal learning, and self-deprioritization, as well as the need to be listened to. Hope emphasized continuous responsibility and the relief of being understood by mothers with similar experiences. Happiness described changing life priorities and the importance of social acceptance. Longing emphasized enduring responsibility, emotional and physical exhaustion, concerns about the future, and focusing on what could be done in the present.

Comparison of these individual experiential accounts revealed four interrelated dimensions: (1) finding new meaning in life, (2) motherhood at the center of life, (3) living with uncertainty, and (4) the need to be seen and understood. Each of the four dimensions was present in the accounts of all six mothers,

whereas individual subthemes were articulated by two to four mothers, reflecting the different ways in which each mother lived these shared dimensions. These dimensions, their corresponding experiential meanings, and the number of mothers contributing to each subtheme are presented in Table 2.

Table 2

Themes, subthemes, and phenomenological meanings derived from participants' experiential accounts

Theme	**Subtheme**	**Phenomenological meaning**	**Participants (n)**	**Illustrative quotation**
Finding New Meaning in Life	Destiny and trials	The effort to make sense of and accept hardship	Joy, Love (2)	"To me, this process is like a test" (P2)
	Growing alongside your child	Transformation in the perception of self and life	Joy, Compassion, Happiness (3)	"My child taught me a lot in this sense" (P3)
	Lifelong responsibility	A continuous experience of motherhood	Hope, Longing (2)	"You feel that this responsibility will never end" (P6)
Motherhood at the Center of Life	Taking on multiple roles	The expansion of the role of motherhood	Joy, Hope, Longing (3)	"You have to follow up constantly" (P4)
	Putting oneself second	Putting your own needs on hold	Joy, Compassion, Happiness (3)	"My life has been shaped entirely around their education" (P1)
	Feeling like you have to stay strong	The pressure to maintain emotional resilience	Love, Longing (2)	"Even if I cry, I have to keep going" (P2)

Living with Uncertainty	Concerns about education	Uncertainty regarding the adequacy of the educational process	Joy, Compassion (2)	"My biggest concern is whether education will be sufficient in the future" (P1)
	Concerns about independent living	Concerns about being able to live independently in the future	Hope, Happiness (2)	"I want them to do what they can by themselves" (P4)
	Anxieties about life after parents	Fears about the child's life without parents	Love, Longing (2)	"What will happen when I am gone?" (P6)
The Need to Be Seen and Understood	Social isolation	The experience of feeling misunderstood and excluded	Love, Happiness (2)	"Even people's stares can be exhausting" (P5)
	Solidarity with those who have had similar experiences	Drawing strength from shared experiences	Joy, Love, Compassion, Hope (4)	"Mothers who go through the same things understand me best" (P4)
	The need for support and acceptance	Expectations for emotional and social support	Compassion, Longing (2)	"Sometimes I just want someone to listen to me" (P3)

Note. P = participant; n = number of mothers whose individual experiential accounts contributed to the subtheme. Quotations are English translations of the original Turkish.

When the themes presented in Table 2 are considered together, it becomes evident that mothers experienced raising a child with a disability as a comprehensive life experience that reshaped their understanding of life, everyday priorities, maternal responsibilities, expectations for the future, and relationships with others. The findings are presented below according to the four interrelated dimensions identified through the phenomenological analysis.

Theme 1: Finding New Meaning in Life

The first dimension concerned the ways in which mothers made sense of raising a child with a disability and how this experience influenced their understanding of themselves and their lives. Three interrelated experiential meanings emerged: destiny and trials, growing alongside the child, and lifelong responsibility.

Destiny and trials. Joy and Love described the experience partly through the concepts of destiny and trial. Joy recalled the questioning that marked the early period: “At first it was a really difficult time. You inevitably keep asking, ‘Why did this happen to us?’ I searched for the answer for a long time. There were even times when I blamed myself, wondering whether I had done something wrong. Then I realized that it was not in my control, and I began to look at it differently.” Love emphasized that acceptance did not mean that the difficulty had disappeared: “To me, this process is like a test. Accepting does not mean that everything is fine. You simply know that this is now a part of your life, and you begin to live accordingly.” These accounts indicate that mothers initially experienced questioning, self-blame, and uncertainty but gradually attempted to incorporate the experience into their life narratives through acceptance and meaning-making. Joy also described a shift from asking why the experience had happened toward focusing on what she could do for her child in the present: “Even if you find the reason, some things do not change. But if there is something you can do for your child today, you can focus on that, and that makes you feel a little stronger.”

