Unveiling Challenges Faced by Mothers of Children with Disabilities: A Qualitative Exploration

Angga Sisca Rahadian[1], Andhika Ajie Baskoro[2], Isnenningtyas Yulianti[3],
Mochammad Wahyu Ghani[4], Sri Sunarti Purwaningsih[5], Zainal Fatoni[6]

{angg011@brin.go.id[1], andh005@brin.go.id[2], isne001@brin.go.id[3]}
{National Research and Inovation Agency (BRIN) [1, 2, 3, 4, 5, 6]}

Abstract. In the conventional paradigm of parenting, mothers are often exclusively burdened, yet those raising children with disabilities grapple with a more complex reality. This qualitative study, employing two focus group discussions, delves into the multitude of challenges confronting these mothers, particularly in efforts to access health services for their children in Indonesia. Study findings show that children's disabilities are unique, and the challenges faced by mothers and families are complex and varied. There are at least four challenges faced by mothers and families caring children with disabilities, namely attitude (stereotype and social stigma), finance (health insurance, poverty, high costs, and extra costs), physics (public facilities not yet inclusive), and information (limited access). The study underscores the urgency of comprehensive and inclusive policies to address these challenges and to encourage increased societal awareness to eradicate stigma. Ultimately, the research highlights the imperative need for a more empathetic and supportive society for mothers navigating the unique challenges of raising children with disabilities.

Keywords: Disability, Mother, Gender, Childrearing

1 Introduction

Children with disabilities are those who experience physical, mental, intellectual, or sensory impairments, posing long-term difficulties in their capacity development and social participation [1]. Despite the global challenge of accessing precise disability-related data, it is estimated that there are at least 240 million children with disabilities worldwide, representing roughly 1 in 10 children. Pertinent data reveals that over half of these children (51%) express discontent with their lives, and almost half (47%) are at significant risk of educational discontinuation due to their disabilities. Within Indonesia, the Ministry of Women's Empowerment and Child Protection's 2021 data indicated that approximately 0.79% of Indonesian children are living with disabilities, translating to around 650,000 out of a total of 84.4 million children [2]. This substantial segment of the population undoubtedly requires conscientious attention from relevant governmental bodies to ensure their optimal development.

In light of these insights, the development of children with disabilities is an issue necessitating earnest consideration. The family, as the primary nurturing environment, plays a critical role in the upbringing of children with disabilities. This caregiving dynamic presents a myriad of challenges, especially for families with disabled children, demanding high levels of patience and time commitment due to the children's limitations in conducting basic daily activities. In some cases, children with disabilities are perceived as a familial burden [3]–[5].

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Aligned with traditional views on child-rearing, mothers are often posited as the principal caregivers, while fathers are predominantly seen as breadwinners [6]. This notion is even more pronounced in families with children with disabilities, where mothers frequently bear the brunt of caregiving responsibilities [7]. Consequently, many mothers have to forsake their career aspirations to devote themselves entirely to their disabled children [8]. This centralization of caregiving around the mother often predisposes them to various health issues, both physical and mental, compared to fathers [9]–[12].

It is apparent that cultural aspects significantly influence the determined role of mothers in caregiving. Furthermore, the enduring stigma associated with disabilities impacts not only the children with disabilities but also their primary caregivers, primarily the mothers. Stigmatization involves labeling individuals or groups as different, often leading to negative perceptions [13]. For persons with disabilities, this stigma frequently translates into societal views of helplessness due to their impairments. Such stigmatization affects both the individuals and their families [14]. They find themselves navigating a landscape filled with unique challenges, from societal prejudice to institutional barriers.

Studies related to the experience of caregivers, especially mothers with children with disability have been done in many countries. Several studies highlighted the issue of family quality of life among families who have children with disabilities. Previous studies found that the role of caregiving children heavily relied on the mothers. In addition, this situation puts a burden that affects the mother's health condition, both physically and mentally which affects the quality of family life [15]–[17]. In terms of research method, several studies were focused on the use of the quantitative method, while the current study uses the qualitative method to capture deeper understanding of the experience of mothers with children with disability. Within this context, the present study delves deeply into the multifaceted experiences of mothers caring for children with disabilities. The term "experiences" here is comprehensive, encapsulating the mothers' subjective perceptions of their children's disabilities, the manifold challenges they encounter in their caregiving roles, and their journeys in seeking and accessing necessary healthcare and services for their children. These experiences, often overshadowed by broader societal narratives, are crucial in understanding the nuanced realities these families live.

