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The Resilience Process Among Mothers of Children with Intellectual Disabilities: A Phenomenological Study of Primary Caregivers

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Abstract

Background: Mothers who serve as primary caregivers for children with intellectual disabilities may face sustained emotional, social, and caregiving pressures, including shock, sadness, guilt, stigma, uncertainty about the child's future, and intensive daily caregiving demands. Previous studies have frequently examined parental resilience in terms of levels or associated factors, whereas the lived process through which mothers develop resilience remains less explored. Objective: This study aimed to describe the resilience process among mothers who serve as primary caregivers for children with intellectual disabilities. Methods: A qualitative descriptive phenomenological approach was used with four mothers selected through purposive sampling. The children had intellectual disability classifications ranging from mild to profound. Data were collected through repeated semi-structured in-depth interviews and supporting documentation, and analyzed using thematic analysis. Credibility was strengthened through prolonged engagement and source and method triangulation. Results: The resilience process developed dynamically across three domains of family resilience: family belief systems, organizational patterns, and communication and problem solving. Initially, participants experienced emotional shock, sadness, anxiety, confusion, and difficulty accepting the child's condition. Over time, they developed acceptance, spiritual meaning-making, positive hope, adaptive family-role arrangements, social and spousal support, emotional regulation, and problem-solving strategies. Although all participants shared the goal of sustaining caregiving, their coping strategies differed according to family circumstances, the child's level of disability, social support, and individual meaning-making. Conclusion: Maternal resilience was not an instantaneous state but a continuing adaptive process involving transformation of meaning, family reorganization, supportive relationships, and adaptive coping. These findings highlight the importance of psychological support that addresses both the mother's individual needs and the wider family system.

Keywords: resilience; intellectual disability; primary caregiver; family resilience

Introduction

Having a child with an intellectual disability can alter family expectations and create continuing demands for parents. Intellectual disability is characterized by significant limitations in intellectual functioning and adaptive behavior, including conceptual, social, and practical skills (American Psychological Association, 2013; Heward et al., 2016). These limitations may increase the need for assistance in daily activities and make parents more involved in education, therapy, behavior management, and the development of the child's independence.

Mothers frequently occupy a central role in daily caregiving. The intensive nature of this role can expose mothers to emotional and psychological pressures, including fatigue, sadness, anxiety about the child's future, and concerns about social acceptance. Research has documented caregiving stress and emotional exhaustion among mothers of children with intellectual disabilities, particularly when demands are prolonged and support is limited (Marliana et al., 2021; Zulkifli et al., 2022). Social stigma and exclusion may further complicate the caregiving experience (Chandra & Tambun, 2021; Hassanein et al., 2021).

Resilience provides a framework for understanding how individuals and families adapt to adversity. Rather than referring only to a stable personal trait, resilience can be understood as a dynamic process through which people and families mobilize resources, reorganize functioning, and construct meaning in response to significant stressors (Masten, 2013; Southwick & Charney, 2012). In families, Walsh (2006) conceptualizes resilience through three interrelated domains: family belief systems, organizational patterns, and communication and problem solving. These domains encompass how families make meaning of adversity, reorganize roles and resources, and communicate and solve problems during periods of stress.

Studies in Indonesia have identified social support, adaptive appraisal, and family resources as relevant to parental resilience and quality of life among families of children with developmental disabilities (Widyawati et al., 2022). Other research has linked resilience with parenting stress, religious coping, optimism, and social support (Nur'aeni et al., 2024; Rahma et al., 2025). However, much of the available evidence emphasizes levels, predictors, or relationships among variables. Qualitative inquiry is valuable for examining how resilience is experienced and constructed over time from the mother's own perspective.

Accordingly, this study focused on the resilience process among mothers who serve as primary caregivers for children with intellectual disabilities. The study sought to understand how mothers move through emotional disruption, meaning-making, family adaptation, communication, and coping while continuing to fulfill caregiving responsibilities. A phenomenological approach was selected because the research question concerned the meaning and lived experience of resilience rather than its quantitative measurement.