Growing alongside your child. Participants also described changes in their perspectives, priorities, and understandings of themselves. Compassion described learning patience through supporting her child’s development: “I used to be very impatient. Now I know that some things can take time. My child taught me a lot in this sense; I began to see not only my child’s development but also myself differently.” Happiness described how loss and new meaning coexisted: “You give up some things, that is true. But at the same time, together with your child, you notice the meaning of other things. Even a small improvement can be a great happiness for you.” Joy similarly indicated that the experience had changed her perspective on life and increased her attention to what was meaningful in the present. Thus, mothers did not describe the experience solely as a source of difficulty; they also associated it with learning, personal change, and a reorganization of priorities.

Lifelong responsibility. Motherhood was described as an enduring responsibility that continued as the child grew. Longing chose the word “responsibility” to describe her experience and explained: “You feel

that this responsibility will never end. Some parents feel a little relieved when their children grow up. For me, it does not seem that it will be like that, because you are constantly thinking about how your child will live later on and what they will be able to do on their own." Hope similarly emphasized the need to remain continuously attentive: "You have to follow everything all the time: their education, their needs, what they will do. Sometimes a whole day is spent on things related to your child. You feel that if you do not keep track, something will fall behind." This experience of responsibility extended beyond immediate caregiving and remained closely connected to mothers' perceptions of the future.

Theme 2: Motherhood at the Center of Life

The second dimension reflected the extent to which motherhood became intertwined with mothers' everyday lives. Participants described assuming multiple roles, organizing their daily lives around their children, postponing their own needs, and feeling pressure to remain strong despite emotional and physical exhaustion.

Taking on multiple roles. Mothers described themselves as more than caregivers in their children's educational and developmental processes. They also assumed roles resembling those of teachers, guides, advocates, and continuous sources of support. Hope described the constant monitoring this required: "You don't do something once and leave it. You have to follow up constantly: what happened at school, what happened at home, what they struggled with, what they need. Sometimes, even while you are doing something else during the day, your mind stays with your child." Longing explained how education extended into the home: "There are things you have to continue at home; you try to reinforce what your child has learned. Education stops being something that happens only at school and becomes a responsibility that continues at home. Sometimes I feel more like a teacher than my child's teacher." Joy similarly described feeling that she had to continuously check, follow up on, and, when necessary, intervene in her child's education. These accounts demonstrate that mothers perceived responsibility for their children's education, development, and well-being as extending considerably beyond conventional caregiving.

Putting oneself second. Participants described organizing substantial parts of their lives around their children's education, care, and daily needs. Joy stated, "My life has been shaped entirely around their education," and added, "While following your child's education, you sometimes postpone the things you need to do yourself, because you think, 'If I don't take care of this today, it could become a bigger problem

tomorrow.'" Compassion described how her own needs were repeatedly deferred: "Sometimes at the end of the day, when I look back, I realize that I did something for everyone all day but nothing for myself. You keep postponing time for yourself, saying, 'I'll do it later.' But that 'later' never comes." Happiness similarly referred to the accumulation of childcare, household, and other responsibilities. These accounts indicate that mothers frequently prioritized their children's needs over their own personal needs and self-care, often without a deliberate decision to do so.

Feeling like you have to stay strong. Participants described strength as an obligation associated with motherhood rather than simply a personal characteristic. Love explained: "I mostly feel that I have to be strong, because when you stop, your child's life does not stop. Sometimes you don't feel like doing anything, but you still get up and do it. Even if I cry, I have to keep going." Longing distinguished between appearing strong and feeling strong: "From the outside, you may look strong, but inside you may be going through very different things. Sometimes you are very tired, sometimes you worry about the future, but you still have to keep daily life going. That is why looking strong sometimes becomes an obligation." At the same time, mothers expressed a need for spaces in which fatigue, fear, and vulnerability could be acknowledged without judgment; as Longing put it, "Sometimes what a person needs most is for someone to say, 'You can get tired too.'"

Theme 3: Living with Uncertainty

The third dimension centered on mothers' concerns about their children's future. Three closely related areas emerged: education, independent living, and life after parents. These concerns reflected not only anticipated difficulties but also uncertainty about how their children's lives would unfold over time.