2 Disability, Gender, Mother’s Role, Family Resilience, and Barriers: Literature Review

The lives of children with disabilities as well as their faimilies are undoubtedly influenced. The influences were related to the issue of long-term limitations in physical, mental, social, and emotional aspects [18]. This situation in the end might impacted the resilience within the family with the children with disability. Family resilience varies greatly, as noted by Black and Lobo [19], with every family, regardless of ethnicity, experiencing different levels of resilience, setbacks, and severity of risks. McCubbin, Thompson, and McCubbin [20], [21] propose that family resilience is a fusion of positive behavioral patterns and functional competencies present in family individuals and the family unit as a whole. Positive attitudes and individual competencies are crucial in responding to stressful and adverse conditions. These also dictate the family's capacity to rebound by preserving its integrity, continually safeguarding, and promoting the welfare of its members and the familial unit overall. The issue of family resilience were much discussed already, especially among families who have children with disability [22]–[24] In the Indonesian context, one study revealed that several protective factors, such as positive perception of parenting and knowledge of child's characteristics, play a crucial role in the aspect of family resilience and the well-being of children with disabilities within the families [25].

Women are socially constructed as caregivers throughout their lives, significantly impacting perceptions of their labor [26]. Utilizing data from a survey conducted in 1998–1999, Leiter *et al.* [27] broadened our understanding of lifelong family caregiving by assessing the caregiving roles and employment consequences experienced by women with children who have special needs. The significant role mothers play in childcare persists, often shaped by societal norms that primarily assign them this responsibility [28]. Thus, the issue of caregiving, especially for children with disability mostly falls to the mother. This role might put the mother in an overwhelming situation, especially when the mother has no external support. Singh, Kangri, and Kumar [29] articulate the myriad challenges families face when raising children with disorders, encompassing mental, physical, social, marital, and financial struggles. In their research, these authors discovered that mothers of children with disabilities exhibit significantly lower average scores than those with non-disabled children. This finding is echoed in Peer and Hillman's study [30], which compared the stress levels of parents with developmentally challenged children to those with typically developing children, revealing higher stress levels in the former group.

Parents of children with developmental disorders tend to experience heightened stress and find it more daunting to manage their children's issues compared to those with children who develop typically [25], [31], [32]. Another research [33] explains that it is important to distinguish between service use and service availability to understand the relationship between stress and public services. What is surprising is that although parents in this study reported stress and care demands in a variety of areas, they reported relatively limited use of the services available to them. and creates a burden for mothers. The stress levels escalate, particularly for single mothers grappling with the complexities of caring for special needs children amidst the COVID-19 pandemic [34]. Studies indicate that parents, particularly those with autistic children, experience significantly higher levels of stress [11]. Education and proper caregiving are foundational for children with disabilities, necessitating well-planned and quality caregiving approaches. Yet, within families, caregiving often defaults to the mother, impacting her opportunity for employment and personal well-being [3], [8]. This scenario can strain her mental and physical health, potentially destabilizing the family unit.

Children with disabilities often face barriers due to non-inclusive infrastructure, hindering their independence [35]. Families struggle to provide appropriate care, partly due to a lack of essential information about various disabilities and the specifics of effective caregiving. This situation not only impacts the children's rights but also places a considerable emotional and financial burden on these families. This responsibility, however, should not fall solely on families. They need state support to address these challenges effectively. Traditional societal roles, unfortunately, often impose the primary caregiving responsibility on mothers, complicating the situation further, especially if the child experiences any difficulties [6]. This dynamic can even lead to mothers being unfairly blamed for their child's disability [7].

Thus, fostering resilience is crucial for families with disabled children, particularly for the primary caregivers who face these daily challenges [36]. This situation underscores the need for greater support and understanding from both society and the state. The disability services systems, along with the families and communities they inhabit, need to extend substantial social support to single mothers with disabled children, so these mothers could feel a sense of security [37]. The COVID-19 pandemic, enforcing a regime where all students must undertake home learning under parental supervision, has compounded the difficulties for single mothers with special needs children. Resilience becomes essential as these circumstances pressure single mothers to become stronger. Parents can navigate numerous challenges, including childcare and financial hardships, by fostering resilience, significantly enhanced through social support [38].