Literature Review

Resilience and Family Resilience

Resilience is commonly described as a process of positive adaptation in the context of adversity. Masten (2013) emphasizes that resilience may emerge through ordinary adaptive processes rather than through exceptional qualities alone. Individual resilience frameworks also highlight emotional regulation, impulse control, causal analysis, self-efficacy, realistic optimism, empathy, and reaching out as capacities that can support adaptation (Reivich & Shatté, 2002). In family contexts, resilience is not located solely within one individual; it is supported by relational and organizational processes that enable family members to respond flexibly to stress.

Walsh's (2006) family resilience framework identifies three central domains. Family belief systems include meaning-making, a positive outlook, and transcendence or spirituality. Organizational patterns concern flexibility, connectedness, and the mobilization of social and economic resources. Communication and problem solving involve clear and open communication, emotional expression, collaborative problem solving, and the capacity to generate alternatives. The framework is particularly relevant to caregiving because chronic caregiving stress affects both the individual caregiver and the functioning of the family system.

Mothers as Primary Caregivers of Children with Intellectual Disabilities

Caregiving for a child with intellectual disability may involve continuous supervision, assistance with daily living, support for learning and independence, and coordination with educational or health services. These demands can be associated with caregiver burden and stress (Marliana et al., 2021; Rahmawati & Aviani, 2023). Parents may also experience uncertainty regarding the child's future independence and well-being (Purwati et al., 2025). At the same time, social support and adaptive family functioning can act as protective resources (Hassanein et al., 2021; Widyawati et al., 2022). Understanding resilience therefore requires attention not only to distress but also to the adaptive processes through which mothers maintain caregiving and reconstruct meaning.

Methodology

Research Design

This study employed a qualitative descriptive phenomenological approach. The purpose was to explore and describe the meaning of the resilience process as experienced by mothers who serve as primary caregivers for children with intellectual disabilities. Phenomenological inquiry emphasizes the lived experience of participants and seeks to describe the essence of that experience (Moustakas, 1994). The qualitative design was appropriate because the study did not aim to quantify resilience but to examine how resilience developed through the mothers' experiences.

Participants

Participants were selected using purposive sampling. Eligibility criteria were: (1) being a mother of a child with intellectual disability who had undergone psychological assessment; (2) the child's diagnosis being supported by psychological assessment and school classification; (3) direct involvement in the child's daily caregiving; and (4) willingness to describe caregiving experiences openly. Four mothers participated, representing children classified in the thesis as having mild, moderate, severe, and profound intellectual

disability. The use of four participants was consistent with the phenomenological emphasis on rich and in-depth descriptions (Moustakas, 1994).

Data Collection

Data were collected through semi-structured, in-depth interviews and supporting documentation. Interviews were conducted repeatedly with participants to deepen the information, clarify responses, and understand the context of the caregiving experience. The interview guide used open-ended questions concerning the mother's background, caregiving experience, emotional responses, family relationships, coping, and experiences of resilience. Interviews were recorded with participants' consent and transcribed for analysis. Written informed consent was obtained before data collection.

Data Analysis and Trustworthiness

Data were analyzed thematically. The analysis involved familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report, following the thematic analysis procedure described by Braun and Clarke (2008). The analysis was conducted iteratively alongside data collection and interpretation. Credibility was strengthened through prolonged engagement with participants, source triangulation across participants, and method triangulation between interviews and documentation. Dependability was supported through consistent use of the interview procedure while retaining flexibility to follow participant responses.

Ethical Considerations

The study followed the ethical procedures described in the thesis, including written informed consent, confidentiality through participant pseudonyms, secure handling of research data, and attention to the emotional sensitivity of interviewing mothers of children with intellectual disabilities. An ethics review/approval document was included in the thesis research documentation.