Concerns about education. Mothers expressed uncertainty about whether their children's current educational opportunities and support would be sufficient for their future needs. Joy explained: "My biggest concern is whether education will be sufficient in the future. Right now my child is receiving support and making progress, but you keep thinking, 'Will this education be enough later on?' As the child grows, their needs change, and something that is sufficient today may not be sufficient in a few years. That is why education is like a never-ending question for me." Compassion similarly stated: "The fact that my child is receiving support now does not mean that the future will continue in the same way. Will we be able to find the right support? Will the education be sufficient? You cannot know these things." Thus,

education was perceived not merely as a current developmental need but as an important factor shaping the child's future opportunities and quality of life.

Concerns about independent living. Participants also expressed concerns about whether their children would be able to meet their own needs and live as independently as possible in the future. Hope connected this concern to her awareness that she would not always be present: "Right now I can be with my child in many matters and intervene when there is a problem. But I also know that I will not always be able to be by their side. So I want them to do what they can by themselves, to express their needs, and to ask for help when necessary." Happiness defined independence not as the absence of support but as having a voice in one's own life: "They may need support in some matters; I accept that. But I want them to sustain their own life to the highest possible degree. What matters to me as a mother is that they do not live a life in which only others make the decisions. I want them to build their own life one day." These accounts reveal a tension between hope for the child's independence and uncertainty about whether such independence will be achieved.

Anxieties about life after parents. Concerns about the period when parents would no longer be able to provide care were particularly salient. Love expressed this fear in terms of her child being left without someone who truly understands them: "My real fear is that they will be alone. When I say alone, I don't only mean having no one beside them. It is also frightening that there may be no one who knows them and understands what they need, because you know some of your child's characteristics best." For Longing, these thoughts were intertwined with her own aging: "As your child grows, you start thinking about adulthood. Then you think about your own age too: 'How old will I be then? Will I still be by my child's side?'" Elsewhere she asked simply, "What will happen when I am gone?" Love added: "A person does not want to think about her own death, but when your child's future is concerned, you cannot entirely escape this thought." These concerns extended beyond education or independent living and focused on the child's future security, care, and well-being in the absence of parental support. Thus, mothers' concerns about the future were closely connected to the enduring nature of their maternal responsibility and to their awareness of their own aging and mortality.

Theme 4: The Need to Be Seen and Understood

The fourth dimension concerned mothers' experiences of social exclusion, their need for connection with people who had similar experiences, and their expectations for emotional support and acceptance.

Social isolation. Mothers described feeling excluded or emotionally alone because of insufficient social understanding, prejudices, and insensitive attitudes toward children with disabilities and their families. Happiness described how others' reactions gradually narrowed her social life: "Even people's stares can be exhausting. I used to go places without thinking much. Now I sometimes think, 'How will my child behave there? How will people react?' Sometimes I stay away from certain settings because I think I will be less tired that way. Over time, this can narrow your social circle." Love stated, "Someone who has not lived through it cannot truly understand," and described a similar withdrawal: "I feel as if I will constantly have to explain something, such as why my child behaves this way. After a while you say, 'It's better not to explain.'" These accounts show that the burden experienced by mothers was related not only to their children's needs but also to how they were perceived and treated by others.

Solidarity with those who have had similar experiences. Interaction with mothers who had similar experiences was described as particularly meaningful. Hope explained: "Mothers who go through the same things understand me best. When you tell them something, you don't have to explain everything from beginning to end. When you say, 'I am very tired today,' you don't have to explain why." Joy described the relief of recognizing shared experiences: "When you see that another mother has the same worries and similar fatigue, you feel a little relieved. The problem does not go away, but you feel that you are not carrying the burden alone." Compassion emphasized that shared experience made room for ambivalent feelings: "That person knows how much you love your child and also how tired you are; they understand that both can exist at the same time. A mother can love her child very much and be very tired at the same time." Love similarly noted that, when she admitted exhaustion, she feared being seen as not loving her child. Participants' accounts therefore suggested that shared experience provided a context for recognizing and articulating difficult emotions.

