

## Parentification of the Eldest Sibling in the Care of a Sibling with Special Needs and Multiple Disabilities (Cerebral Palsy, Autism and Epilepsy)

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### Abstract

This study examines the phenomenon of parentification experienced by a 20-year-old elder sibling who cares for a younger sibling with dual special needs (Cerebral Palsy, Autism Spectrum Disorder, and Epilepsy) aged 12 years. Parentification occurs after the subject loses their father at age 16, leading them to take on significant caregiving and family responsibilities. The research employs a case study approach with a qualitative method, involving in-depth interviews, participatory observation, and supporting documentation. The findings indicate that the subject plays a significant emotional and instrumental role, including caring for the sibling, assisting with household chores, and contributing financially while continuing their education. This role impacts their personal life, especially in managing time and prioritizing between college, work, and caregiving. Despite the heavy burden, the subject demonstrates maturity, independence, and a high sense of responsibility. The study emphasizes the importance of social support and appropriate interventions to assist children and adolescents experiencing parentification, particularly in families with children with special needs. These findings are expected to serve as a basis for developing family support programs and enhancing psychosocial well-being.

**Keywords:** Cerebral Palsy, Elder Sibling, Family Responsibility



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## INTRODUCTION

The family is a social unit that is formed permanently through marriage and blood relations. The family is also the initial environment for children, their first place of protection, and the main source for children to feel safe.

Parents have the primary responsibility to care for, educate, and raise children so that they can function well in society. However, in reality, many children are forced to take over the role of caregiving due to various obstacles experienced by parents, such as economic difficulties, negligence, or death. In the context of the family, children have sibling role relationships, such as older and younger siblings, which are formed through parental parenting patterns to train responsibility and care for each other (Damiano & Leonard, 2015; Fins dkk., 2024). However, children who take on the role of caregivers often face significant emotional and physical burdens, which can hinder their own development because they sacrifice time to play, learn, and socialize with peers, According to Hurlock (1978). Children who take on the role of caregivers often face significant emotional and physical burdens that can hinder their own development, because they sacrifice time to play, learn, and socialize with peers. East, PL (2010)

In Indonesia, with more than 4 million orphans, the phenomenon of teenagers acting as parents or caregivers is not new (Fonzi dkk., 2021; Pavlopoulou dkk., 2025). Teenagers who have lost both parents or have parents who are unable to carry out their parenting functions often have to take on the responsibility of caring for their siblings (Hou dkk., 2018; Huang, 2023). This results in sacrifices in their development process in various aspects of life, Ministry of Social Affairs of the Republic of Indonesia.

This phenomenon is known as parentification, where children, especially the eldest sibling, have to sacrifice their childhood and developmental tasks in order to meet the needs of the family (Gayathri dkk., 2024; Somerville, 2022). Parentification is a phenomenon where children take on roles and responsibilities that should belong to adults in the family. Murray Bowen (1978), a pioneer of family systems theory, emphasized that when children take on adult roles, the balance in family relationships can be disturbed. Parentification is divided into two main types: The aspects of parentification consist of emotional aspects and instrumental aspects.

The emotional aspect occurs when a child consistently responds to a parent's emotional needs, such as being a listener, a conflict mediator, or a source of emotional support. Children in this position often neglect their own needs, which can have a negative impact on their emotional and psychological development (Alirahmi dkk., 2024; dos Santos dkk., 2017). This situation is especially problematic if the parent has a mental health disorder or a dysfunctional attachment pattern.

The instrumental aspect involves taking over practical daily tasks, such as preparing meals, cleaning the house, managing finances, earning a living, and caring for siblings (Lennon dkk., 2024; Maciá-Andreu dkk., 2023). It usually occurs when a parent is physically injured, dies, or faces economic hardship.

Children who experience parentification often neglect their own developmental tasks, such as identity formation, academic achievement, and independence, in order to fulfill their roles as caregivers or breadwinners Jurkovic (Bourke-Taylor dkk., 2015; Kassim dkk., 2015). In fact, when these adolescents grow up, they may repeat the same parenting patterns, which

may cause their children to also experience parentification (Bekir et al., cited in Stein et al., 1999).

Children who experience parentification often feel the need to grow up quickly and show physical symptoms such as headaches and stomachaches (Fontes dkk., 2025; Ni dkk., 2022). Signs of the emergence of emotional aspects of parentification include the expectation to entertain, help solve problems, act as a mediator, provide for the family, a sense of responsibility, involvement in parental conflict, and guilt (Askeland dkk., 2025; Marques & Sá, 2016). Meanwhile, signs of the emergence of instrumental aspects of parentification include physical exhaustion and stress, difficulty building social relationships, obligations to care for family members, and sacrifice of personal needs such as social and academic activities (Chase, 1999)., has been widely studied in various countries, but research in developing countries such as Indonesia is still very limited.

Families with children with special needs, especially those with multiple disabilities such as Cerebral Palsy, Autism Spectrum Disorder (ASD), and Epilepsy, are faced with much more complex parenting challenges. Children with these conditions require comprehensive attention, including physical, emotional, and social support, and often require prolonged medical care and consistent therapeutic interventions (Hirt dkk., 2023; Maronga-Feshete dkk., 2024; Miller & Graber, 2020). This burden is not only felt by parents, but also has a significant impact on siblings, who are often involved in the caregiving role both in the form of emotional support and instrumental tasks. This involvement can affect mental health, the formation of personal identity, and the quality of social relationships of siblings, especially firstborns (Freeman dkk., 2018; Rachamose & Harvey, 2025). Without an adequate support system, this involvement risks causing psychological stress, anxiety, and role conflict that can affect their overall development.

Research by Levante (2023) from the University of Udine, Italy, examines the phenomenon of parentification in the family context, especially when a child, especially the eldest sibling, takes on the role of caregiver for a sibling with a disability. The research was conducted quantitatively involving 605 adult participants aged 19–26 years with the research title the relationship between the level of sibling-focused parentification and the quality of sibling relationships, through the mediation of stress and the quality of relationships with parents. The results showed that the high burden of caregiving carried out by the eldest sibling increased stress levels and decreased the quality of sibling relationships.

Darioti (2023) conducted a systematic literature review using a mixed method which highlighted that parentification forces adolescents to take on adult roles and responsibilities that are not appropriate for their developmental stage. This phenomenon has a negative impact on adolescents' mental health and emotional well-being. Research by Borchet (2021) in Poland considered that parentification can have an impact on emotional, physical, and neglect aspects. This study confirms that children who are forced to take on adult roles in the family experience normal developmental disorders that have a negative impact on short- and long-term mental health and emotional well-being.

Based on the presentation of previous research data, it can be concluded that understanding the dynamics of parentification in older siblings is important to do, considering the many psychological impacts that arise due to parentification (Shore dkk., 2019; Toovey dkk., 2020). Therefore, researchers want to see the dynamics of parentification aspects in siblings who have younger siblings with special needs (Lee dkk., 2020; Nurhidayah dkk.,

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2022). This study will be conducted using a qualitative method because researchers see that the results of research related to parentification have not discussed in depth how parentification occurs in older siblings with children with special needs.