Results and Discussion

Participant Characteristics

Four mothers participated in the study. Their profiles are summarized in Table 1. All participants were married and directly involved in the daily care of their children. The children represented different levels of intellectual disability, allowing the study to capture variation in caregiving demands and adaptation.

Participant	Age	Occupation	Child's age	Child's intellectual disability
S	45	Trader	15	Mild
KH	45	Housewife	17	Moderate
V	33	Housewife	8	Severe
HI	53	Housewife	19	Profound

Table 1. Participant characteristics

Family Belief Systems: From Emotional Shock to Acceptance and Meaning

The first major domain concerned changes in how mothers understood and interpreted their children's conditions. Across participants, the resilience process began with emotional disruption. Mothers described sadness, disappointment, anxiety, confusion, inner struggle, and difficulty accepting the diagnosis or the discrepancy between expectations and reality. These early reactions illustrate that resilience in this context did not mean the absence of distress; rather, distress formed part of a longer adaptive process.

Over time, the participants developed greater acceptance and reconstructed the meaning of caregiving. Positive meaning was often linked to recognizing small developmental gains, maintaining hope for the child's future, and viewing caregiving as a responsibility that could be lived with patience and sincerity. Spiritual

beliefs also became an important source of meaning. This pattern is consistent with Walsh's (2006) view that family resilience is supported by meaning-making and a positive outlook, including spiritual or transcendent beliefs. The finding also resonates with Indonesian research linking religious or spiritual coping with the experience of parents of children with special needs (Hidayati & Dewi, 2024).

The participants differed in how this transformation occurred. The mild and moderate cases were described in terms of persistent efforts to support development and manage social pressures, while the participants caring for children with severe and profound intellectual disability described more intensive demands and efforts to locate services and sustain daily caregiving. Nevertheless, all participants gradually moved toward a more accepting interpretation of their circumstances. Thus, acceptance in this study was not equivalent to resignation; it involved a shift toward recognizing the child's needs while continuing to pursue attainable developmental and caregiving goals.

Organizational Patterns: Reorganizing Family Roles and Mobilizing Support

The second domain involved changes in family roles, routines, and sources of support. Mothers were generally the dominant caregivers and adjusted daily routines around the child's needs. This included allocating time for education, therapy, supervision, daily living assistance, and behavioral support. Such demands are consistent with previous findings that mothers may experience substantial physical and psychological fatigue in caring for children with intellectual disabilities (Marliana et al., 2021; Zulkifli et al., 2022).

Each family, however, organized caregiving differently. Participant S described adaptation and negotiation of caregiving roles within the family. Participant KH demonstrated persistence in supporting the child's development while managing social stigma and emotional demands. Participant V showed strong maternal dominance in caregiving because her spouse experienced difficulty responding to the child's behavior and because the family experienced long-distance-marriage circumstances. Participant HI described a clearer division of tasks between mother and father, which helped maintain family stability.

Support from spouses, extended family, and the surrounding social environment functioned as an important resource. This finding is consistent with evidence that social support is associated with parental resilience and quality of life among families of children with developmental disabilities (Hassanein et al., 2021; Widyawati et al., 2022). The findings also align with Rahma et al. (2025), who reported the relevance of social support in the relationship between resilience and parenting stress. From a family-resilience perspective, support does not simply reduce burden; it expands the family's capacity to redistribute roles and maintain functioning.

Communication and Problem Solving: Emotional Regulation and Adaptive Coping

The third domain concerned how mothers managed emotional responses, responded to social challenges, communicated within the family, and searched for practical solutions. Participant S adapted communication to the child's behavior and tried to remain patient when facing difficult behaviors. Participant KH used emotional regulation, distraction when fatigued, spousal support, and spiritual strategies when caregiving pressure became intense. Participant V actively searched for therapy, medical services, and other possible solutions while coping with limitations in available services and experiences of social isolation. Participant HI used religious practices, rest, caring for plants, simple recreation, and continued efforts to train the child's independence as ways of maintaining emotional stability.