3 Methodology

This research aims to explore the challenges faced by mothers of children with disabilities using a qualitative research paradigm. The qualitative paradigm is very important to use in disability research because its view can explore the interest in defending the rights of people with disabilities who experience great difficulties [39]. In this research, a phenomenological approach to study design was also used. Phenomenological studies highlight the life experiences experienced by different informants that are correlated, and then each set of experiences is analyzed by the researcher paying attention to the hermetic circle [40]. In the phenomenon we have studied, we have tried to understand our informants who have a background as mothers of children with disabilities. Our informants share the same pattern of experiences, namely caring for children with disabilities, especially the experience of difficulties in accessing health services for children with disabilities. Phenomenological studies of disability allow researchers to see the experiences of people with disabilities in a more gradual and complex way, by separating them into the experiences of families and of the people with disabilities themselves [41].

In October 2022, an intensive focus group discussion (FGD) were conducted online with four mothers, each nurturing a child with a distinct disability. Previously, an FGD with five mothers was also convened in Yogyakarta in June 2022. These FGDs with groups of mothers who have children with disabilities allow experiences to be explored through structured interview guides. This allows informants to reflect on the causes and challenges of (a) the burden of having a child with a disability; and (b) caring for people with disabilities [42]. The children in this study had a range of disabilities, including autism, cerebral palsy, paraplegia and down syndrome, and the focus was on identifying common challenges in accessing healthcare. FGD was also conducted in two modes, namely direct FGD and online FGD using zoom media. The FGD method is currently experiencing increasing interest in the use of technology to speed up time efficiency and reduce expensive accommodation costs [43].

The selected informants were identified using a purposive sampling method. Purposive sampling in qualitative research involves the deliberate selection of specific informants, events or settings because of special characteristics that cannot be adequately obtained through other channels [44]. In this case, the characteristics of the purposive sampling informants must ensure representation not only in the typology of disability, but also in the depth of experience of mothers caring for children with disability. Many families go beyond the role of respondents by initiating communities that promote awareness, support and dissemination of information about specific disabilities. Data collected through interviews and FGDs were subjected to thematic descriptive analysis, with the aim of accurately representing participants' opinions in line with the research objectives. Rigorous categorization and synthesis will be used to provide an in-depth academic discourse on the topic. This study involves people with disabilities, positions them not only as research subjects but also as active participants in the research process, and is fundamentally inclusive. This research has received ethical approval from the Social Humanities Ethics Committee of the National Agency for Research and Innovation, letter number: 026/KE.01/SK/4/2022.

4 Result and Discussion

4.1 Disability is Unique for Each Individual

Caring for children with disabilities poses significant challenges in supervision and caregiving. The intricacy of this task is influenced by the diverse spectrum of disabilities [45] that children may have, creating a highly varied group. This diversity results in distinct caregiving experiences for families, shaped by the nature of the child's disability, socio-cultural contexts, support structures, personal beliefs, and emotional resilience. This section aims to thoroughly examine the caregiving experiences of four unique informants, each responsible for children navigating life with different disabilities. These narratives provide a holistic understanding of the caregivers' lived realities, surpassing mere categorizations of disabilities.

At the core, there are several commonalities among our four informants in caregiving for children with disabilities. One striking similarity is the caregiving burden predominantly shouldered by the mothers. Findings also highlight an informant resigning from her job to focus entirely on caregiving and the shared experience of facing stigma, both from society and healthcare professionals, underscoring the need for greater understanding and support.

> *"I had to quit my job to take care of my child, and later, my husband left his office job to start a business, so he could be here (always near from home) if anything happened."* (R, mother of a child with cerebral palsy)

In the world of caring for children with disabilities, moms face daily physical and mental exhaustion, and our informants are no exception. The range of disabilities brings varied experiences. For example, with autism, one mom mentioned a tough challenge: taking her child to the hospital. Her son, who has autism, finds it hard to stay still during medical treatments and doesn't like getting out of the car when they reach the hospital. The mom explained that, for autistic children, being in a moving vehicle becomes a specific need.

> *"So, my child finds it very difficult to go to the hospital, preferring only the larger ones with mall-like facilities. Then, once we get there, it's a real challenge to get him out of the car because he enjoys the ride so much. So, for autistic children, being in a moving vehicle becomes a need."* (T, mother of a child with autism)

Children with progressive disabilities, worsening over time, bring unique stress. An informant with children diagnosed with Spinal Muscular Atrophy (SMA) experienced the shock of seemingly healthy children developing disabilities as they grew, feeling unprepared for the progressive condition. Furthermore, another informant detailed the physically demanding task of breastfeeding her child with down syndrome for three hours due to a heart condition, resulting in bruised breasts. A lack of empathy was felt, as the informant received information on increased life span without guidance on enhancing the child's quality of life, leaving her feeling her child was not seen as a dignified human being.