## RESEARCH METHOD

This research method uses a qualitative approach with a case study design to explore the experiences of adolescents experiencing parentification (Bartlett dkk., 2017; Rabello dkk., 2021). According to Yin (2018), a case study is an empirical research method that aims to examine in depth a contemporary phenomenon in a real-life context, especially when the boundaries between phenomenon and context cannot be clearly separated. The implementation of a case study includes five main stages. First, formulating exploratory research questions, such as "why" or "how", to gain an in-depth understanding of the phenomenon being studied. Second, compiling a research design, which includes determining the type of exploratory case study, as well as selecting a single case study approach (O'neill & Wilkinson, 2020; Pastor-Bédard dkk., 2023). Third, data collection is carried out through various sources, such as in-depth interviews and documents. Fourth, data analysis is carried out using thematic coding, pattern matching, and explanation building to identify relationships between themes and reveal the dynamics that shape participants' experiences. Fifth, the preparation of the report is carried out by presenting the results and interpretations in relation to the real context and relevant theoretical frameworks.

In addition, the analysis is directed at interpreting the participants' narratives in order to understand the meaning of their experiences in social and psychological contexts (Poojari dkk., 2022; Rao dkk., 2021). The case study approach was chosen because it allows researchers to gain a deep understanding of the social and emotional dynamics that subjects face in everyday life.

The selection of subjects was based on consideration of the unique characteristics possessed by the subjects where in the subject's younger sibling therapy place there were 30 children with special needs but only subjects with the status of siblings were actively involved in the therapy received by their younger siblings. While in the assistance of 29 other children with special needs who played an active role were their parents or child caregivers (O'neill & Wilkinson, 2020; Rao dkk., 2021). In addition, the condition of the subject's younger sibling who had multiple disabilities, namely cerebral palsy, autism and had health problems in the form of epilepsy and had not yet completed independence in daily life such as not being able to toilet train, wear clothes, wear pants, wear shoes.

Data were collected through in-depth interviews with the main subjects, namely adolescents who act as caregivers, as well as two research informants, namely the subject's mother and a teacher at the therapy institution where the younger sibling is studying. Interviews were conducted face-to-face with a duration of 60-90 minutes. The researcher also conducted a documentation study in the form of the presence of the RD subject in therapy sessions to accompany his younger sibling (Poojari dkk., 2022; Rao dkk., 2021). This was done to objectively determine that the RD subject did indeed experience parentification in caring for his younger sibling. To ensure the accuracy and reliability of the data, the triangulation method was applied by comparing the results of interviews between the subject and the informant, in addition to matching with documentation data in the form of attendance at therapy sessions.

## RESULTS AND DISCUSSION

### General Description

The subject of the study was a 20-year-old male RD, the eldest of two siblings, with a 12-year-old younger brother who has multiple special needs (non-verbal). RD is an orphan who lost his father at the age of 16. Currently, RD is an active student at a private university in Jakarta.

RD and his family live in the house of his 84-year-old grandmother from his mother's side who is elderly and requires special attention and care so that the subject's mother becomes a caregiver for two people, namely the elderly grandmother and her second child who is disabled and is also the younger sibling of the subject RD. The subject's mother, APK, aged 50 years, is a housewife without a formal job.

**Based on interview data conducted by researchers, the following results were obtained:**

#### 1. Emotional aspect

##### a. Hope to entertain

RD acts as a source of emotional comfort for his mother. He actively takes the initiative to take his mother out and treat her to meals to ease her mother's mood. Although it is acknowledged that the results are not always effective, these actions reflect the child's efforts to meet the emotional needs of the parent. This is also reinforced by the statement from the mother (APK) who expressed gratitude and emotional dependence on RD's presence as a "very, very helpful" figure. This is in accordance with Hooper's findings (2007) that emotional parentification occurs when children are required to provide emotional support to parents or other family members, such as being a listener, calmer, or entertainer. Children in this position often feel responsible for the stability of their parents' feelings.

Based on the results of the interview:

*"I have entertained my mother directly... Come on, where are we going, I'll treat you to a meal, but that rarely stops my mother from being annoyed..." (RD. April 30, 2025.656)*

##### b. Help Solve Problems

RD is actively involved in finding solutions to the problems of social relations of RF (a special needs sibling) with other family members. RD plays a role in analyzing, understanding, and resolving interpersonal problems that occur in the family, RD takes on the role of a thinker and solution maker in relationships between family members, and also contributes to solving domestic work problems when the mother is sick.

This is in line with the findings of Cicirelli (1995) who stated that siblings are often a reliable source of support and care for children with special needs, especially when the primary caregiver is unavailable or exhausted. In addition, Heller and Arnold (2010) emphasized that families with children with special needs benefit from the sharing of caregiving responsibilities, where older

siblings often act as problem solvers and co-caregivers, especially when parents are unable to fully fulfill their roles.

The results of the interview were:

*"Yes, if RF is related to RF, the whole family must be involved because RF's growth really depends on the stickiness of who, on the closeness of himself and his family, so if he is annoyed with one person, we try to research, we try to examine, we try to observe, why can this child be annoyed with people, let's say with his aunt, his grandmother, his uncle, whoever it is, we will definitely try to find a good solution."*(RD, interview 17 April 2025.700)

*"It really helps, sometimes when I'm, honestly I should be... I'm having a relapse (back pain due to HNP), he does all the housework, except cooking. Because he said that he can still cook, ma'am, he cooks, he can. It's just that he doesn't feel confident when it comes to cooking. to cook. Because everything like cleaning the house, he can do it all. Like feeding my little brother and stuff, bathing him and stuff, all that. I'm only one, he's only one, if I'm sick, even if I'm sick, just cook, that's it. The rest is up to my older sibling."*(APK.7 May 2025.194)

c. Act as a Mediator

The subject is not actively involved in mediating the conflict. This attitude is reflected in his statement stating that his involvement as a mediator only occurs when the situation is already heated, while in general he plays a more observer role who avoids conflict so as not to add to his mental burden and maintain peace at home. protective attitude towards his mother by not telling her about problems that occur outside the home so as not to add to his mother's emotional burden. This shows high emotional maturity and empathy, where RD tries to maintain the mental well-being of his family members, especially his mother. The role of RD is in line with the findings of Meyer and Vadasy (1994) who stated that siblings of children with special needs tend to foster a high sense of responsibility, empathy, and act as emotional mediators in the home environment. Although not always a direct mediator in conflict, this role as an observer and emotional supporter is very important in maintaining family stability and harmony.