The need for support and acceptance. Mothers emphasized that support did not necessarily mean receiving advice or practical solutions. Compassion explained: "Sometimes I just want someone to listen to me. I feel lighter when someone listens without trying to correct me. Sometimes what a person needs is not a solution but room for her feelings." Love described the wish to be seen as a person in her own right: "Sometimes I just want someone to ask, 'How are you?' Not how my child is, but how I am." She also distinguished being understood from being pitied: "I don't want to be pitied. Rather than being told how hard it must be, I would prefer to hear, 'I understand you; I am with you,' because pity can make you feel

even more alone." Longing summarized this need by stating, "We need to be understood without being judged." Accordingly, emotional support, attentive listening, acceptance, and non-judgmental understanding emerged as important aspects of the support mothers expected from others.

Composite Textural Description

Across the six individual experiential accounts, raising a child with a disability was experienced as an enduring responsibility that shaped mothers' everyday lives, priorities, emotional experiences, and expectations for the future. Mothers described continuously attending to their children's educational, developmental, and daily needs while assuming multiple roles and frequently postponing their own needs. This responsibility was accompanied by fatigue, fear, uncertainty, and pressure to remain strong. At the same time, mothers did not experience this process solely as a source of difficulty. They described changes in their perspectives on life, increased patience, learning, changing priorities, and finding meaning in their children's small developmental achievements. Acceptance was experienced as a gradual process of living with the circumstances and focusing on what could be done in the present. Future uncertainty centered on the adequacy of education, children's ability to live independently, and what would happen when parental support was no longer available. Mothers also expressed a strong need to be seen, heard, accepted, and understood without judgment. Interaction with mothers who had similar experiences reduced the need to explain themselves, fostered a sense of not being alone, and enabled difficult feelings to be expressed more freely.

Composite Structural Description

The mothers' experiences unfolded within continuing caregiving demands, uncertainty about their children's developmental and future trajectories, and the perceived need to remain continuously attentive to their children. These conditions shaped how mothers organized everyday life and contributed to prioritizing their children's needs over their own. Motherhood was lived not only through direct caregiving but also through monitoring, educational involvement, decision-making, emotional support, and anticipation of future needs.

The experience was also shaped by mothers' relationships with their social environment. Feeling misunderstood or judged contributed to loneliness and emotional burden, whereas interactions with mothers who had similar experiences provided a context in which difficult emotions could be expressed and understood more freely.

Structurally, the mothers' lived experience was characterized by the coexistence of enduring responsibility and exhaustion, the need to remain strong and the experience of vulnerability, and uncertainty about the future alongside efforts to remain engaged with the present.

Phenomenological Essence

Raising a child with a disability was experienced as an enduring form of motherhood that reorganized mothers' everyday lives, priorities, sense of self, and expectations for the future. Across the six individual experiential accounts, mothers described a continuous responsibility to monitor, anticipate, and respond to their children's educational, developmental, emotional, and daily needs. This responsibility was accompanied by the tension between caring for the child and postponing personal needs, between feeling compelled to remain strong and experiencing fatigue and vulnerability, and between uncertainty about the future, particularly regarding education, independent living, and life after parents, and efforts to remain engaged with the present. Yet the experience was not understood solely as hardship: mothers also described learning, personal transformation, changing priorities, and finding meaning in small developmental achievements, and acceptance emerged as an ongoing process of learning to live with circumstances rather than a complete resolution of difficulty. Being seen, heard, accepted, and understood was also central, and interactions with mothers who had similar experiences reduced feelings of isolation. Although these meanings were articulated within the focus-group interaction, the phenomenological essence was derived from the commonalities across individual experiential accounts, preserving each mother as an experiencer of the phenomenon. This shared structure is grounded at the level of the four dimensions, each of which was present in all six accounts; the subthemes, by contrast, capture the varied and partly individual ways in which mothers lived these dimensions and should not be read as experiences shared equally by all participants.

Discussion

The findings indicate that raising a child with a disability was experienced as an ongoing reorganization of mothers' everyday lives, priorities, responsibilities, relationships, and expectations for the future. The four interrelated dimensions—finding new meaning in life, motherhood at the center of life, living with uncertainty, and the need to be seen and understood—illustrate the coexistence of burden and transformation: mothers described fatigue, self-deprioritization, and uncertainty alongside acceptance, learning, personal transformation, and changing priorities. Beyond confirming the caregiving burden and

support needs documented in previous studies, the findings contribute two insights to the literature. First, mothers' concerns about their children's futures were inseparable from their awareness of their own aging, vulnerability, and mortality, so that future-oriented uncertainty concerned the mother's life course as much as the child's. Second, culturally and spiritually grounded frames, such as understanding the experience as destiny or a test, played an important role in how mothers accepted difficulty and assumed responsibility, while cultural expectations of maternal patience and strength also made it harder to voice fatigue. Each dimension is discussed below in relation to the existing literature.