4.2 Various obstacles encountered by families of children with disabilities: Attitude, Finance, Physic, and Information

Attitudinal barriers, rooted in stereotypes and societal stigmas, have significant implications. These prejudices may lead to tangible discrimination, such as a child with a disability being excluded from sharing a classroom with non-disabled peers due to objections from parents opposing integration in educational methodologies and environments [46]. This, in turn, reinforces and perpetuates the cycle of discrimination, stymieing the potential for societal progress towards inclusivity and equality in educational opportunities.

Individuals with disabilities face societal stereotypes, rooted in ableism, that link disability to perceived sins, constituting a form of karmic retribution. This perception is encapsulated in 'religious models,' associating certain behavior or practices with a 'fall from grace' leading to disability [47]. Consequently, the response to disability has often been steeped in attempts at atonement, including various rituals or specific prayers for healing, or interventions from tribal elders or traditional leaders [48]. The responsibility for one's disability was often likened to dealing with an illness [49]. Rooted in the principle that illness must be cured, the belief persisted that disabilities could be 'healed' through medical intervention. This approach, known as the medical model, has its foundations in the work of scholars [50].

Societal perspectives began to evolve, recognizing disability not merely as a medical issue but also a social concern [51]. Societal mindset still lags, entrenched in a social viewpoint, hence the entrapment in charitable acts and the continued belief that individuals with disabilities, with their limitations, are incapable of participating in community life [52]. Cynicism, underestimation, and various other forms of negative labeling continue to mark the lives of people with disabilities. Resistance persists when they integrate into educational settings [53]. Our study In Yogyakarta, children with cognitive disabilities, like autism, are often labeled as disruptive, placing an extra burden on mothers. Harmful stereotypes, including the misconception of their asexuality, make them vulnerable to abuse. Parents, influenced by these misconceptions, neglect educating their children about signs of readiness for sexual activity.

Another barrier faced by parents of children with disabilities is finance which makes them strive for a sustainable life, as found by a study in Blitar [54]. The economic impediments are interlinked with poverty, given their struggle with basic needs, capabilities, and limited economic resources [55]. Similarly, Xiao and O'Neill [56] discovered that people with disabilities in America find it exceedingly challenging to possess investment instruments due to difficulties in accessing information and the financial constraints spent on daily living expenses. Financial barriers are a significant issue in caring for a child or family member with disabilities [57], [58]. Informants in Yogyakarta noted that despite Regulation Number 4 of 2012 allowing individuals with disabilities to access health services through the Jamkesus (*Jaminan Kesehatan Khusus* or special health insurance) scheme for free, implementation is hindered. The government's perspective, limiting entitlement to the financially disadvantaged among the disabled community, hampers effective execution. N, a participant in our Yogyakarta FGD, highlighted this issue.

> *" Jamkesus services require proof of one's housing conditions and vehicle ownership. Many individuals who own homes deemed habitable and three-wheeled motorcycles are ineligible for Jamkesus healthcare services. Three-wheeled motorcycles are not merely a mode of transportation but also a mobility aid for individuals with disabilities..."*

The stipulation that disability support is contingent upon poverty effectively perpetuates a form of discrimination that entraps individuals with disabilities into a state of perpetual financial vulnerability. According to Goodley [50], such discrimination is an expected consequence of what is termed 'neoliberal ableism,' a global phenomenon where individuals with disabilities are marginalized by societies striving for a "normal" state of affairs aligned with the ideals of free-market economic progress. This paradigm ensures the continued discrimination of individuals with disabilities, perceived not in terms of health but rather as a deviation from the "healthy body" norm [59].

Individuals with disabilities tend to have frequent healthcare encounters, necessitating a high usage of medical services and prescriptions, compounded by the substantial costs associated with specialized transportation [60], [61]. The most significant barrier to accessing healthcare services for individuals with disabilities consistently correlates with financial constraints [62]. Our informant (S, a mother of a child with SMA) explained that BPJS (Healthcare and Social Security Agency) does not cover DNA test expenses that high costs, and not available in every city. Having a child with disabilities is like holding a death card as the expenses for their care are extraordinarily high, as added by D, who has a child with Down syndrome. The cost for specialized examinations such as screening for Down syndrome is very expensive.

