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Meaning and Challenges: Mothers' Experiences in Caring for Children with Mild Intellectual Disabilities

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ABSTRACT

Introduction: Caring for children with mild intellectual disabilities poses significant emotional and social challenges for mothers, often compounded by stigma and limited support. In Indonesia, spirituality and social support play a crucial role in strengthening resilience and framing caregiving as a moral responsibility.

Objective: This study aims to explore how mothers perceive the care of children with mild intellectual disabilities and the coping strategies they employ to address physical, emotional, and social challenges.

Method: A qualitative phenomenological approach was used, involving semi-structured in-depth interviews with 10 mothers. Data saturation was reached with the eighth participant, confirming no emergence of new significant information. Participants were selected through purposive sampling. Thematic analysis was conducted, complemented by source and theoretical triangulation to enhance the validity of findings.

Results: Four key themes emerged from the analysis: (1) caregiving as an act of worship and moral responsibility, where mothers view their role as a life calling; (2) challenges in caregiving, including physical strain, emotional stress, and stigma-related pressures; (3) coping strategies that rely on social and spiritual support, with family and religious communities serving as key resources; and (4) the inadequacy of formal services, which often forces mothers to depend on community and faith-based organizations.

Conclusion: This study highlights the need for community-based programs that address the emotional and spiritual needs of families with children with special needs. Effective collaboration between healthcare providers, community organizations, and religious leaders is crucial for developing inclusive and responsive services tailored to the needs of these families.

Keywords: intellectual disability, social support, spirituality, worship

Introduction

Caring for children with mild intellectual disabilities involves more than routine tasks; it encompasses a complex interplay of emotional and social responsibilities, particularly for mothers who often act as the primary caregivers (Hosseini et al., 2024). Children with mild intellectual disabilities commonly experience difficulties in problem-solving and abstract thinking. Nevertheless, with appropriate guidance and support, they can develop fundamental skills (Karabulut & Özmen, 2018; Suryaningsih et al., 2024; Yıkmış & Terzioğlu, 2022). For mothers, the caregiving role presents significant physical and psychological challenges, often exacerbated by societal stigma, which can negatively impact their emotional well-being (Fitriyah, 2020; Mabaso, 2024; Raliphaswa et al., 2022).

In the Indonesian context, spirituality and social support are integral to daily life (Herlina et al., 2023). For many mothers, spirituality provides strength in fulfilling their caregiving duties, while family and community support enhance their psychological resilience (Pandya, 2018). However, limited access to healthcare and educational services often compels mothers to seek informal support from religious communities and organizations (Radey, 2018). Such support not only offers practical assistance but also fosters spaces for sharing experiences, reinforcing caregiving as an act of worship and devotion (Jahani & Parayandeh, 2024).

Despite the importance of spirituality and social support, prior studies have predominantly emphasized medical aspects or formal services. The spiritual and social dimensions, particularly within Indonesia’s cultural framework, remain underexplored (Cipta et al., 2024). This study seeks to address this gap by examining the subjective experiences of mothers caring for children with mild intellectual disabilities. Highlighting caregiving as both worship and a moral responsibility aims to shed light on coping strategies and the positive impact of spiritual and social support.

A phenomenological approach was utilized to investigate participants' profound experiences and subjective interpretations. Semi-structured in-depth interviews were conducted to explore how mothers perceive their caregiving roles, confront challenges, and develop coping mechanisms in daily life. The findings contribute not only to the academic literature but also to practical efforts in designing community-based services that are inclusive and sensitive to emotional and spiritual dimensions.

The study offers significant implications for stakeholders, including healthcare providers, community leaders, and policymakers. Enhanced collaboration between the healthcare sector and local communities is essential for creating services that meet the needs of families with children with special needs. By integrating spiritual and social dimensions, the development of more holistic and sustainable support systems can be anticipated.

Objective

This study aims to explore how mothers perceive caregiving for children with mild intellectual disabilities and the coping strategies they employ to manage physical, emotional, and social challenges. Additionally, it highlights the role of spirituality and social support in strengthening mothers' emotional resilience while emphasizing the limitations of formal services and the importance of community support within Indonesia's cultural context.