Finding New Meaning in Life

The first dimension shows that mothers continuously reinterpreted the meaning of raising a child with a disability. Participants described destiny, trial, acceptance, learning, personal transformation, and hope, but their accounts did not reflect a linear movement from difficulty to complete acceptance. Rather, meaning was repeatedly reconstructed through everyday experiences. Mothers described shifting from asking why the experience had occurred toward considering what could be done in the present, valuing small developmental changes, becoming more patient, and reorganizing their priorities.

This finding is consistent with qualitative research in Türkiye identifying transformation, adaptation, acceptance, and changes in maternal responsibilities (Gökçek & Boyacıoğlu, 2025). Similarly, Özsavran et al. (2025) reported that mothers experienced their children as central to their lives while also describing psychological strain, social restriction, and the importance of support. The present findings extend this literature by showing that transformation and meaning-making coexist with continuing uncertainty and fatigue. This coexistence resonates with Green's (2007) observation that mothers of children with disabilities may be "tired, not sad," experiencing the burdens of caregiving alongside its benefits. Mothers could experience greater meaning while remaining exhausted, accept aspects of their circumstances while worrying about the future, and perceive personal growth without describing the experience as uniformly positive.

In this context, adjustment did not appear to be a static endpoint but an ongoing negotiation in which conflicting emotions, exhaustion and meaning, burden and love, coexisted rather than canceling each other out. As Joy's shift from questioning why the experience had happened toward acceptance, and Longing's description of a responsibility that would *"never end,"* suggest, each new developmental stage or unanticipated difficulty could reactivate this negotiation, so that adjustment was less a destination

than a recurring, lifelong process. Mothers appeared to attach purpose, through care, responsibility, and love, to difficulties that disrupted normative life expectations and could not be avoided, a pattern consistent with the concept of posttraumatic growth, whereby individuals experience positive psychological change through their struggle with adversity even as distress persists (Tedeschi & Calhoun, 2004).

These meaning-making processes should also be understood within the socio-cultural context of the study. Joy's and Love's descriptions of the experience as destiny and as a test reflect culturally and spiritually grounded frames through which hardship is commonly interpreted in Türkiye; similarly, a synthesis of qualitative studies from African contexts has shown that caregivers' understanding of the condition and their coping strategies are embedded in their cultural settings (Mkabile et al., 2021). Rather than signaling passive resignation, these frames appeared to offer mothers a meaningful narrative within which difficulty could be accepted and responsibility assumed, supporting the shift from asking why the experience had occurred toward what could be done in the present. At the same time, cultural expectations that mothers embody patience, sacrifice, and strength may make it more difficult to voice fatigue or ask for help, a tension that also emerged in the second dimension. Practitioners working with families in similar contexts may therefore benefit from acknowledging spiritual and cultural meaning-making as a potential resource while remaining attentive to the burdens that such expectations may impose.

Motherhood at the Center of Life

The second dimension concerned the increasing centrality of motherhood in everyday life. Mothers described extensive responsibilities involving caregiving, education, household management, advocacy, monitoring, and emotional support, often resulting in the postponement of their own needs. These findings are consistent with evidence showing substantial caregiving burden, stress, changes in maternal roles, and effects on mothers' own needs (Alataş et al., 2026; Sevgi & Ayran, 2024).

Importantly, participants did not merely report having many responsibilities; they described how these responsibilities gradually reorganized their lives. Children's needs became central to decisions concerning time, routines, education, social participation, and personal priorities. Thus, "putting oneself second" was experienced as an everyday pattern rather than necessarily a conscious decision. Although mothers recognized their own fatigue and need for rest or personal time, these needs were repeatedly

postponed because the child's needs were perceived as more urgent. This finding is also consistent with evidence linking caregiving responsibilities to lower quality of life among mothers of children with disabilities (Tarigan et al., 2024).

