

Exploring Coping Strategies of Parents of Children with Rare Diseases: A Qualitative Study

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Abstract. Parents of children with special needs, such as those with rare diseases, are known to experience higher levels of stress and encounter greater challenges compared to those caring for children without special needs. However, despite its importance, this issue is often unrecognizable and remain insufficiently explored. This current study is a confirmatory study with a qualitative approach that aims to investigate how parents cope with the stress associated with caring for children with rare diseases. This study aims to explore parents' strategies to manage challenges on daily basis. Data collection involved five parents who raise children with rare diseases to explore coping strategies in dealing with parental stress when dealing with everyday caring for children with special needs. Understanding coping strategies to face challenges and stress

Keywords: *children with disabilities, coping mechanism, parental stress*

Abstrak. Orang tua yang memiliki anak berkebutuhan khusus, seperti anak dengan penyakit langka, diketahui memiliki tingkat stres dan tantangan yang lebih tinggi dibandingkan orang tua yang mengasuh anak tidak berkebutuhan khusus. Namun, meskipun penting, masalah ini sering kali tidak dapat dikenali dan kurang dieksplorasi. Penelitian kali ini merupakan penelitian konfirmatori dengan pendekatan kualitatif yang bertujuan untuk menyelidiki bagaimana orang tua mengatasi stres yang terkait dengan merawat anak dengan penyakit langka. Penelitian ini bertujuan untuk mengeksplorasi strategi orang tua dalam mengelola tantangan sehari-hari. Pengumpulan data melibatkan lima orang tua yang membesarkan anak dengan penyakit langka untuk mengeksplorasi strategi coping dalam menghadapi stres orang tua ketika menghadapi pengasuhan anak berkebutuhan khusus sehari-hari. Memahami strategi coping untuk menghadapi tantangan dan stres

Kata kunci: *anak dengan disabilitas, mekanisme koping, stress orang tua*

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Introduction

Parenting a child with rare diseases or disabilities presents a unique set of challenges, often accompanied by significant psychological and emotional stress. While parenting universally demands adaptability and resilience, the experiences of parents raising children with disabilities extend beyond normative challenges, requiring specific coping mechanisms to navigate daily

stress (Guajardo et al., 2009; Raphael et al., 2010; Hsiao, 2017). This paper explores the coping strategies employed by such parents and highlights the importance of addressing parental stress as a critical factor in maintaining family well-being.

Parental stress can be understood through various theoretical frameworks. Lazarus and Folkman's (1984) transactional model of stress and coping provides a foundational perspective, emphasizing the interplay between an individual's perception of stressors and the resources available to address them. According to this model, coping is defined as cognitive and behavioral efforts to manage specific internal or external demands appraised as taxing or exceeding an individual's resources.

Another relevant framework is the Double ABCX model, which extends Hill's ABCX model of family stress and adaptation. This model posits that parental coping is influenced by the accumulation of stressors (A), the family's resources (B), and the parents' appraisal of the situation (C). Over time, these factors interact dynamically, shaping the family's ability to adapt (X). In the context of parenting children with disabilities, both frameworks underscore the critical role of coping mechanisms in mitigating the impact of chronic stressors and fostering resilience.

Managing stress in parents is crucial for several reasons. First, chronic parental stress can lead to adverse outcomes for both parents and children. Research has demonstrated that high levels of stress in parents are associated with increased risks of anxiety, depression, and burnout. Furthermore, parental stress can negatively affect parenting practices, potentially impairing the parent-child relationship and the child's overall development (Margarida, 2018; Padden & James, 2017; Kumar, dkk., 2018).

For children with disabilities, parental stress poses an additional risk factor. Parents who are overwhelmed by stress may have difficulty accessing or utilizing resources, advocating for their child's needs, or maintaining consistent caregiving routines (Sharma & Thapa, 2020). Effective stress management not only benefits the parents' well-being but also contributes to a stable and supportive environment for the child, which is essential for their physical, emotional, and cognitive development.

