ISSN NO. 2320-5407

Journal Homepage: -www.journalijar.com

INTERNATIONAL JOURNAL OF ADVANCED RESEARCH (IJAR)

Article DOI:10.21474/IJAR01/21908
DOI URL: http://dx.doi.org/10.21474/IJAR01/21908

RESEARCH ARTICLE

LIVING THE BURDEN: THE LIVED EXPERIENCE OF CAREGIVING BURDEN AMONG PARENTS OF CHILDREN WITH CEREBRAL PALSY

Norah Garallah Alkhaledi [1,2] and Abdualrahman S. Ashehry[3]

1. PhD Candidate, King Saud University, Riyadh, Saudi Arabia.
2. Community Nursing and Health Care Department, UQU, Makkah, Saudi Arabia.
3. Professor, College of Nursing, King Saud University, Riyadh, Saudi Arabia.

……………………………………………………………………………………………………....

Manuscript Info

Manuscript History
Received: 07 August 2025
Final Accepted: 09 September 2025
Published: October 2025

Key words: -
Parenting, Disability, Burden, Cerebral Palsy, Caregivers, Qualitative Research

Abstract

Background: Cerebral palsy (CP) affects not only the child but also the entire family. Raising a child with CP creates numerous challenges for the entire family.

Aim: To explore the lived experience of the burden on parents caring for children with cerebral palsy.

Methods: This qualitative study was conducted in March 2025 using a descriptive phenomenological approach to elucidate the phenomenon through parents' experiences. A purposive sample of caregivers of children diagnosed with CP was used.

Results: One core theme, "Never give up," emerged. Five main themes were identified: the physical burden of parents, the emotional burden of parents, challenges facing parents, the child's needs, and treatment.

Conclusion: The study's findings indicate that family caregivers face significant burdens when raising children with CP, including increased financial, mental, and physical difficulties.

……………………………………………………………………………………………………....

Introduction: -

Cerebral palsy (CP), stemming from a non-progressive encephalopathy, is recognized as the leading cause of permanent physical disability in children globally (National Institute of Neurological Disorders and Stroke, 2025). According to the National Institute of Neurological Disorders and Stroke (2025), CP exists in various forms (including spasticity and hemiplegia), and its prevalence is rising, particularly among children who survive preterm births (DeMauro et al., 2024). CP stands as a major public health problem in Saudi Arabia because it represents the most prevalent neurological disorder affecting children at a rate of 23.4 per 10,000 (Al Salloum & Abdelaziz, 2022). The primary responsibility of caring for a child with CP falls on parents who function as the main caregivers according to O'Connor et al. (2019). The prolonged demands of caring for a child with CP result in a significant caregiver burden (Ghazawy et al., 2020). This burden creates enduring stress for parents, reduces their quality of life, and increases their susceptibility to depression and anxiety (Ni et al., 2022; Park & Kim, 2020). The degree of caregiver burden is directly related to the child's disability severity, and socioeconomic difficulties and limited access to services exacerbate the situation (Mercan et al., 2020). Research has shown that caregiver burden affects parents worldwide, but there is a major knowledge gap regarding how Saudi parents experience caring for children

Corresponding Author: -Norah Garallah Alkhaledi
Address: -1. PhD Candidate, King Saud University, Riyadh, Saudi Arabia.2. Community Nursing and Health CareDepartment, UQU, Makkah, Saudi Arabia.

with CP and what support they need. The daily experiences of Saudi Arabian caregivers of children with CP remain understudied, as researchers have not fully examined how local cultural traditions, healthcare systems, and community resources affect their lives. The lack of detailed research on the context-specific emotional, social, and practical needs of these families makes it difficult to develop support interventions that truly help them.

Aim of the Study: -

The purpose of this study was to explore the lived experience of caregiving burden among parents of children with cerebral palsy.

Method: -

Study Design and Setting: -

This study employed a descriptive phenomenological design to examine caregiver experiences. According to van Manen (2017), descriptive phenomenology focuses on uncovering and accurately describing the core essence of personal life experiences. The research took place at the “Association of Disabled Children” in Riyadh, Saudi Arabia, in March 2025. The facility provides comprehensive care, rehabilitation, and educational programs to children with physical and developmental disabilities, including those with CP.

Study Participants and Sampling Strategy: -

The study focused on parents of children with CP as the main participants. Purposive sampling was used to select participants capable of providing detailed personal accounts of the phenomenon. The study included participants who met three conditions: (1) They cared for a child with CP (2) They had provided continuous care to their child for at least two years (3) They spoke Arabic and could give consent. Six participants were included in the study, consistent with its qualitative design. The small participant count in this study aligns with descriptive phenomenological research because it focuses on obtaining detailed information rather than statistical representation (Holloway & Galvin, 2017).

To achieve a thorough understanding of the experience, the researchers collected extensive information from each participant. Data collection ceased once interviews yielded no new codes, themes, or relevant findings related to the study objective, indicating that a full understanding of the phenomenon had been reached (Speziale et al., 2011). The researchers obtained sufficient detailed information from participants to meet qualitative requirements for understanding the phenomenon. Participants with severe neurological or intellectual disabilities or major mental illnesses were excluded, as such conditions could impede clear communication and reliable responses during interviews. Participants without parental status (e.g., siblings, professional nannies) were also excluded.