This is shown from the interview results:

*"If my involvement, right? Oh, how often is my position actually involved as a mediator? Actually, the position of RD when the family experiences conflict or problems and how often am I involved, I am not that often involved in my family's problems because it is not that often because I am also told to focus on the important points of my life, namely my younger siblings.. and also to work to earn money and then prioritize education, that's it.. "*(RD, interview 17 April 2025.730)

*“Oh, I'm more of an observer, then when things start to get heated, I become the mediator. As a person, I don't really like making a fuss, like, gosh, I'm tired after coming home, I want to rest, then suddenly there's a fuss, I have no choice but to find a solution to calm things down.”(RD, interview 17 April 2025.920)*

*“He never told me, ma'am. If for example he was... again... maybe he was visiting (the subject's mother's ex-in-law) at that house. I don't know what happened there, ma'am, because he's like this, you know.*

*I will never tell you what happened to me there because if I tell my mother, she will be disappointed, she will be sad again, my sister will avoid my mother to get hurt and disappointed again. That's right... it's also a form of protection, ma'am, because I don't want my mother to get hurt, I mean hurt, so... mental burdens, burdens on my mind, that's why she, whatever happens there, my sister will never tell my mother.”(APK.7 May 2025.265)*

d. Supporting the Family Financially

Based on the interview data obtained, RD did not directly provide financial assistance, but he showed an effort to be responsible even though in a limited capacity, trying to help with daily needs, such as petrol money and his own needs, without burdening his mother by choosing to work part-time as a film crew and online motorcycle taxi, while still focusing on his education.

This is supported by the interview results:

*“For me, I became more open to start earning a living, to help earn a living, because I am connected, yes, to earn money..., because my mother, she and her family agreed that we should not work together, yes, my father's family and my family, I became more open*

*to start earning a living, to help earn a living, because I am connected, yes to earn money..., because my mother and her family agreed that they could not work together, yes, the family from my father's family and the family”(RD, interview 17 April 2025.215)*

*“I'm not full-time in earning money, ma'am, I can only work part-time as a film crew and part-time motorcycle taxi driver, courier at Lala Move, because I'm still in college, thank God I only have one semester left, and my mother also doesn't want my studies to be disturbed so she told me to focus on studying, side jobs are free, don't overdo it, my mother feels sorry for me...”(RD, interview 17 April 2025.765)*

*“Not bad. Not bad. Sometimes he's a freelancer. He can't help much. At most, he only has money for petrol, money for his own needs. He doesn't invite anyone anymore.”(APK.7 May 2025.541)*

e. Sense of Responsibility

The sense of responsibility that emerged in RD towards his special needs sibling came from a combination of internalization of family values, personal awareness, and emotional maturity and personality that developed faster than his age. Parental education instilled the importance of prioritizing younger siblings as the main priority, so that this responsibility became a lifelong commitment, not merely because of coercion or orders.

This is in line with several developmental psychology theories which state that responsibility is the result of internalization of social and family values, as well as the emotional and cognitive maturity of the individual (Erikson, 1968; Deci & Ryan, 1985). and "Children who have siblings with special needs often show faster maturity than their peers because they are accustomed to taking on physical and emotional responsibility from an early age."

Burke, P. (2010).

In addition, RD showed a high sense of responsibility as a high school student who had to help his mother take care of his younger sibling. This is in line with Erikson's theory (1968), that in adolescence, individuals begin to form self-identity and feel responsible for the social roles they play, including in the context of the family. In addition, according to Kohlberg (1981), adolescents in the conventional moral stage tend to consider family expectations, so RD's decision to "cut time" is part of his morals and responsibility towards his family.

Results of the interview support:

*"I feel like... I feel like this is my responsibility. At first I felt it because I thought that my little brother RF has special needs. Of course because... I thought that my little brother was also my responsibility. And my parents have indeed taught me to prioritize my little brother over the two of them, because even if my parents pass away, the only one I will take care of is my little brother and my family is only my little brother, so... wherever I am, my little brother is still my priority. It's too fast, huh? Oh yeah, too crazy. Sometimes I feel like, gosh, why is it so fast for me, like"*(RD, interview 17 April 2025.465)

*"Yes, it's so fast, I think it's like... sometimes high school students are in junior high school... people are still having fun and all sorts of things, I already have to cut back on time to take care of my little brother... Then I have to cut back on time to go home quickly so that my mother doesn't worry, because my mother is also our father and mother. She must also be stressed..."*(RD, interview 17 April 2025.515)

*"In my opinion, what would it be, ma'am? Like I said earlier, he will grow up before his age."*(APK.7 May 2025.601)

*“What, sometimes I’m not the one helping, RD, ma’am, sometimes it’s like this because he’s the one who knows when it’s time for college, what’s that, Ummi, so for example, I want to mop, I want to sweep but later after college, like I said earlier ma’am, so it’s not him who decides, it’s not me who controls.”(APK.7 May 2025.627)*

*“I know RD because his younger sibling RF is in therapy where I teach and provide therapy. Because his father has passed away, he has a younger sibling who is in need, his mother does not work, then while studying, RD took the time to accompany his younger sibling while waiting for his younger sibling to have therapy, even asking, “How is Mrs. AZ doing RF therapy, which will be done at home... yes, it's more attentive to the development of the younger sibling.”(AZ.6 May 2025.25)*

*“Oh yes, that's clear, he already knows that this means that... my little brother is my responsibility for the rest of his life... he already understands that he has been entrusted to me even though we don't know his age, but he knows that my little brother is my responsibility, that's what RD said.(AZ.6 May 2025.265)*

*“If you look at his responsibilities, he is actually above children of his age... mature... but if you look at his style and appearance, he is below his age... childish in the way he dresses, in his choice of style, but his attitude is mature..(AZ.6 May 2025.295)*

f. Involved in Parental Conflict

In dealing with family conflicts, RD is more of a neutral party, RD tries not to side with one particular party, but rather focuses on finding solutions so that the family can get through the problem in a more constructive way. RD chooses not to burden his mother with stories or problems that could disappoint or hurt her. This protective attitude shows RD's great dedication and affection for his mother, trying to protect her feelings and avoid additional emotional burdens.

Although it is not always true In spite of the difficulties he faces, RD continues to show loyalty and commitment to always defend his mother, focusing on his mother's happiness. This shows emotional depth and an extraordinary sense of responsibility towards his family, especially his mother and sister.

Matter This is supported by the interview results:

*“Of course I make sure that I am as good as possible as a neutral party where I don't blame one party but I don't blame one party and don't favor the party that I don't blame, but I try to take the middle path. Always looking for a solution. Where if my family focuses more on the problem, I focus more on the solution. That's the only form of involvement.”(RD, interview 17 April 2025.635)*

"He never told me, ma'am. If for example he was... again... maybe he was visiting (the subject's mother's ex-in-law) at that house. I don't know what happened there, ma'am, because he's like this, you know.