Method

This study employed a qualitative phenomenological approach to explore the experiences of mothers caring for children with mild intellectual disabilities. This method was selected to enable a deep investigation into the subjective meanings of caregiving, particularly as an act of worship and a moral responsibility.

Participants were selected using purposive sampling to ensure relevance to the research focus. Inclusion criteria included mothers actively involved in daily caregiving, having children diagnosed with mild intellectual disabilities by medical or educational professionals, and willingness to participate in in-depth interviews. A total of 10 participants were involved, with data saturation achieved at the eighth interview, confirming the richness and representativeness of the data.

Data collection involved semi-structured in-depth interviews lasting 45 to 90 minutes, supported by supplementary documents such as school progress reports and clinic health records. Open-ended questions allowed participants to express their experiences freely while remaining aligned with the research objectives.

To enhance validity and credibility, multiple triangulation methods were employed:

1. **Source Triangulation**: Cross-checking interview data with school and clinic records.
2. **Method Triangulation**: Supplementing interviews with data from community and medical documents.
3. **Theoretical Triangulation**: Interpreting findings through theories of social support and spirituality.
4. **Researcher Triangulation**: Engaging multiple researchers in data analysis to minimize bias.

Data analysis followed a thematic approach, beginning with verbatim transcription and open coding to identify key themes (Braun & Clarke, 2006). These themes included the meaning of caregiving, emotional challenges, coping strategies, and the inadequacy of formal services. Findings were contextualized using social support and spirituality theories and iteratively refined for deeper insights. Validation was achieved through member checking, where participants confirmed the accuracy of the researchers' interpretations.

Ethical principles were rigorously observed. Written informed consent was obtained from all participants before interviews, ensuring their privacy and confidentiality. Personal identifiers were replaced with codes (P1–P8) to protect identities, and all data were securely handled and used solely for research purposes.

Result

This study delves into the deep experiences of mothers in caring for children with mild intellectual disabilities through thematic analysis. Four main themes emerged: (1) The Meaning of Caregiving, (2) Caregiving Challenges, (3) Coping Strategies, and (4) Limitations of Formal Services. Each theme reflects the participants' subjective experiences, as well as the supporting and inhibiting factors encountered in their daily caregiving processes.

The Meaning of Caregiving as an Act of Worship and Moral Responsibility

For most mothers, caring for a child with mild intellectual disabilities is seen as an act of worship and devotion that must be undertaken with sincerity. Mothers perceive this role as a life calling, providing them with the motivation to persevere despite various challenges. One participant shared:

> *"I feel that God has entrusted me with this responsibility, and I will carry it out as best as I can. Caring for my child is not just a duty but also an act of worship."* (P1, P2, and P3)

This sense of spirituality becomes a source of strength, helping mothers remain optimistic and patient when facing emotional and physical pressures. These findings demonstrate that religious values play a significant role in giving meaning to caregiving and maintaining the emotional resilience of mothers.

Caregiving Challenges: Physical, Emotional, and Social Stigma

Although mothers find meaning in caregiving, challenges remain an inseparable part of their lives. Participants reported significant physical and emotional burdens, particularly due to limited access to adequate healthcare and education services. Some mothers also felt isolated due to social stigma. One participant shared her experience:

> *"Sometimes I feel that people around me don't understand what we go through. Such stigma makes me feel alone."* (P3, P4, P5)

The dual role of homemaker and caregiver increases their emotional burden, especially when they lack support from their surroundings.

Coping Strategies: Social Support and Spirituality as Defense Mechanisms

Mothers have developed various coping strategies to overcome the challenges they face. Social support from family, friends, and religious communities proved to be a crucial factor in helping them maintain emotional balance. One participant explained:

> *"The mosque community is always ready to help us, both morally and materially. That means a lot to me and makes me feel less alone."* (P6, P7, P8)

In addition to social support, spiritual activities such as prayer and worship are integral parts of their coping strategies. For these mothers, spirituality not only strengthens their connection to God but also provides peace and meaning in caregiving (Kurnia, 2018; Oti-Boadi, 2017).