Recruitment Process: -

The Association of Disabled Children served as the first point of contact to identify potential participants. The screening process followed the inclusion/exclusion criteria to determine participant eligibility. All participants provided informed consent before data collection, and their participation was voluntary.

Data Collection: -

In qualitative research, the researcher serves as a key instrument for data collection. To gather comprehensive information, the researchers conducted in-depth interviews (Creswell & Poth, 2007). For individuals who satisfied the inclusion requirements, open-ended questions were used in in-depth interviews to gather data for this study. Researchers explored the difficulties of caring for children with CP in great detail. Each interview lasted approximately 25–30 minutes. Although participants shared similar experiences, each provided unique information during the interviews. Researchers asked questions in a natural, spontaneous manner and in language participants could understand, allowing them to respond as freely as possible. The main question asked in this study was: “Could you tell me about your experiences caring for your child at home?” To go further into the explanations, more in-depth and exploratory interview questions were employed, such as "Can you explain this more?" Every interview was audio-recorded and transcribed verbatim.

Data Analysis: -

The researchers used Thematic Analysis to analyze data through the six-phase framework developed by Braun and Clarke (2006). They chose this flexible method because it allowed them to identify, analyze, and report recurring patterns of meaning (themes) in the data. The researchers transcribed all interviews verbatim. The authors doublechecked the transcripts against the audio recordings to ensure accuracy. The authors read all transcripts multiple times to gain a complete understanding of the data and its context. The researchers began the initial coding by independently marking interesting data points across the entire dataset. The researchers used MAXQDA 2022 (VERBI, Berlin) to assign codes that captured both explicit semantic content and implicit latent content. The authors examined the codes to identify patterns that could form potential themes. The first set of themes encompassed all aspects of caregiver experiences.

The authors met to critically evaluate and refine the proposed themes. They checked each theme's coherence against the raw data and evaluated internal consistency and external diversity by reviewing the entire dataset. Redundant or weak themes were merged or eliminated, resulting in a cohesive set of final themes. The researchers established clear definitions for the final themes while selecting names which precisely represented the core aspects of each experience. The authors reached a consensus on the thematic structure and its subcategories. They evaluated each theme in light of the research question and incorporated specific participant quotations as evidence. An independent third author reviewed the results and selected representative participant statements to ensure authenticity.

Trustworthiness/ Rigor: -

This study addressed credibility, dependability, confirmability, and transferability to ensure the trustworthiness of its analysis and findings. Several strategies were used during the study to enhance credibility. Prolonged engagement with the data allowed the researchers to immerse themselves in participants' stories, ensuring a thorough understanding of their experiences. Additionally, the researchers used peer debriefing, regularly consulting independent qualitative specialists about emerging themes and coding decisions to reduce bias and enhance analytical rigor. Transparency and consistency were achieved by methodically documenting every phase of the study, thereby establishing dependability.

To enhance confirmability, the authors collaborated and reached agreement on the theme analysis and coding to minimize potential bias. The COREQ guidelines were followed in reporting the findings. The provision of thorough, in-depth explanations of the phenomena, which allowed others to evaluate the findings' applicability in other contexts, finally supported transferability. The researchers employed multiple reflexive strategies to examine their own positions and potential influences on the study. Each author maintained a reflexive journal to record personal thoughts, assumptions, and emotional reactions throughout data collection and analysis. They used these reflections to identify potential biases in light of their professional experiences. The team held regular discussions and maintained critical reflection to ensure that the findings were grounded in participants' real-life experiences.

Ethical Considerations: -

Ethical approval was obtained from the appropriate ethics committee in King Saud University. The study was conducted in accordance with the Declaration of Helsinki. Participants were informed about the study's nature and purpose, the data to be collected, the expected interview duration, and the benefits and risks of participation. Participants were also informed that the interviews would be audio-recorded. Informed consent was obtained from each participant in accordance with the ethical principles of respect for persons, beneficence, and justice. The researchers ensured that participation entailed no more than minimal risk. Participants were told that their participation was voluntary and that they had the right to withdraw at any time without penalty or loss of benefits. Participants were assured that their confidentiality would be maintained throughout the study. To protect anonymity, the researchers assured participants that personal information and responses would remain unidentifiable.

Findings: -

Participant Characteristics: -

The findings are reported in accordance with the COREQ (Consolidated Criteria for Reporting Qualitative Research) guidelines (Tong et al., 2007). Six caregivers of children with CP were included through purposive sampling. Participant demographic information is presented in Table 1. The sample consisted of five mothers and one father, aged 38–46 years All children (aged 5–10 years) were not attending school.