Parents of children with rare diseases or disabilities often face multifaceted challenges that can amplify stress. These challenges may include medical and caregiving demands. Managing a child's complex medical needs often involves navigating healthcare systems, coordinating multiple treatments, and providing intensive daily care. Such demands can be physically and emotionally exhausting. Other than that, financial strain associated with medical care, specialized equipment, therapy, and other resources can place a significant financial burden on families (Zablotsky et al., 2013). This financial stress is often compounded by the reduced earning capacity of parents who may need to leave the workforce to provide care. Exacerbating the challenge, many parents report feelings of isolation due to the stigma associated with disabilities and the challenges of maintaining social connections. Limited understanding or support from extended

family, friends, or community members can exacerbate this sense of isolation. Furthermore, parents may experience a wide range of emotions, including guilt, grief, frustration, and fear (Pottie & Ingram, 2008; Zablotsky et al., 2013). These emotions, coupled with the uncertainty of their child's prognosis, can contribute to ongoing emotional stress. Lastly, inadequate access to healthcare, educational accommodations, or community support services can further hinder parents' ability to cope effectively.

The urgency of understanding and addressing parental coping mechanisms in the context of rare diseases and disabilities cannot be overstated. With the growing recognition of family-centered care as a cornerstone of disability services, there is a pressing need for evidence-based strategies to support parents. This is particularly relevant in societies where systemic barriers, such as limited healthcare infrastructure or cultural stigma, may amplify parental stress (Lyons et al., 2010). Qualitative research on this topic is essential for capturing the nuanced and diverse experiences of parents. Unlike quantitative approaches, qualitative methods allow researchers to delve deeply into parents' lived experiences, uncovering the strategies and resources they find most effective. Such insights can inform the development of targeted interventions that address the specific needs of families raising children with disabilities.

This paper underscores the critical importance of addressing parental stress as a pathway to supporting families of children with rare diseases and disabilities. By exploring the coping mechanisms employed by parents, this research aims to contribute to the broader understanding of family resilience and inform the development of interventions that enhance the well-being of both parents and children. The findings will serve as a valuable resource for practitioners, policymakers, and researchers dedicated to advancing inclusive and family-centered care.

Methods

Participant

Five representative parents recruited using purposive sampling. Participants were selected based on their experience of parenting a child diagnosed with a rare disease or disability, ensuring a diverse range of perspectives. The participants were part of the project with Enabled.id community, a parent support community for parents with children with rare disease/tracheostomy users. The mean age of the participants was $M=39,6$; $SD=2,34$, and all the five participants were mothers. The mean age of their children who have rare disease/disabilities was $M=9,2$; $SD=5,78$, three girls and two boys.

Study design

This descriptive qualitative study employed thematic analysis to explore the coping mechanisms of parents raising children with rare diseases or disabilities.

Data collection

Data were collected through semi-structured, online interviews. The interviews were conducted in a private and comfortable setting, allowing participants to share their experiences openly. Each

interview lasted approximately 60-90 minutes and was recorded with the participants' consent. Sample of the questions including "What is the daily challenge raising your child related to his/her special needs?" and "How do you deal with such challenge?". To further probe the question, participants were asked questions such as "Do you have any strategy or tips to manage your emotion or stress?".

Data analysis

Researchers transcribed the interviews verbatim to ensure accuracy and fidelity to the participants' narratives. Data analysis followed a collaborative and iterative process. Initially, researchers independently coded the transcripts to identify recurring patterns and significant statements. Subsequently, the research team met regularly to discuss the coding process, resolve discrepancies, and refine the thematic framework. This teamwork approach enhanced the dependability and consistency of the analysis. Themes were derived inductively, capturing the core strategies and resources parents utilized to manage stress. To ensure credibility, member checking was employed, wherein participants reviewed the preliminary findings and provided feedback on the accuracy of the interpretations. This process ensured that the themes reflected the participants' lived experiences authentically. Ethical considerations were prioritized throughout the study. Participants were provided with detailed information about the research objectives, and informed consent was obtained before participation. Confidentiality was maintained by anonymizing all data and securely storing the recordings and transcripts.

Results

Five mothers participated in this study. The mean age of the participants was 39.6 years (range: 30–48 years), and each participant had one child diagnosed with a rare disease or disability. All participants (100%) were married, and the mean age of the children was 9.2 years (range: 3–15 years). Through thematic analysis, two overarching dimensions and their respective sub-dimensions were identified: Individual Coping Strategies and Relational and Structural Coping Mechanisms.

Table 1.