Limitations of Formal Services and the Importance of Community Support

Most participants expressed frustration with the limited access to formal services, such as specialized therapy and inclusive education. This has compelled them to seek support from informal sources, such as communities and religious organizations. One participant noted:

> *"We often cannot rely on formal services because they are very limited. So, I rely more on the community for help."* (P5)

These limitations highlight the need for the development of more responsive and inclusive community-based services that are accessible to families with children with special needs.

The findings of this study underscore that caregiving, when seen as an act of worship, provides mothers with strong motivation to carry out their roles. Additionally, social and spiritual support serves as vital resources that help mothers cope with physical and emotional challenges. The limitations of formal services emphasize the importance of collaboration between communities, healthcare providers, and educational institutions in creating a more comprehensive and accessible support system. These findings align with Kurnia (2018) theory of social support, which emphasizes the importance of social networks in helping individuals cope with stress. Furthermore, spirituality in this study enriches the understanding of the role of religious values in caregiving, as also highlighted by Oti-Boadi (2017).

Discussion

This study offers new insights into the experiences of mothers caring for children with mild intellectual disabilities. The findings reveal that the meaning of caregiving, challenges, coping strategies, and limitations of formal services are closely interconnected in shaping mothers' daily lives (Currie, 2018). This section discusses the research results by linking the findings to existing theories and previous studies, while also identifying practical and theoretical implications.

Caregiving as Worship and Moral Responsibility

The finding that mothers view caregiving as a form of worship and moral responsibility aligns with the spiritual coping theory by Kurnia (2018). In the context of this study, spirituality is not only a source of meaning but also serves as a sustaining force for mothers amidst physical and emotional challenges. The perception of caregiving as worship provides mothers with strong motivation to perform their caregiving role sincerely, despite facing social pressures and limitations in services. In the Indonesian cultural context, this religious value is highly relevant, as religion often forms the foundation of daily life. This enriches the findings of Karabulut & Özmen (2018), who emphasized that spirituality can act as a buffer against stress, particularly for parents facing significant challenges (Kurnia, 2018).

Challenges of Caregiving: Stigma and Emotional Burden

Consistent with Niedbalski (2021), this study demonstrates that mothers of children with special needs often face social stigma and feel isolated. In addition to the physical burden, this stigma adds emotional strain and increases the risk of stress. These challenges are further compounded by limited access to healthcare and educational services. Such limitations force mothers to seek alternative support outside formal services, such as from communities and religious organizations (Mkabile et al., 2021; Raliphaswa et al., 2022). This aligns with the stress and coping theory by Mohd. Ali & Ismail (2020), which emphasizes that environmental support plays a crucial role in helping individuals cope with psychological stress.

Coping Strategies through Social Support and Spirituality

Social support and spiritual activities serve as effective coping mechanisms for mothers. This study confirms that support from family, friends, and community acts as emotional protection, helping mothers feel heard and cared for. As found by Cipta et al (2024), social support not only reduces mental burdens but also enhances the well-being of caregivers. Spiritual activities, such as prayer and communal worship, provide not only inner peace but also strengthen mothers' social ties with their community. These findings are consistent with Kurnia, (2018) theory, which states that spirituality can be one of the most significant coping resources for individuals facing life's challenges.

Limitations of Formal Services and the Role of Community

Most participants reported that healthcare and educational services for children with mild intellectual disabilities are highly limited. This forces mothers to rely more on community support, particularly from religious-based communities, which are more accessible and responsive to their needs. This finding suggests that while formal services are important, informal support is often more relevant and quicker in addressing mothers' needs. This reinforces the social support theory, which posits that access to both formal and informal support is crucial for individual well-being (Goff et al., 2023; Nicholson et al., 2023). In the Indonesian context, collaboration between communities, educational institutions, and healthcare providers is necessary to address these limitations and create more inclusive and holistic services.

This study makes a significant contribution to the theory of coping and social support by demonstrating that spirituality plays a crucial role in supporting mothers caring for children with special needs. Additionally, these findings enhance the understanding of the importance of community support in the socio-cultural context of Indonesia, where religion and local communities play a central role in people's lives.