I will never tell you what happened to me there because if I tell my mom, she will be disappointed, she will be sad again, my sister will avoid my mom to get hurt and disappointed again. That's right... it's also a form of protection, mom, because she doesn't want her mom to get hurt, I mean hurt, right? So... mental burdens, burdens on her mind, that's why she, whatever happens there, my sister will never tell her mom..." (APK. May 7, 2025.265)

*"That's all, so I don't know what he was talking about there, I don't know, I don't know, and I don't know what happened there either, because he's like this. I want my mom to be happy. Just be happy. Mom is happy. Don't listen to what stories they tell you. What's important, the point is, I still, whatever, whatever happens, I still defend my mom. Because with mom and dad, I see mom, mom alone. Mom is alone there. No one ever defends me. Mom is blamed because she's forced to. Mom is blamed and then Mom is called a troublemaker Because she doesn't accept that. That's all she does"*(APK.7 May 2025. 300)

g. Guilty feeling

RD faced a severe emotional dilemma as a result of the parentification role he was undergoing, where he often felt guilty when fulfilling his personal needs because he felt he had to prioritize the needs of his family, especially his sibling with special needs and his mother, feelings of anxiety, panic, and inner conflict experienced by RD, including suppressing personal desires such as interest in someone, reflect a significant emotional burden. This is in accordance with the findings of Hooper (2007) who stated that children who experience parentification often feel guilty when prioritizing themselves, as well as with Meyer and Vadasy (1994) who revealed that siblings of children with special needs often experience inner conflict and denial of personal desires for the sake of family welfare. RD's dedication and sacrifice show emotional maturity far beyond his age, but also indicate the presence of psychological stress that needs to be considered in the context of family care and support.

This was obtained from the interview results:

*"Guilty, huh... Well, that wasn't demanded, but sometimes I just feel it... What I feel is of course I feel guilty, then I also don't talk where I can focus on myself while the people at home, the people at home should focus on my younger sibling again, it should be their turn to feel disappointed maybe...really disappointed"*(RD, interview 17 April 2025.965)

*"Yes, yes, very often I see a dilemma Between what if I don't help mom, Mom will be hurt badly, especially honestly, if I take my little brother to therapy, it means money", that's what he said, oh that's why he's the one who tries to take*

*him, so he tries, but later when he works, he says, Mom doesn't need to worry, God willing, I just said that, that's it, Mom, that's it, so there's often a dilemma, Mom, he often has a confused face, when he's confused, he panics, Mom, hmm, he has panic attacks, the same as me actually, he sleeps at 11-12, like me, Oh yeah, he's worried, so it's like this.. starting, especially when his child starts to get sick, like he has a fever, we both panic.. But the one who can often please RD. Let him panic like that. But he's like this. We take a deep breath, Mom. Like that. You can't panic like that..”(APK.7 May 2025.655)*

*“He even loves someone, Mom. He never talks to anyone, only to me, Mom. Oh my God. He likes girls. Because he is like this, because for my sister, feelings are not allowed to be told to people. Those feelings, Mom said, are a gift, Mom said.*

*But he... He kept it to himself. So he... Everything from his disappointment with the lecturer, disappointment with people. He meant, his happiness came from his social life, ... That's why I don't want to. Making mom disappointed, that's enough. Yesterday I was here many times he apologized, I cried. I don't know why he just apologized. He said, my voice is my final assignment, mom. I just said sorry, I apologized for 3 days in a row, sad, that's why I'm like this, mom, come home, don't just apologize, forgive me, mom, if you like a woman, maybe mom doesn't like you as a person.”(APK.7 May .350)*

## **A. Instrumental Aspect**

### **a. Daily tasks and roles in the family**

RD actively takes part in various daily household responsibilities such as cooking, cleaning the house, and taking care of his special needs sibling. Although RD still feels less confident in cooking, he still tries his best to help ease his mother's burden, especially when she is sick. RD's caring and concern are also seen from his efforts to maintain his mother's health by asking her not to do heavy activities while studying.

This phenomenon is in accordance with the concept of instrumental parentification, where children take over responsibilities that are usually the task of adults, such as cooking and caring for younger siblings (Jurkovic, 1997).

This data was obtained from the results of subject interviews, namely:

*“Oh, when it comes to preparing food, it's quite often, yes. If mom is cooking, I'm eating, prepare the onions, cut the ingredients, or later mom will cut the ingredients, I'll fry, boil, stir the ingredients or not, then mom will cut the ingredients, I'll fry and boil, that's how it is, but when it comes to plating or serving, it's been a long time, so it's the usual thing to prepare food, almost “Every day, yes, I also really like cooking, ma'am.”(RD.30 April 2025.480)*

*“I also sometimes shop for vegetables and groceries and so on... from shopping to preparing, washing, then washing the ingredients, until cooking... Yes, that's*

*me alone. Sometimes if I want to cook for myself, it's really me alone... Okay, I'm the one who shops for everything. Look in the refrigerator to see what's in it.*

*If there is none, just improvise. After improvising, look for materials that... materials that are available.. Yes, materials that are available”(RD.30 April 2025.480)*

*"Oh, if you clean the house at home... Oh, that's normal, ma'am. It's true that I'm like that every day, like, when I go to college, it's never 8 o'clock... I'm in the morning, I can mop first or sweep first, wash first, wipe first, or throw away the trash. Yes, it's as simple as that, ma'am or not, mom will do the washing.”(RD.30 April 2025.480)*

*“It really helps, sometimes when I'm, honestly I should be... I'm having a relapse (back pain due to HNP), he does all the housework, except cooking. Because he said that he can still cook, ma'am, he cooks, he can. It's just that he doesn't feel confident when it comes to cooking. to cook. Because everything like cleaning the house, he can do it all. Like feeding my little brother and stuff, bathing him and stuff, all that. I'm only one, he's only one, if I'm sick, even if I'm sick, just cook, that's it. The rest is up to my older sibling.”(APK.7 May 2025.194).*

*"RD doesn't feel disturbed. It's just that he likes to talk about Mama. Later in the afternoon, he'll go to college first thing in the morning. Mama, don't do anything. Anyway, at home, that's all. For example, if I'm determined to do something (so I complain about being sick), then he'll be angry, because RD doesn't want Mama to get sick.”(APK. May 7, 2025.579)*

*"Eh, as an older brother, he is caring, always asking "how is Mrs. AZ.. how is little brother RF, what should I do".. as a giver of what.. encouragement.. the person directly involved is only limited to.. ee what.. encouragement, motivation.. ee motivational words like that.. no one has actually taken action because it's an internal problem and I'm outside the family,, yeah, that's all..”(AZ.6 May 2025.115)*

b. Family financial management.

Based on the interview results, RD's involvement in family financial management is limited and more on providing small input such as choosing products to buy, while the mother is the main financial manager. RD hands over his income to his mother as a form of contribution and entrusts her with managing the money. This is in accordance with the theory of financial socialization which states that adolescents learn the values of responsibility and self-control through the experience of managing their own money and contributing to the family (Shim et al., 2009).

This statement obtained from the results of subject interviews, namely:

*“involved but not often, for example, if mom just asks which vitamins she wants to buy or wants to buy, which ones, or, wants to buy pampers for little one, because little one is still wearing pampers tonight... well little one, which pampers, just like that, this is when managing money, because sometimes, mom chooses something that is too expensive or not suitable so that's a consideration, right? So actually the one who plays a bigger role in managing is mom, but only as a consideration. If you compare it, mom is better at managing her money.”*(RD, April 30, 2025.565)

"He never does. When it comes to finances, he's sensitive, ma'am. If it's me alone, but for example, when it comes to making decisions, it's only sometimes, ma'am."