Themes, Definitions, and Illustrations of Subthemes for Parents of Children with Disabilities Coping Strategies

Theme	Sub-theme	Description
Individual coping strategies	Self-Acceptance and emotion regulation	Involves internal processes such as accepting the child's condition and managing emotions to stay composed and resilient.
	Practical and Behavioral Coping	Includes creating routines, seeking practical solutions, and focusing on actionable steps to address challenges in daily life.
	Managing stress and stigma	Highlights self-care through "me time" and strategies for

		handling or avoiding negative societal perceptions.
Relational and structural coping	Social Support and Advocacy	Encompasses seeking family, friends, and community support while educating society to build acceptance and reduce stigma.
	Optimism, Perseverance, and Growth	Reflects forward-looking actions rooted in maintaining hope, striving for the child's development, and engaging in sustained efforts for solutions.

The findings of this study reveal a diverse range of coping strategies employed by parents of children with special needs, which can be grouped into five overarching themes: self-acceptance and emotional regulation, social support and advocacy, practical and behavioral coping, managing stress and stigma, and optimism, perseverance, and growth. These themes highlight the multifaceted approaches parents take to manage the challenges and stressors they face.

1. Self-Acceptance and Emotional Regulation

Self-acceptance emerged as a fundamental strategy, particularly emphasized by Bu RR. Accepting their child's condition is viewed as a crucial first step in providing appropriate support and creating a positive environment. In conjunction with this, emotional regulation was highlighted as an essential skill for maintaining focus and composure. Bu FI emphasized the need to manage emotions to stay calm during difficult situations, while Bu RR highlighted that emotional regulation serves as a key to overcoming stress and maintaining inner peace.

2. Social Support and Advocacy

The importance of a strong support system was frequently mentioned by the respondents. Bu FI and Bu EE noted the role of family and friends in alleviating emotional burdens, while Bu AD stressed the significance of community support groups where experiences and practical advice could be shared. Beyond personal support, advocacy through education was also identified as a coping mechanism. Bu RR discussed the value of educating society to foster greater understanding and acceptance of children with special needs, which in turn reduces stigma and enhances social inclusivity.

3. Practical and Behavioral Coping

Practical strategies emerged as another prominent theme. Bu EE emphasized the importance of identifying and implementing practical solutions to everyday challenges, such as modifying the home environment to better accommodate the child's needs. Similarly, Bu AD highlighted the role of creating structured routines to provide a sense of comfort and predictability for the child, which facilitates their adaptation and reduces stress for the family.

4. Managing Stress and Stigma

To cope with stress, respondents reported prioritizing self-care through "me time." Both Bu FI and Bu RR stressed the necessity of taking time for oneself to maintain mental and physical well-being. In addition, parents actively worked to counteract stigma and negative perceptions. Bu FI and Bu RR shared strategies for avoiding the impact of negative opinions from others by focusing on their family's needs and maintaining a positive outlook. Bu RR also discussed the importance of assertiveness when responding to negative comments, emphasizing the need to educate others and advocate for respect and understanding.

5. Optimism, Perseverance, and Growth

Optimism and perseverance were recurring themes in the narratives. Bu EE described the importance of maintaining hope for the child's future despite ongoing challenges, while Bu AD underscored the significance of continually striving to provide therapy and seek solutions despite uncertainties. This persistence reflects a commitment to the child's growth and development, demonstrating a forward-looking approach to coping with stressors.

Overall, the findings illustrate the adaptive and multifaceted strategies employed by parents of children with special needs. These strategies span from internal processes such as self-acceptance and emotional regulation to external mechanisms like social support, advocacy, and practical problem-solving. Additionally, managing stigma, prioritizing self-care, and maintaining a sense of hope and perseverance play pivotal roles in these parents' efforts to navigate their challenging circumstances.

Discussion

The findings of this study highlight the diverse and adaptive coping strategies employed by parents of children with rare diseases or disabilities to manage parental stress. These strategies can be categorized into two overarching themes: Individual Coping Strategies and Relational and Structural Coping Mechanisms. Each theme reflects the complex interplay between internal resilience and external resources required to navigate the challenges of raising a child with special needs. Parents consistently emphasized the importance of self-acceptance and emotional regulation as foundational coping mechanisms. Self-acceptance allows parents to come to terms with their child's condition, which is critical in reducing self-blame and fostering a positive mindset (Margarida, 2018; Padden & James, 2017; Kumar, dkk., 2018; Sharma & Thapa, 2020). Emotional regulation, such as staying calm and focused, enables parents to manage their responses to stressful situations effectively. These strategies align with Lazarus and Folkman's (1984) stress and coping model, which posits that adaptive coping relies on an individual's capacity to cognitively appraise and emotionally manage stressors. The emphasis on practical and behavioral coping, including creating routines and seeking practical solutions, reflects a problem-focused coping approach. Structured routines help children with disabilities feel secure and adaptable, reducing parental stress linked to unpredictability in daily life (Dervishaliaj, 2013).