These patterns demonstrate that coping was heterogeneous and context-dependent. The mothers did not rely on a single strategy. Instead, they combined emotion regulation, social support, practical problem solving, spiritual practices, and persistent caregiving. Such flexibility corresponds with Walsh's (2006) communication and problem-solving domain, in which clear communication and collaborative or adaptive responses help families manage adversity. It also reflects broader resilience models that emphasize adaptive coping and the mobilization of internal and external resources (Masten, 2013; Ungar, 2012).

The findings also indicate that social stigma remains a meaningful challenge. Mothers reported or described experiences involving negative social responses toward their children, and some responses required emotional regulation and efforts to protect the child's well-being. Similar concerns have been documented in studies of mothers of children with intellectual or developmental disabilities, where stigma and limited social acceptance can affect quality of life and family functioning (Chandra & Tambun, 2021; Hassanein et al., 2021).

The Resilience Process as a Dynamic and Interconnected Process

Taken together, the three domains were not independent stages. Rather, they operated as interconnected processes. Acceptance and meaning-making supported mothers in reorganizing family roles; family support created conditions for emotional regulation and problem solving; and successful problem solving generated new experiences that reinforced hope and positive meaning. The resilience process therefore moved recursively between internal meaning, family organization, and practical coping.

This interpretation is consistent with Walsh's (2006) systemic view of family resilience. It also extends quantitative findings by showing how protective factors are enacted in everyday caregiving. For example, social support becomes meaningful when it allows a mother to rest, share responsibilities, discuss difficulties, or make decisions; spiritual belief becomes meaningful when it helps reinterpret adversity and sustain hope; and coping becomes adaptive when it enables the mother to continue caregiving while responding flexibly to new problems.

The findings should nevertheless be interpreted within the study's boundaries. Four participants cannot represent the full range of experiences among mothers of children with intellectual disabilities. Resilience may vary according to socioeconomic circumstances, family background, the child's level of disability, and available social support. In addition, the study focused on mothers as primary caregivers, so the resilience experiences of fathers, siblings, and other family members were not explored in depth. Finally, because the study relied substantially on participants' accounts, the findings remain dependent on their willingness and ability to articulate their experiences.

Conclusion

This study shows that resilience among mothers who serve as primary caregivers for children with intellectual disabilities develops through a dynamic and continuing process rather than appearing as an immediate or fixed state. The process was organized around three interconnected domains of family resilience: family belief systems, organizational patterns, and communication and problem solving. Mothers initially experienced emotional shock and distress, but gradually developed acceptance, positive meaning, spiritual conviction, and realistic hope. They simultaneously reorganized family roles and routines, mobilized support, and developed diverse coping and problem-solving strategies.

The findings suggest that psychological support for mothers should consider the wider family system rather than focusing exclusively on individual distress. Support may include opportunities for emotional processing, strengthening family communication, facilitating access to social and professional support, and supporting adaptive meaning-making. Future research should involve more diverse participants and family members and examine how resilience processes vary across socioeconomic contexts, levels of intellectual disability, and forms of social support.

Declarations

Author Contributions

Isma Fadilatun Nisa was responsible for the conceptualization, methodology, investigation, data analysis, and preparation of the original manuscript. Nuraeni contributed through research supervision and critical review and editing of the manuscript.

Data Availability Statement

The qualitative interview data are not publicly available because they contain sensitive personal information that could potentially identify the participants and their families. The data are protected in accordance with the ethical requirements of the study.

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Institutional Review Board Statement

This study received ethical approval from the Health Research Ethics Committee of Universitas Muhammadiyah Purwokerto (KEPK-UMP), Indonesia (Registration No. KEPK/UMP/267/IV/2026; approval date: 27 April 2026).

Informed Consent Statement

Written informed consent was obtained from all participants before data collection. Participants were informed about the purpose and procedures of the study, the voluntary nature of participation, and their right to withdraw from the study at any time.

Declaration of Competing Interest

The authors declare no competing financial interests or personal relationships that could have influenced the research or the publication of this article.

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