*For example, if I want to shop for this, oh no, Ridho always says, "Mom, I have money from my motorbike taxi business. I'll give it straight to my mom."*

*So it's mom who controls what you want,*

*"Can I buy shoes? Maybe I never asked RD how much savings he had left, I never did because I made him like this for my brother, money is sensitive so there's no need to ask, the important thing is that the money I get is always halal, God willing, with God's permission and Mama's prayers, that's all he said."*(APK.7 May 2025.495)

c. Family economic contribution

RD's involvement in contributing to the family's economy with part-time work reflects intrinsic motivation, autonomy, and a high sense of responsibility towards her family. RD tries to balance between college and work to help with household needs, such as buying diapers and daily necessities, although the main financial management remains in the hands of her mother. This is in accordance with the Self-Determination theory (Deci & Ryan, 1985) which emphasizes the importance of intrinsic motivation and autonomy in carrying out responsibilities, as well as research by Fuligni & Pedersen (2002) which shows that adolescents with a high sense of responsibility tend to be involved in productive activities to support their families.

As shown in the results of interviews with the following subjects:

"I've only been in the packaging business for 2 years, being a courier, around the age of 18, ma'am. I started working as a motorcycle taxi driver, even though it was just a What's It Called? Just delivering packages. The longer I got here, the more I thought about it. Even though the income was part time, it wasn't much because the work was more than the profit. Well, finally my friend offered me a job as a lighting man for a film crew. Yes, I was finally invited to do that for films, that's it, but I worked like that for only a year or less, 6 months... The

lighting one, yeah.. Yes, it was only 3 months, if I was a motorcycle taxi driver and a courier When I was 18 after graduating from high school... so it was quite good, I could help my mother with my pocket money, help buy diapers for my little brother, treat my mother and little brother to eat out, buy household necessities, that's all ma'am." (RD, April 30, 2025.220)

“Not bad Not bad Sometimes he is a freelancer, yes, he can't help much, at most he only needs money for gasoline, money for his own needs. He doesn't invite me anymore.. "(APK. May 7, 2025)

d. Caring for and raising a sibling with special needs

RD plays an important role as an informal caregiver for her sibling with special needs. Her involvement in caring for her sibling, from helping with bathing, supervising at night, to replacing the role of her father, greatly helps lighten her mother's burden, especially when her mother is sick. This role not only provides practical support, but also strengthens family relationships and shapes RD's caring and resilient character. This finding is in line with research by Cicirelli (1995), Stoneman (2005), and Burton & Parks (1991) which emphasize that siblings are often the main source of support and long-term caregivers for children with special needs, and contribute to the continuity of care and family harmony.

Subject statements obtained from interview results:

“If I take care of my little brother all day, it’s actually as simple as just dropping him off at school on weekdays and then when he comes home. Sometimes mom comes home from school. Sometimes mom is tired. After cooking, washing and stuff.... Okay,...I’m the one who bathes him. Little brother... I’ve never fed him, while mom is around, rarely. Only at dinner.

*Then if for example her mother is sleeping I take care of my little brother.. It's as simple as that.. Because my mother is.. a typical person who can't stand waking up at night, Because she also likes to sleep at 9 o'clock So sometimes my little brother has a "Jackpot", If sometimes he "poops" (defecates) or suddenly goes to the bathroom by himself, takes off his pants, I have to listen, I have to be sensitive, the term is like this, why is the door opening, go straight into the bathroom.. look, oh my little brother suddenly pees what.. it's as simple as that. so we understand each other's condition.. both of them are between mother and little brother.(RD.30 April 2025.85)*

*“It really helps, sometimes when I’m, honestly I should be... I’m having a relapse (back pain due to HNP), he does all the housework, except cooking. Because he said that he can still cook, ma’am, he cooks, he can. It’s just that he doesn’t feel confident when it comes to cooking. to cook. Because everything like cleaning the house, he can do it all. Like feeding my little brother and stuff, bathing him and stuff, all that. I’m only one, he’s only one, if I’m sick, even if*

*I'm sick, just cook, that's it. The rest is up to my older sibling.*"(APK.7 May 2025.194)

*"What kind of question, ma'am? Like I said, it's very helpful, and he can be a substitute for RF's father, okay, as RF's older brother, as a friend, okay, okay, as a friend."*(APK.7 May 2025.476)

*"So far, I've seen... from what I can see directly here, it's good... they care about taking care of him (his younger sibling) and all sorts of things."*(AZ.6 May 2025.196)

- e. The condition of parents and its influence on the role of the eldest sibling.

RD has a big responsibility in taking care of her younger sibling and helping her mother who is suffering from chronic back pain (HNP). Although she feels tired and sometimes does these tasks reluctantly, RD remains committed to maintaining the welfare of her family. She routinely shifts household tasks and takes care of her younger sibling when her mother is unable to do activities due to illness. This phenomenon is also included in the category of sibling caregiving, where the eldest child consistently provides long-term support and care to her younger siblings, especially in families with economic pressures or parental health problems (Burton, 2007). Although sometimes feeling pressured by the burden, RD understands that this is a responsibility that must be carried out, especially considering the absence of her father. In addition, RD also shows an attitude of sacrifice, such as postponing personal activities or college in order to help the family, even though she sometimes feels difficult or tired. This role arises naturally due to the absence or limitations of parents in carrying out their duties, which is in accordance with the concept of role stress and role adaptation in the family (Biddle & Thomas, 1966).

In interviews conducted with subjects, it was found that:

*"Mom has an illness...chronic back pain, mom has HNP, because mom used to work as a flight attendant, well mom used to lift cabin luggage, they said she was in the wrong position when lifting weights... eee... so when she was taken to the hospital the doctor said there was a tear or something, ma'am, I don't understand the medical term,... so I asked if mom had a back pain attack, I would take over the household chores, RF's younger sibling could be with me all day, sometimes for days with me if mom just lay on the bed... that's how it is ma'am..."* (RD. April 30, 2025.690)

*"Because my father has been gone for a long time, ma'am, so I'm used to it. Sometimes I don't need to be told by my mother what my duties are, I already know them. I'm used to it. Yes, taking care of my younger sibling, cooking and cleaning the house."* (RD.30 April 2025)

*"RD doesn't feel disturbed. It's just that he likes to talk about Mama. Later in the afternoon, he'll go to college first thing in the morning. Mama, don't do anything. Anyway, at home, that's all. For example, if I'm determined to do something (so I complain about being sick), then he'll be angry, because RD doesn't want Mama to get sick."(APK.7 May 2025.579)*

*"It really helps, sometimes when I'm, honestly I should be... I'm having a relapse (back pain due to HNP), he does all the housework, except cooking. Because he said that he can still cook, ma'am, he cooks, he can. It's just that he doesn't feel confident when it comes to cooking. to cook. Because everything like cleaning the house, he can do it all. Like feeding my little brother and stuff, bathing him and stuff, all that. I'm only one, he's only one, if I'm sick, even if I'm sick, just cook, that's it. The rest is up to my older sibling."(APK.7 May 2025.194)*