Households with a member who has a disability typically experience a six-fold increase in the rate of poverty [55]. Numerous mothers of children with disabilities become even more economically vulnerable due to the lack of time to engage in employment, especially during their children's school years [63].

Physical or environmental barriers are other impediments to accessing public services for individuals with disabilities. Research in China revealed that not a single respondent was free from physical obstacles when attempting to access public amenities [64], spanning aspects of education and health [58], [65], [66]. Our study found that the mother of a child with SMA often encounters obstacles when escorting her child to the classroom as the school has yet to accommodate the needs of students with physical disabilities. Our study also found that mothers of children have difficulties in accessing health services as the physical environment hinders their mobility. This predicament was articulated by S, mother with a physical disability and also has a child with disability:

> *My child's severe stomach issues led me to Hospital X, but its lack of dedicated pediatric rooms prompted a move to the more distant Hospital Y, which lacked an elevator to the top floor. Managing tasks, from obtaining diapers to handling paperwork, proved challenging.*

This issue mirrors the findings of a study conducted by Clemente et al. [67], which identified physical barriers within healthcare facilities as a predominant challenge faced by families of children with disabilities. In Yogyakarta, healthcare facility's regulations stipulate compensation for any damages caused to hospital property. This rule discourages the parent from seeking necessary healthcare services for her children.

Information barriers are also reported by parents of children with disabilities. Raising children with disabilities in remote settings presents challenges, including limited access to data and information, legal protocols and rules, and the availability of rehabilitation and specialized service facilities for those with special needs [68].

Mothers of children with disabilities struggle to access information on causes, types, degrees, supervision, care, health services, and support from both government and non-governmental organizations. One of the problems is related to accurate information from health workers about their child's condition [69]. The provided excerpts shed light on the perspectives of the study's participants on the difficulties in getting information expressed by R, a mother of an 11-year-old child with cerebral palsy/CP). R felt that she missed out on early detection because the doctor she consulted often said normal even though her 3-month-old child have fever and seizures. It continued until the child could not sit up when he was 7 months old, and often fell when he got older.

4.3 Family and environmental support

Mothers who have children with disabilities have a heavier burden than fathers. A mother must be willing to give up her career to provide care and welfare for her disabled child. From helping with basic needs such as eating, dressing, even transportation and facilitating body mobilization [3]. This exacerbates mental conditions, causing high stress and health issues. In this study, mothers care for children with disabilities without family involvement or intervention. Thus, mothers require support from their husbands, families, and the government.

Support can manifest through tailored access considering individual needs and residence, ensuring inclusivity in health and public services. Accessible transportation facilitates mobility for mothers caring for children with disabilities. Additionally, the integration of helpful technologies is essential in aiding the care of children with disabilities.Other support from the environment is promotional media and campaigns to voice the interests of mothers and advocate for their needs. With the media, society will understand the difficulties of mothers with children and disabilities and provide awareness to pay more attention to them [70].

5 Conclusion and recommendation

Family resilience is a crucial issue faced by families with children with disabilities. This issue is becoming increasingly complicated, influenced by traditional views which still place women as the main caregivers in caring for children with disabilities. Disabilities in children are unique, both in terms of the type and severity of the disability. This has an impact on the complex and varied challenges faced by each mother and family. Focusing on the life experiences of mothers with children with disabilities in Indonesia, this study found that there are at least four challenges they face, especially related to accessing the health programs and services they need. First, attitudinal barriers in the form of stereotypes and societal stigma which have an impact on maternal mental health. Second, financial constraints related to high health costs, indirect costs that must be borne (such as transportation costs), family economic conditions, and limited health insurance available. Third, physical barriers, especially related to public facilities (such as health services and schools) which are not yet inclusive. Fourth, information barriers in the form of limited data and information that can be easily accessed by mothers and families with children with disabilities. By shedding light on these challenges, the study underscores the pressing need for inclusive policies and societal enlightenment in fostering a more understanding and supportive environment for these mothers in their distinctive parenting journey. Government reassessment of disability policies, with a focus on health, education, public services, and social protection, is essential. Additionally, society must increase understanding to alleviate stigmas burdening mothers of children with disabilities.

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