This finding is consistent with previous research indicating that predictability and structure reduce uncertainty and provide a sense of control for parents managing their child's needs.

Parents also prioritized managing stress and stigma, often through self-care activities such as "me time." This strategy serves as a means of psychological restoration, enabling parents to recharge and build emotional capacity to face ongoing challenges. By disengaging temporarily from caregiving responsibilities, parents mitigate the risk of burnout, a common issue in this demographic. Furthermore, avoiding or confronting negative societal perceptions allows parents to protect their mental health and maintain focus on their family's well-being rather than external judgment. Parents highlighted the role of social support and advocacy in reducing stress. Support networks, including family, friends, and community groups, provide emotional encouragement, practical advice, and shared experiences. Engaging in advocacy and educating others about their child's condition not only fosters societal acceptance but also empowers parents to contribute to systemic change (Sharma & Thapa, 2020). These findings echo Bronfenbrenner's ecological systems theory, emphasizing how mesosystem interactions, such as family and community relationships, influence parental coping and well-being.

Another key coping mechanism was optimism, perseverance, and growth, with parents emphasizing hope and forward-looking efforts to support their child's development. Sustained optimism helps parents maintain emotional resilience and view challenges as opportunities for growth. Perseverance reflects their commitment to ongoing therapeutic interventions and problem-solving, despite the uncertainty surrounding their child's condition. These strategies align with positive psychology frameworks that highlight the protective effects of hope and goal-directed efforts in enhancing well-being.

The adoption of these strategies is deeply rooted in the unique stressors faced by parents of children with rare diseases or disabilities. Chronic uncertainty regarding their child's prognosis, high caregiving demands, and societal stigma necessitate a combination of individual and relational strategies. Individual coping mechanisms, such as self-acceptance, emotional regulation, and self-care, empower parents to internally manage their stress and build resilience. Relational strategies, including seeking social support and advocating for societal change, address external stressors by fostering a sense of community and reducing isolation (Yamaoka, et al., 2015; Pfeifer, 2014).

Furthermore, these coping strategies are adaptive responses to the dual demands of caregiving and navigating social stigma. The emphasis on routine creation and practical solutions reflects a need to reduce chaos and create a sense of predictability in daily life. Simultaneously, advocacy and education efforts demonstrate parents' desire to create an inclusive environment for their children, reducing barriers and promoting acceptance (Zablotsky et al., 2013). These findings underscore the importance of designing targeted interventions to support parents of children with rare diseases or disabilities. Interventions should include resources to enhance self-

acceptance and emotional regulation, such as counseling and mindfulness training, as well as programs to strengthen social support networks and advocacy skills.

The findings of this research have several important implications. At the individual level, understanding parental coping mechanisms can guide the design of interventions to enhance parents' resilience and well-being. These interventions may include stress management training, counseling, or support groups tailored to the unique challenges faced by parents of children with disabilities. At the systemic level, the research can inform policy development aimed at improving access to resources and services. For example, healthcare systems can integrate parent-focused support programs into their offerings, while educational institutions can provide more inclusive environments that alleviate stress for both parents and children. Furthermore, the research can contribute to public awareness campaigns that challenge stigma and promote understanding of the experiences of families affected by disabilities.

Conclusion

In conclusion, parents employ a combination of individual and relational coping strategies to manage the multifaceted challenges of raising children with rare diseases or disabilities. These adaptive approaches not only mitigate stress but also foster personal growth, resilience, and a supportive environment for both parents and children. Future research should explore how these coping mechanisms evolve over time and across different cultural contexts, offering insights into more tailored support systems for these families. The methodological rigor of this study, grounded in its qualitative design, provides a comprehensive understanding of the coping mechanisms employed by parents of children with rare diseases or disabilities. The insights gained contribute to the growing body of knowledge on family resilience and inform strategies to support these families effectively.

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