*"But it once came out during the evaluation of RF's younger sibling, RD, there was a statement that said "Mrs. AZ, if I help my mother, God willing, RD lillahi ta'ala, but sometimes I am forced to take care of my younger sibling" if I'm tired or whatever, it's called a condition, sometimes RD takes care of her with a feeling of being forced, yes, but he knows that it's wrong.. but sometimes it's called my condition.. I work while studying, at home I have to take care of my younger sibling, sometimes when I'm tired, he says he has to talk to me, talk to his mother directly, yes, how can I only cry, just want her to understand.. that was during the evaluation, yes."(AZ.6 May 2025.205)*

### **The impact of parentification on personal life.**

RD experienced significant role strain in carrying out her responsibilities as a student, part-time worker, and caregiver for a special needs sibling. She had to sacrifice personal time and social activities to meet the needs of her family, which caused emotional distress and stress. This condition is in accordance with the concept of instrumental parentification which shows that children who take on the role of caregiver often experience emotional exhaustion and psychological burden (Hooper, 2007; Chase, 1999). In addition, this dual role burden triggered internal conflict and stress that affected RD's life balance (Goode, 1960). However, RD showed emotional resilience by relying on religious communication and focusing on family welfare as a top priority, even though this created a dilemma between family obligations and personal aspirations. Subject's statement that

Subject statements obtained from interview results:

*"Oh actually if you say it affects.. Yes of course it affects because we have to cut our hours.. Then being able to manage it again we have to think twice... We want to do what, like if we want to go to college. We only come back at night. Only until the evening, this work. Well, there's my little brother at home.. I*

*forget... Like that, it becomes complicated. If it's late, it's half-hearted. Like that, ma'am, then if you want to play sometimes you have to tell me, before Maghrib, you're back, it's back again like when you were in high school ma'am.. when you were in junior high school, high school, which was junior high, high school, okay, but maybe because there was no one to help, so I just understand, okay, you really have to give in a lot.. maybe me.(RD.30 April 2025.140)*

*“It’s safe ma’am as far as the influence on friendships, this is probably because we’re still in college so it’s still a bit relaxed and even friends are curious like “what’s wrong with your little brother?” and so on, friends know, friends know, right? When they come home they often see your little brother... Oh, your little brother is still young and asks questions... Enthusiastic to know about your little brother’s condition... Yes, they’re curious... Because they’re their own people, even if they have older and younger siblings... They don’t experience it, at most they’re distant relatives, like that, so in terms of friendship, it’s normal.”(RD.30 April 2025.185)*

*"What if I get sick again and I have work that is really needed, there's a dilemma, right? If I don't finish my studies, I'll study in groups, later the group will upload it, but if my little brother is sick, my mother will keep calling, then there's a dilemma that I can only hope for. Hopefully both can be held even though the hours are tight and late. So it's a priority scale, right? I'm actually confused, ma'am. If it's like that because we think that studying has responsibilities, but there are also responsibilities, so I'm confused. So I can only hope, pray, Oh God, hopefully both can be held, it's okay. Sometimes it's like that."(RD.30 April 2025.285)*

*“If it was sacrificed... Oh yes, so when I was doing an internship, I was really busy at the internship place... Suddenly I called my mom and said my little brother was sick. Well, if I got a call like this, of course there was drama and I was told to go home... In my heart, it was like that, okay.*

*I had no choice but to call. I just asked permission from the leader who brought me to do the internship, he said. "Okay, you should just go back there, he said. Rather than something bad happening to your little brother. Because throughout my internship, I never asked for permission. That was just permission. So maybe I was allowed. So what is the internship for, so I sacrificed my time..*

*Yes, but my internship was also in a group so I felt bad for my group too.. But yeah, I have to, sometimes when it comes to family matters, I have to be ready.. I have to be ready to lick our own spit, you know.. We're outside, okay, we're outside talking.. Oh yeah, of course group number one says we're in a group or whatever, but when it's my turn to call my sick sibling, all I'm sick with is a cough and a runny nose. But at least I'm still responsible for submitting other assignments, right? Well, if there's an assignment that I can do from home, I'll just send the college assignment.. Well, with a sibling like that, I've been ready for a long time, no one wants to talk about me.. I'll badmouth me if the group*

*makes me annoyed, taking care of my sibling all the time, assuming I'm ready.. But my friends already know about my sibling's condition, right? My friends already know, right?*

*But what I have to face is that not everyone wants to understand us, you know."(RD.30 April 2025.330)*

*"If I don't help you, Mom, you'll get hurt badly, especially to be honest, taking your little one to therapy means money," he said, oh that's why he's the one who's trying to take him, so he's trying, but later when he's working, he said, Mom, don't worry, God willing, I just said that, Mom, that's all, so it's often a dilemma, Mom, he often has a confused face, when he's confused, he panics, Mom, hmm, he has panic attacks, the same as me actually, he sleeps for 11-12 hours like me, Oh yeah, he's worried, so it's like this... it starts, especially when his child starts to get sick, like he has a fever, we both panic... But the one who can often please RD. Let him panic like that. But he's like this. Let's take a deep breath, Mom. Like that. Don't panic like that."(APK.7 May 2025.660)*

*"Yes, right now, whether you can have a family or not. The problem is that right now your priority is that you can make your mother and sister happy. You don't think about how you'll have a family later, that's just God's business, Mom. Just do it, basically your goal is only one, to make your mother happy, not to make your mother happy, not to make your sister happy. That's all, because I like Allah, Ridho said yes. It's more than what I think, like that."(APK.7 May 2025.156)*

RD playing a very important and complex parenting role in his family. He not only helps physically by taking care of daily needs such as cooking, cleaning the house, and taking his younger sibling to therapy, but also plays an emotional role as a comforter and mediator in the family. Although this responsibility came sooner than expected, RD shows maturity, independence, and a high sense of responsibility.

The phenomenon of parentification occurs when children, both brothers and sisters, are forced to take on roles and responsibilities that should be the task of adults, both in terms of emotional and practical support. This dependence of caregivers on children causes children to have to carry out functions beyond their age. According to Bowen M (1978), a pioneer in family systems theory, interaction patterns in the family greatly influence individual development. He emphasized that when children take on adult roles, this can disrupt the balance of relationships in the family.

This role also affects RD's personal life, especially in managing time between college, part-time work, and taking care of a younger sibling. He must be good at balancing priorities and dealing with dilemmas that arise, including sacrificing time and energy. His mother's health condition, which also requires attention, adds to the burden, but RD is able to adapt well. Overall, RD is a

strong and sacrificial figure for his family, who is able to maintain a balance between family responsibilities and self-development.