Participants' accounts suggest that this pattern was sustained by the perceived urgency of the child's needs and by the belief that no one else could know those needs as well as the mother. Hope, for example, explained, "You think, who could know the child's needs better than you? So most of the time you take on the responsibility yourself," and Compassion noted that even when she tried to rest, "you may rest physically, but you cannot fully rest mentally." Cultural expectations that idealize maternal self-sacrifice may further reinforce this pattern, although the present data do not allow firm conclusions about its origins. What the accounts do show is that, from the mothers' own perspective, what appeared outwardly as strength was often accompanied by considerable inner exhaustion.

Participants' descriptions of having to remain strong further revealed a tension between responsibility and vulnerability. Strength was experienced less as a personal characteristic than as an expectation to keep functioning despite fatigue, fear, and uncertainty; as Love put it, "Sometimes you don't feel strong, but you have to act strong." At the same time, some mothers described learning to share the burden over time. Hope stated that she had learned to ask for support only later and that "asking for help is not always inadequacy; sometimes it simply means sharing the load." These accounts suggest that, for some mothers, strength came to include recognizing one's limits and seeking support, a perspective that psychosocial services may usefully reinforce.

Living with Uncertainty

The third dimension concerned uncertainty about children's education, independence, everyday functioning, and life when parents could no longer provide care. These concerns were not limited to a distant future; they shaped mothers' present parenting experiences and perceptions of responsibility. Concerns about life after the parents were particularly significant because they simultaneously reflected worries about children's future and mothers' own aging, vulnerability, and mortality.

Previous research similarly highlights uncertainty, unpredictability, support needs, and continuing caregiving demands among mothers of children with disabilities (Gökçek & Boyacıoğlu, 2025; Işık-Uslu & Çetin, 2024; Özsavran et al., 2025). The present findings extend these observations by showing that future uncertainty was closely intertwined with mothers' identities and life courses. Concerns about

independence were simultaneously concerns about who would provide care, whether adequate support would be available, and what would happen when mothers' own caregiving capacity changed. Internationally, similar concerns about "what will happen when we are gone" have been documented among older family carers of adults with intellectual disabilities (Brennan et al., 2018), worries about the future have emerged as a central theme in a synthesis of qualitative studies with caregivers in African contexts (Mkabile et al., 2021), and families frequently report such worries without having formalized plans for the future (Lee & Burke, 2020). The present findings suggest that these concerns emerge well before adulthood: although the children in this study were between 7 and 10 years old, mothers were already anticipating their own aging and absence. This points to the value of introducing future-oriented planning and support early, rather than only at the transition to adulthood.

From the perspective of family stress and adaptation models, these future-oriented concerns can be understood as an accumulation of anticipated demands that families must continuously appraise and manage with their available resources (McCubbin & Patterson, 2014; Patterson, 1988). Consistent with an ecological perspective (Bronfenbrenner, 1979), mothers' uncertainty was not located solely in their children's characteristics but also in the perceived adequacy of educational services, long-term care arrangements, and social support systems beyond the family.

The Need to Be Seen and Understood

The fourth dimension concerned mothers' need to be seen, heard, accepted, and understood. Participants did not primarily define support as receiving advice or solutions; instead, they emphasized being listened to, understood without judgment, and having their experiences recognized. They also distinguished understanding from pity, seeking recognition without being positioned as helpless or deficient.

This finding is consistent with research indicating limitations in social participation and support and elevated family burden among mothers of children with developmental disabilities in Türkiye (Rfat et al., 2024; Şahin et al., 2025). The present findings further suggest that the quality of support may be as important as its availability. Relationships with mothers who had similar experiences were particularly meaningful because shared experience reduced the need to explain or justify emotional reactions. This is consistent with evidence that peer support can provide validation, understanding, shared experience, and emotional support (Lancaster et al., 2023; Wong & Shorey, 2022). This support appeared to be

horizontal rather than hierarchical: what mothers valued was experiential understanding shared in a non-judgmental space, which reduced the need to explain themselves and fostered a sense of not being alone.

Overall, the findings suggest that mothers may need support in the form of safe micro-spaces that extend beyond information and problem-solving to include recognition, mutual understanding, and non-judgmental sharing. In this context, mothers appeared to want their considerable efforts to be seen by others and to be valued for their own independent identity, rather than being regarded merely as an extension of the child or as a constant caregiver whose role exists only in service of the child.

Implications for Practice

The findings suggest that psychosocial services for mothers of children with disabilities should address mothers' psychological, social, relational, and future-oriented needs alongside their children's developmental and educational needs.

