

# Dynamics of Family Caregivers in Caring for People with Disabilities Congenital: A Systematic Literature Review (SLR)

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## ABSTRACT

*The role of family caregivers in caring for people with congenital disabilities has a significant impact on the individual's well-being. However, there has been no comprehensive systematic literature review regarding the dynamics, challenges, and support provided by family carers in this context. Therefore, we need a comprehensive literature review to fully comprehend the role of family carers in providing care for individuals with congenital disabilities. This research aims to conduct a systematic literature review to examine the dynamics of the role of family carers, the challenges faced, and the type of support needed in caring for people with congenital disabilities. Thus, the aim of this research is to compile a comprehensive and in-depth picture of this phenomenon based on existing literature. We use a systematic literature review as the research method, searching, selecting, and critically analysing scientific articles relevant to the topic under study. This study also applied strict inclusion and exclusion criteria to ensure the accuracy and validity of the literature review results. This systematic literature review emphasizes the importance of fully understanding the role of family caregivers in caring for people with congenital disabilities. The results of this review can provide a basis for further research and development of interventions aimed at improving well-being and support for family carers in this context.*

### Keywords:

*Caregivers; disabilities congenital; SLR*

## INTRODUCTION

According to the Global Report on Birth Defects, babies with disabilities had a birth rate of 59.3 per 1000, compared to births without disabilities. Another report states that 8 out of 100 children born worldwide have congenital disabilities (Mitayani & Purwoko, 2016). This fact confirms the high number of parents who give birth to children with congenital disabilities, and emphasizes that the phenomenon of bringing a child with a disability into the world is a clear and visible phenomenon in human life. Congenital abnormalities are also known as birth defects or birth defects. Congenital abnormalities are structural or functional changes that occur during the intrauterine period and can be identified before birth, at birth or detected later after the baby is born, such as hearing defects.

according to Arulampalam et al (2023) Congenital abnormalities vary from mild to severe and can affect organ shape, organ function or both. The parts of the body that experience abnormalities play an important role in the health and survival of the baby. Tranggono et al (2023) stated that genetic or non-genetic factors can cause congenital anomalies, which have been present since birth. People also refer to congenital anomalies as birth defects, congenital anomalies, or congenital deformities. Congenital abnormalities are a worldwide problem and one of the leading causes of death in babies. Globally, congenital abnormalities rank fourth globally as the most common cause of neonatal death, accounting for 295,498 deaths in 2016, and rank fourth in Indonesia, with a mortality rate of 11%. with a congenital disability in the family will have a big impact on all family members, parents, and especially the mother.

According to a 2012 study in Pakistan, 38% of women who gave birth to and raised disabled children felt profound sadness, 43% felt anger toward themselves and others, and 19% felt as though life had lost its purpose (Ergün & Ertem, 2012). Muryatini & Buana (2019) He conducted a study on Legal Protection for Children with Disabilities who Experience Parental Abandonment in the Advocacy Journal, volume 9, issue

1, pages 56–66. The results show that several cases of victims of neglect and domestic violence are often victims of neglect committed by their own parents. Ekowarni et al., (2015) The results of his research indicate that victims of domestic violence are often those who suffer the most. Research results from the Solo Community Rehabilitation Development and Training Center (PPRBM) in 2014 showed high rates of violence against children with disabilities in families. Compared to normal children, children with physical disabilities often face marginalization and separation from the community during play and learning. Society often refers to people with disabilities as disabled or incapable of producing anything in their lives (Hartini, 2010; Kurniadi, Y U., 2020; Naufal & Rahmandani, 2020).

according to Houle, J. C., & Berger (2016) It has been said that families with children with disabilities typically face poorer economic conditions compared to those without such children. Of course, this situation will make it even more burdensome for parents to be able to care for their children well, and this can be a source of pride for them in the future. Apart from the obstacles above, other research was also found related to the abilities of children with disabilities. Kang et al (2010) The author explains that children's physical limitations affect their intellectual, perceptual, sensory, and speaking abilities, leading to their low achievement in school. Aduful et al (2023) Apart from academic abilities, children who have physical limitations also experience limitations in motor capabilities, which affect their daily physical activities. McMahan et al (2023) The presence of children with disabilities up to their teenage years in America typically provides sufficient space, including sports facilities, physical play areas, and transportation, to assist individuals with physical disabilities who face limited access. Based on the background above, this research can formulate the dynamics of family care in caring for people with congenital disabilities through the use of SLR. This research aims to observe and analyze the dynamic process of family care while caring for individuals with congenital disabilities.

## METHOD

This research uses a systematic literature review (SLR) approach, namely an analytical study based on data, to look at the dynamics of caregivers in families for children with congenital disabilities. There is a connection between the extensively revealed aspects of the research topic and the areas that require further expansion in future research directions (Paltrinieri, A., Hassan, M. K., Bahoo, S., & Khan, 2020). In SLR research, a prism meta-analysis approach is used. The stages carried out in data processing begin with identification, screening, and analysis. A systematic literature review (SLR) carries out each of these processes. The following is a meta-analysis table for the Prisma method.