**Theme Accumulation Table**

Theme	RD	APK	A-Z
Hope To Entertain	1	-	-
Help solve problems	1	1	-
Act as a mediator	2	1	-
Supporting the family financially	2	1	-
Sense of responsibility	2	2	3
Involvement in parental conflict	1	2	-
Guilty feeling	1	2	-
Daily tasks and family roles	3	2	1
Family financial management	1	1	-
Family economic contribution	1	1	-
Caring for and raising a sibling with special needs	1	2	1
Parental conditions and their influence on the role of the eldest sibling	2	2	1
The impact of parentification on personal life	4	2	1

## CONCLUSION

Based on the theme accumulation table, the most frequently occurring themes are the sense of responsibility and the impact of parentification on personal life which causes complex and multidimensional impacts, including heavy emotional, physical, and psychological burdens. The role conflict that arises from this dual responsibility causes significant stress and pressure, but on the other hand also gives rise to strong emotional resilience. This shows that although children who experience parentification can demonstrate high maturity and responsibility, they still need adequate social and psychological support in order to be able to carry out these roles without sacrificing their personal well-being and future.

Overall, RD is a strong and sacrificial figure for his family, who is able to maintain a balance between family responsibilities and self-development.

Suggestions based on research findings, it is very important for RD subjects and their families to get (1) adequate emotional and psychological support. Family counseling or professional assistance can help reduce the psychological burden felt by RD due to great responsibility. In addition, (2) good time management between lectures, work, and caregiving needs to be considered so that RD does not experience excessive fatigue. Assistance in stress management is also highly recommended to maintain balance in life.

Also (3) Social support from family and the surrounding environment is also very much needed, for example by helping to care for younger siblings or providing practical daily assistance so that RD's burden is not too heavy. Families also need to (4) increase awareness of the importance of dividing roles and responsibilities proportionally so that children are not overburdened. In addition, it is important to (5) provide space for RD to be able to develop themselves and enjoy their teenage years in a balanced way, without having to continuously sacrifice their personal needs.

## AUTHOR CONTRIBUTIONS

Look this example below:

Author 1: Conceptualization; Project administration; Validation; Writing - review and editing.

Author 2: Conceptualization; Data curation; In-vestigation.

## CONFLICTS OF INTEREST

The authors declare no conflict of interest

## REFERENCES

- Alirahmi, M., Kikhavani, S., & Soleimannejad, H. (2024). Compare the effectiveness of two treatments, behavioral activation and acceptance and commitment therapy, on depression and mental rumination in mothers of children with cerebral palsy in Ilam city. *Journal of Education and Health Promotion*, 13(1). Scopus. [https://doi.org/10.4103/jehp.jehp\\_1720\\_23](https://doi.org/10.4103/jehp.jehp_1720_23)
- Askeland, S., Guise, V., Aase, K., & Sogstad, M. K. R. (2025). Families' Strategies for Navigating Care for Their Child With Cerebral Palsy: A Qualitative Study. *Health Expectations*, 28(2). Scopus. <https://doi.org/10.1111/hex.70197>
- Bartlett, D., Chiarello, L. A., Hjorngaard, T., & Sieck Taylor, B. (2017). Moving from parent “consultant” to parent “collaborator”: One pediatric research team’s experience. *Disability and Rehabilitation*, 39(21), 2228–2235. Scopus. <https://doi.org/10.1080/09638288.2016.1219402>
- Bourke-Taylor, H., Cotter, C., & Stephan, R. (2015). Complementary, Alternative, and Mainstream Service use Among Families with Young Children with Multiple Disabilities: Family Costs to Access Choices. *Physical and Occupational Therapy in Pediatrics*, 35(3), 311–325. Scopus. <https://doi.org/10.3109/01942638.2014.975312>
- Damiano, D. L., & Leonard, R. (2015). 2014 Section on Pediatrics Knowledge Translation Lecture: Clinicians and Researchers on the Same Path Toward Facilitating Family Goals for Mobility and Participation. *Pediatric Physical Therapy*, 27(2), 105–112. Scopus. <https://doi.org/10.1097/PEP.0000000000000147>
- dos Santos, K. H., Marques, D., & de Souza, Â. C. (2017). Children and adolescents with cerebral palsy: Analysis of care longtudinality. *Texto e Contexto Enfermagem*, 26(2). Scopus. <https://doi.org/10.1590/0104-07072017000530016>
- Fins, J. J., Knitter, J., Mukherjee, D., Conti, K., Donleavy-Hiller, B., Gerber, L. M., Hersh, J. E., Kotorac-Erlbaum, R., Milch, B., & Klein, S. M. (2024). A Descriptive Analysis of Access to Assistive Technology in Children with Acquired Brain Injury: The Right to Assistive Devices. *Journal of Head Trauma Rehabilitation*, 39(2), 152–159. Scopus. <https://doi.org/10.1097/HTR.0000000000000876>
- Fontes, D. E., Ayupe, K. M. A., Moreira, R. S., de Souza Morais, R. L., de Carvalho Chagas, P. S., Longo, E., de Campos, A. C., de Toledo, A. M., Leite, H. R., & Camargos, A. C. R. (2025). Factors Associated with Performance of Activities and Participation of Brazilian Children and Adolescents with Cerebral Palsy: A Cross-Sectional Study. *Developmental Neurorehabilitation*, 28(1), 36–42. Scopus. <https://doi.org/10.1080/17518423.2024.2438961>
- Fonzi, V., Sheriff, B., Dalglish, S., Anum, A., Agyei, E. D., Diggs, D., Eboigbe, L., Owusu, P. G., & Sakyi, K. S. (2021). The multifaceted care-seeking practices among caregivers of children with cerebral palsy: Perspectives from mothers and providers in Ghana. *PLoS ONE*, 16(10 October). Scopus. <https://doi.org/10.1371/journal.pone.0258650>
- Freeman, M., Stewart, D., Cunningham, C. E., & Gorter, J. W. (2018). “If I had been given that information back then”: An interpretive description exploring the information needs of