First, family-centered services should recognize mothers as active participants in care rather than solely as caregivers. Shared decision-making, family education, recognition of family needs, family engagement, and social and emotional support can contribute to family well-being and empowerment (Dionísio Mestre et al., 2024).

Second, psychosocial interventions should provide safe opportunities for mothers to express fatigue, uncertainty, and vulnerability. Helping mothers normalize help-seeking and challenging the expectation that they must remain strong and manage responsibilities alone may be particularly important.

Third, peer-support opportunities should complement individualized psychosocial support. Peer-support programs may improve parental well-being and quality of life, while group-based psychoeducational interventions have shown promising effects among parents of children with autism in Türkiye (Ağırkan et al., 2023; Lancaster et al., 2023). Such opportunities may also reduce feelings of isolation by providing recognition and shared understanding.

Fourth, family-support and counseling services should incorporate future-oriented planning, including transition to adulthood, independent living, continuity of care, and long-term caregiving arrangements.

Finally, professional training and public awareness initiatives should address social attitudes toward families, as being judged, misunderstood, or excluded may intensify the burden of caregiving.

Limitations and Directions for Future Research

Several limitations should be considered when interpreting the findings. First, the study included six mothers who participated in a single online focus group. Although this design generated detailed experiential accounts, the findings are not intended for statistical generalization beyond the study context.

Second, the use of a focus group within a study drawing on the transcendental phenomenological approach represents an important methodological limitation. Individual interviews are commonly preferred in phenomenological research because they may provide greater privacy and facilitate detailed descriptions of personal experiences; however, focus groups are not necessarily incompatible with phenomenological inquiry when the relationship between the data-generation context and the analysis is explicitly addressed, and interaction among participants may facilitate the recall, comparison, and elaboration of lived experiences (Dimitrakopoulou & Theodorou, 2022). In the present study, individually articulated experiential accounts were distinguished from interactional contributions during analysis, so that the findings represent commonalities across individual lived experiences rather than a collective "group experience." Nevertheless, group dynamics may have influenced disclosure, privacy, elaboration, and convergence among participants (Guler et al., 2023; Love et al., 2020). In addition, no follow-up individual phenomenological interviews were conducted; therefore, some experiences may not have been explored with the depth possible in individual interviews. Future studies could combine focus groups with individual phenomenological interviews to examine both interactionally generated meanings and more private, individually elaborated lived experiences, or use individual interviews when experiences are particularly private or emotionally sensitive.

Third, the study focused exclusively on mothers and therefore does not capture the lived experiences of fathers or other primary caregivers. Future research should examine whether similar experiential structures emerge across different family roles.

Fourth, member checking was not conducted; therefore, participants did not have the opportunity to review the individual experiential accounts or the composite descriptions derived from their contributions. Although credibility was supported through the other strategies described in the Method section, future studies could incorporate participant validation to further strengthen the credibility of phenomenological descriptions.

Finally, the children represented different types of disabilities. This diversity enabled examination of shared caregiving experiences but may have limited exploration of condition-specific experiences. Future qualitative studies could compare mothers across different disability groups to distinguish common experiential structures from condition-specific experiences.

Conclusion

The findings suggest that raising a child with a disability is an enduring life experience that reorganizes mothers' meanings, priorities, responsibilities, relationships, and expectations for the future, with motherhood becoming central to everyday life and often accompanied by the postponement of mothers' own needs. However, the experience was not defined solely by burden: mothers also described learning, personal transformation, acceptance, meaning-making, and hope.

A central finding was that concerns about children's futures were closely intertwined with mothers' own futures. Concerns about education, independent living, and life after parents reflected not only children's long-term needs but also mothers' awareness of aging, vulnerability, and the limits of lifelong caregiving. Alongside these concerns, mothers emphasized the need to be seen, heard, accepted, and understood without judgment. Connections with others who had similar experiences provided recognition and reduced the need to explain their experiences. A second distinctive finding concerned the role of culture: spiritually grounded interpretations of the experience as destiny or a test supported acceptance and meaning-making, whereas culturally reinforced expectations of maternal patience, sacrifice, and strength could make fatigue and vulnerability harder to express.

Overall, the experience can be understood as the coexistence of caregiving, meaning-making, self-reorganization, future-oriented uncertainty, and the search for recognition and connection. These findings highlight the importance of family-centered psychosocial services that support mothers' well-being while addressing children's current and long-term needs.

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