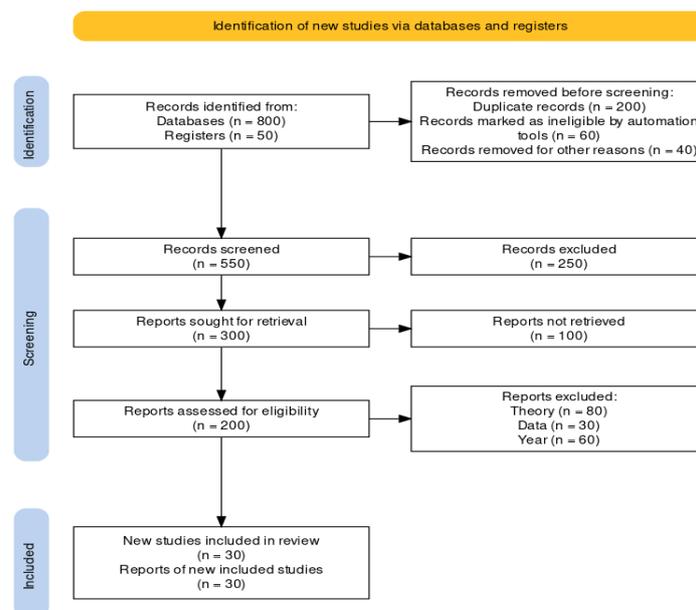


Figure 1. Illustrates the systematic literature review (SLR) process on the parenting theme Dynamics of Family Caregivers in Caring for People with Disabilities Congenital

Source: (Haddaway, N. R., Page, M. J., Pritchard, C. C., & McGuinness, 2022)

## RESULTS AND DISCUSSION

### The study's findings shed light on the dynamics of family caregivers dealing with congenital disabilities.

explanation	Family status	Tema	Sub tema
Congenital disability	Family caregiver	Family dynamics	Psychological pressure, social stigma, time constraints, parents experiencing stress, economic constraints, or needs are all relevant factors.
		Parental support	Parental skills, the congenital nature of the child, the application of therapy, parental support, the child's abilities, and the presence of treatment efforts
Congenital disability	Family caregiver	Child abuse	People throw children in the trash, engage in domestic violence, bully friends, and harass them in schools and public places.
Congenital disability	Family caregiver	Social and cultural	Social services and policies, cultural changes, parenting styles, and behavior management strategies

#### 1. The dynamics of family caregivers with congenital disabilities

Family caregivers of individuals with birth defects face burdens such as psychological stress, financial strain, time constraints, and social stigma, highlighting the challenges they face in caring for their loved ones. The research results show that the phenomenon of caregivers caring for people with disabilities from birth is a burden, including psychological, physical, financial, and social burdens. Wondemu et al (2022) The impact of a child's disability on parental employment and income is a subject of study. This affects parents' income, as it causes a decrease in working hours and income. We analyze employment and income in this context using data from Statistics Norway. We observed that the severity of the child's condition increased the likelihood of the mother ceasing work or earning less. Claudia & Sandu (2020) Parents of disabled children show higher levels of anxiety and depression compared to parents of normal children. There is a significant correlation between anxiety and depression among parents of disabled children. Low socioeconomic status and low self-confidence significantly influence aspects of psychological support. Scherer et al (2019) Parents of children with disabilities have a higher rate of depressive symptoms. We analyzed data from a study on parental depression and anxiety.

#### 2. Parental support

Parents make efforts towards their children through therapeutic treatment. Social skills that are practiced through family activities are skills that can be developed through routine family activities (Mumpuniarti et al., 2021). Arabis-Quijote et al (2023) Parents of children with physical disabilities, such as musculoskeletal or visual impairments, share their life experiences. It highlights parents' acceptance, care, and concern for the well-being and future of their children. We studied the life experiences of parents of physically disabled children. However, despite their apparent condition, the participants happily and gratefully accepted their children as blessings from God. Benešová & Sikorová, (2022) Parents of children with disabilities experience higher levels of stress compared to those of children without disabilities. Caring for a child with disabilities is associated with high levels of stress, and health professionals should identify parental stress and offer parents professional assistance in caring for their child according to their needs.

Shahdadi, H., & Mahmoudirad (2022) This article explores the experiences of parents who practice spiritual self-care while raising children with disabilities. It explains how older people rely on spirituality to overcome challenges and adapt to new conditions. This paper conducted a qualitative study using conventional content analysis methods, purposefully sampling 17 parents of children diagnosed with a disability for at least a year, to understand their experiences of spiritual self-care. Lasco et al (2022) Family members share the experience of disability, highlighting the importance of a family-centered approach in policy, clinical care, and communication initiatives for children with disabilities in the Philippines. Haraz (2019) The challenges faced by parents who have children with disabilities in their care require a thorough understanding of the attitudes that govern the daily behavior of those around them. This paper examines the social exclusion of parents of disabled children. This emphasizes the need to prevent and overcome this phenomenon.

### 3. Child abuse

Children with disabilities experience physical and sexual violence. (Hartini, 2010). Islam & Sudibyo (2023) There are more than 1 billion people with disabilities in the world, around 82 percent of whom are in developing countries, who live below the poverty line, experience high levels of violence, and are one of the most marginalized or marginalized groups in crisis situations. Social and cultural aspects, such as schools and public services, as well as the presence of children with congenital disabilities, often witness violence against children with disabilities.

### CONCLUSION

In the dynamics of family caregivers with congenital disabilities, there are various factors that influence the experiences and challenges they face, such as psychological pressure, social stigma, time constraints, parental stress, and economic constraints. In addition, the support they receive encompasses parenting skills, the nature of the child's congenital condition, and the execution of essential therapy. Parents' ability to manage care and treatment efforts demonstrates their role in supporting their children. Conversely, social and cultural obstacles like child abuse and societal stigmas like rejection or exclusion, along with alterations in policies and cultural norms, significantly impact these dynamics, shaping the management of family behavior and the surrounding environment.

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