- adults with cerebral palsy looking back on their transition to adulthood. *Child: Care, Health and Development*, 44(5), 689–696. Scopus. <https://doi.org/10.1111/cch.12579>
- Gayathri, M. V., George, R., Renjith, V., Khan Nadira, R. B., Riaz, K. M., Aswin, K., Raju, A., Thomas, C., & Kurien, J. P. (2024). Challenges in Parenting Experienced by Mothers of Young Children with Cerebral Palsy: A Phenomenological Study. *Journal of Psychosocial Rehabilitation and Mental Health*. Scopus. <https://doi.org/10.1007/s40737-024-00424-0>
- Hirt, E., Wright, A., Kehring, A., Wang, Y., Toraño, V., & Boles, J. (2023). “Fitting the Pieces Together”: The Experiences of Caregivers of Children With Medical Complexity. *Hospital Pediatrics*, 13(12), 1056–1066. Scopus. <https://doi.org/10.1542/hpeds.2022-007112>
- Hou, Y.-J., Liu, W.-Y., Lin, Y.-H., Lien, H.-Y., Wong, A. M. K., & Chen, C.-M. (2018). A Pediatric Service-Learning Program in Physical Therapy Education. *Pediatric Physical Therapy*, 30(2), 149–154. Scopus. <https://doi.org/10.1097/PEP.0000000000000498>
- Huang, S. (2023). Activating disability care: The formation of collective disability care networks in China’s COVID-19 outbreak. *Disability and Society*, 38(10), 1826–1847. Scopus. <https://doi.org/10.1080/09687599.2022.2045188>
- Kassim, P. N. J., Ushiro, S., & Najid, K. M. (2015). Compensating cerebral palsy cases: Problems in court litigation and the no-fault alternative. *Medicine and Law*, 34(2), 335–356. Scopus.
- Lee, M. H., Matthews, A. K., Park, C. G., Vincent, C., Hsieh, K., & Savage, T. A. (2020). Relationships among parenting stress, health-promoting behaviors, and health-related quality of life in Korean mothers of children with cerebral palsy. *Research in Nursing and Health*, 43(6), 590–601. Scopus. <https://doi.org/10.1002/nur.22074>
- Lennon, N., Kalisperis, F., Church, C., Niiler, T., Miller, F., Biermann, I., Davey, J., Sees, J. P., & Shrader, M. W. (2024). Self-reported Health-related Quality of Life in Adolescents With Cerebral Palsy. *Journal of Pediatric Orthopaedics*, 44(1), E46–E50. Scopus. <https://doi.org/10.1097/BPO.0000000000002519>
- Maciá-Andreu, M. J., Vaquero-Cristóbal, R., Meroño, L., Abenza-Cano, L., García-Roca, J. A., Cánovas-Álvarez, F. J., Díaz-Aroca, A., Capranica, L., Stanescu, M., Pereira, A., Doupona, M., Mendes, F., Figueiredo, A., Isidori, E., Sánchez-Pato, A., & Leiva-Arcas, A. (2023). Self-perception of dual career barriers and athletic identity in student-athletes with disabilities according to disability type and level of professionalization. *Scientific Reports*, 13(1). Scopus. <https://doi.org/10.1038/s41598-023-47881-4>
- Maronga-Feshete, F., Pilusa, S., & Dreyer, A. (2024). ‘I’m proud of my son with CP’: Cerebral palsy caregivers’ experiences, Gauteng province. *African Journal of Disability*, 13, 1–8. Scopus. <https://doi.org/10.4102/AJOD.V13I0.1357>
- Marques, J. M., & Sá, L. O. (2016). Feeding a child with cerebral palsy: Parents’ difficulties. *Revista de Enfermagem Referência*, 4(11), 11–19. Scopus. <https://doi.org/10.12707/RIV16041>
- Miller, J. M., & Graber, E. (2020). Growth Attenuation for the Child with Cerebral Palsy. Dalam *Cerebral Palsy: Second Edition* (hlm. 979–984). Springer International Publishing; Scopus. [https://doi.org/10.1007/978-3-319-74558-9\\_74](https://doi.org/10.1007/978-3-319-74558-9_74)
- Ni, Z. H., Ding, S., Wu, J. H., Zhang, S., & Liu, C. Y. (2022). Family Caregivers’ Experiences of Caring for Children With Cerebral Palsy in China: A Qualitative Descriptive Study. *Inquiry (United States)*, 59. Scopus. <https://doi.org/10.1177/00469580221121510>
- Nurhidayah, I., Nugraha, M. N., & Nuraeni, A. (2022). Quality of Life among Parents of Cerebral Palsy Children. *Malaysian Journal of Medicine and Health Sciences*, 18, 181–185. Scopus.
- O’neill, T., & Wilkinson, K. M. (2020). Preliminary investigation of the perspectives of parents of children with cerebral palsy on the supports, challenges, and realities of integrating

- augmentative and alternative communication into everyday life. *American Journal of Speech-Language Pathology*, 29(1), 238–254. Scopus. [https://doi.org/10.1044/2019\\_AJSLP-19-00103](https://doi.org/10.1044/2019_AJSLP-19-00103)
- Pastor-Bédard, N., Pituch, E., Lamata, E., Grondin, M., & Bottari, C. (2023). Parenting with a physical disability: A scoping review of assessment methods. *Australian Occupational Therapy Journal*, 70(2), 257–300. Scopus. <https://doi.org/10.1111/1440-1630.12845>
- Pavlopoulou, G., Sim, E., Peter, S., Gardani, M., Beevers, V., Kassa, C., & Sideropoulos, V. (2025). ‘Who Listens to the Listener, Who Cares for the Carer?’ A Cross-Sectional Study of Social Connectedness and Sleep Experiences of Young Siblings of Neurodivergent People. *Child: Care, Health and Development*, 51(1). Scopus. <https://doi.org/10.1111/cch.70014>
- Poojari, D. P., Umakanth, S., Maiya, G. A., Rao, B. K., Brien, M., & Narayan, A. (2022). Perceptions of family-centred care among caregivers of children with cerebral palsy in South India: An exploratory study. *Child: Care, Health and Development*, 48(2), 286–297. Scopus. <https://doi.org/10.1111/cch.12929>
- Rabello, F., Prado, H. V., Angelo, G. L., Martins, M. B., Carneiro, N. C. R., & Borges-Oliveira, A. C. (2021). Mothers of a Child with Cerebral Palsy: Perception on the Diagnosis Moment and the Child’s General and Oral Health. *Pesquisa Brasileira Em Odontopediatria e Clinica Integrada*, 21. Scopus. <https://doi.org/10.1590/PBOCI.2021.144>
- Rachamose, N., & Harvey, C. (2025). ‘It shuttered down our hearts’: The mental health of caregivers of children with cerebral palsy in rural Limpopo, South Africa. *South African Journal of Psychology*. Scopus. <https://doi.org/10.1177/00812463251315869>
- Rao, A. P., Shah, H., Guruvare, S., Gore, M., Nayar, K. R., & Vijayan, B. (2021). Perspectives of caregivers on pubertal changes among young adolescent girls with cerebral palsy: A qualitative analysis. *Disability, CBR and Inclusive Development*, 32(3), 76–90. Scopus. <https://doi.org/10.47985/dcidj.465>
- Shore, B. J., Allar, B. G., Miller, P. E., Matheney, T. H., Snyder, B. D., & Fragala-Pinkham, M. (2019). Measuring the Reliability and Construct Validity of the Pediatric Evaluation of Disability Inventory–Computer Adaptive Test (PEDI-CAT) in Children With Cerebral Palsy. *Archives of Physical Medicine and Rehabilitation*, 100(1), 45–51. Scopus. <https://doi.org/10.1016/j.apmr.2018.07.427>
- Somerville, K. (2022). Boxed in: The Art of Assemblage. *Missouri Review*, 45(1), 149–165. Scopus. <https://doi.org/10.1353/mis.2022.0006>
- Toovey, R., Willoughby, K. L., Hodgson, J. M., Graham, H. K., & Reddihough, D. S. (2020). More than an X-ray: Experiences and perspectives of parents of children with cerebral palsy when engaging in hip surveillance. *Journal of Paediatrics and Child Health*, 56(1), 130–135. Scopus. <https://doi.org/10.1111/jpc.14537>

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