Practically, this study highlights the need to develop community-based services that are sensitive to the emotional and spiritual aspects of families with special-needs children. Collaboration between healthcare professionals, local communities, and policymakers is essential to create comprehensive and accessible support programs. Training programs for healthcare professionals on how to provide support that is sensitive to social and cultural contexts are also highly recommended.

This study has some limitations. First, it focuses on the experiences of mothers at a single point in time (cross-sectional), thus failing to capture changes or developments in their coping strategies over time. Future studies with a longitudinal approach will provide richer insights into how mothers adapt and evolve over time. Furthermore, this study only involves participants from a specific geographic area, so the findings may not fully represent the experiences of mothers from diverse social and cultural backgrounds. Future research is suggested to expand the geographic scope and involve participants from various backgrounds. A mixed-methods approach can also be employed to enrich understanding by combining qualitative and quantitative data.

This discussion illustrates that mothers caring for children with mild intellectual disabilities face complex challenges, but they are able to find strength through spiritual meaning and social support. This study makes a significant contribution to understanding the role of spirituality and community in supporting caregivers of children with special needs, while also highlighting the need for more inclusive community-based services. These findings are expected to serve as a foundation for the development of policies and practices that are more sensitive to the emotional and spiritual needs of families, particularly in Indonesia. Thus, this study not only enriches the academic literature but also provides practical relevance for society at large.

Limitation

This study is limited by its cross-sectional design, which does not capture changes in coping strategies over time. Future research should consider a longitudinal approach to explore the dynamic adaptation of mothers to caregiving challenges. Expanding the scope of the study to include participants from diverse cultural and geographical backgrounds would enhance the generalizability of the findings. Employing a mixed-methods approach is also recommended to provide a more holistic understanding, combining qualitative insights with quantitative data to elucidate the relationship between social support, spirituality, and family well-being.

Conclusion

This study offers valuable insights into the experiences of mothers caring for children with mild intellectual disabilities. The findings highlight that perceiving caregiving as an act of worship and moral responsibility motivates mothers to fulfill their roles with sincerity, despite encountering significant physical, emotional, and social challenges. In the Indonesian cultural context, spirituality emerges as a critical coping mechanism, providing personal strength and emotional balance.

Social support from family, friends, and local communities is a key factor in alleviating emotional burdens and enhancing resilience. Religious-based communities, as informal support systems, offer accessible alternatives to formal services, which are often limited. This underscores the urgent need for inclusive and responsive community-based interventions that address the unique needs of families with special-needs children.

Theoretically, this study contributes to the literature by emphasizing the role of spirituality in caregiving for children with special needs, complementing existing coping and social support theories that have predominantly focused on practical and medical dimensions. In societies with strong religious values, spirituality can be one of the most significant sources of support, reinforcing its relevance in family-centered care strategies.

The findings emphasize the importance of collaboration among healthcare providers, local communities, and educational institutions to create a comprehensive and accessible support system. Training healthcare professionals to deliver culturally and spiritually sensitive care is essential. Additionally, partnerships between educational institutions and community organizations are needed to develop inclusive services that cater to both children with special needs and their families.

Ethical consideration

This study was conducted in accordance with ethical research principles, such as respect for participants' rights and protection of data confidentiality. Prior to the interviews, each participant was provided with a thorough explanation of the study’s purpose, procedures, and their right to withdraw at any time without any consequences. Participation was entirely voluntary. To protect privacy and confidentiality, participants' identities were anonymized using codes P1 to P8. The data collected was used exclusively for the purposes of this research.

Conflict of interest

The researchers stated that there is no conflict of interest related to the implementation and publication of the results of this research. The entire research process, from planning, data collection, analysis, to report preparation, was carried out independently without any influence or pressure from any third party. A commitment to research ethics is upheld throughout the research process, ensuring transparency, accuracy and honesty in reporting results. Respondents' participation was voluntary with informed consent, and their confidentiality and privacy were maintained in accordance with applicable research ethics standards. With this statement, researchers hope that the research results can be trusted and used as a valid reference for the development of science and health practices related to ethnomedicine and reproductive health.

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Authors' contribution

Each author makes an equal contribution to all parts of the research. All authors have reviewed and approved the final draft critically and are responsible for the index and similarity of the manuscript.

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