Table 1: Characteristics of the child and the parents

	Caregiver1	Caregiver2	Caregiver3	Caregiver4	Caregiver5	Caregiver6
Age of child	7 years	5 years	10 years	9 years	6 years	7 years
Sex of child	Female	Male	Female	Female	Male	Male
The educational level of the child	not studying	not studying	not studying	not studying	not studying	not studying
Number of family members	8	7	6	5	7	5
Order among sibling	5	5	3	2	5	3
Age of caregiver	40 years	46 years	39 years	38 years	43 years	40 years
Relation to child	Mother	Mother	Mother	Father	Mother	Mother
Mothers' education	Primary	High school	High school	Primary	Bachelor's	Bachelor's
Mothers' job	Housewife	Housewife	Housewife	Housewife	Teacher	Teacher
Father' education	Primary	High school	High school	High school	Bachelor's	Bachelor's
Fathers' job	Retired military	government employee	Military	Not Working	government employee	lab specialist
Family income	9000 SR	13000 SR	11000 SR	5000 SR	25000 SR	35000 SR
Enough income	Not enough	Not enough	Not enough	Not enough	Enough	Enough

Table 2: Themes and subthemes

Themes	Subthemes
1. The physical burden of the parents	**A. Headaches** **B. Sleep Problems** **C. Back pain** **D. Fatigue**
2. The emotional burden of the parents	**A. Social isolation** **B. Sadness** **C. Stress** **D. Worries** **E. Anxiety** **F. Fear** **G. Depression** **H. Crying**
3. Challenges facing parents	**A. Lack of support** **B. Financial issue**
4. Child needs	**A. Improve daily living skills.** **B. Intensive physical therapy sessions**
5. Treatment	**A. Traditional healer** **B. Convulsion** **C. Epilepsy**

Thematic Findings: -

The analysis of the interviews revealed one dominant narrative, distilled into a core theme and five main themes that describe the caregiving burden experienced by parents.

Core Theme: Never Give Up: -

The core theme "Never give up" emerged as a symbolic representation of the ongoing struggle and unyielding dedication experienced by all caregivers. This theme serves as a fundamental belief system that enables caregivers to maintain their strength through overwhelming difficulties It also provides a motivational framework that helps caregivers make sense of and cope with their challenges. Caregivers remain strongly dedicated to creating the best possible life for their children, even while enduring a full range of financial, emotional, and physical challenges.

Main Themes: -

As shown in Table 2, five main themes capture the breadth of the caregiver experience: (1) Physical Burden of the Parent, (2) Emotional Burden of the Parent, (3) Challenges Facing Parents, (4) Child Needs, and (5) Treatment.

1**.** Physical Burden of The Parent: represents the physical strain that caregivers endure. Ongoing tasks such as lifting, carrying, and providing care at night result in long-term health problems for caregivers. Subcategories of this theme included headaches, sleep problems, back pain, and fatigue. The physical impact of caregiving was evident in the mobility difficulties faced by parents, as one parent described:

"We're having a hard time carrying it. I live in a second-floor apartment. Carrying it up the stairs and down the stairs is considered the biggest difficulty I face, my daughter is heavy, and it is hard for us to carry her up and down. This affects my lower back; it tires me a little" (Participant No. 4).

Another participant said:"I was suffering from chronic back pain, fatigue, and a lot of severe headaches" (Participant No. 5).

One of the caregiver's statements is as follows: "In the past, he sleeps in my bed. He often wakes up in the middle of the night and sits and makes some noise, so I wasn't getting enough hours of sleep." (Participant No. 6).

2. Emotional Burden of The Parent: The emotional burden of caregiving affects parents deeply, manifesting in feelings of anxiety, fear, and social detachment. Subcategories of this emotional experience included anxiety, sadness, stress, worry, fear, depression, crying, and social isolation. Caregivers' main concern was their child's future development and ability to connect with others.

"When I see her situation affected psychologically, it's not like the rest of the kids are playing and enjoying their lives, I worry about her and think about her future and how the people deal with her" (Participant No. 1).

Another caregiver reported that:

"I sit thinking about her and her condition. I have anxiety, stress, and depression, and sometimes I cry for no reason. I try to get over it because I see the condition of people and their children. I say I am blessed, thank God". (Participant no. 3)

3. Challenges Facing Parents: This theme revealed two main obstacles: financial issues and a lack of social support. The primary challenge in obtaining regular, effective therapy stemmed from financial difficulties.

"Financially it affected me and it is one of the difficulties that I face with her. Sometimes I sit for two or three months and don't attend the treatment sessions at all and as you know the government hospitals are difficult appointments and half an hour you enter and take a session and half an hour you don't do anything you don't benefit from it and the private centers are very expensive" (Participant No. 4).

"Also, physical and occupational therapy sessions need money, and government hospitals do them once a month, and they are ineffective and not useful" (Participant No. 2).

4. Child Needs: This theme highlighted specific needs parents noted, such as improving daily living skills and obtaining intensive physical therapy sessions. The high cost of specialized care was a recurring complaint, underscoring a strong need for financial support.

"I want intensive physiotherapy for her. I hope someone will pay for her treatment. Physiotherapy is very expensive. I entered a center whose name I do not want to mention...they told me the price of sessions is from two months to Three months, which equals 40,000 or 35,000 SR! I left this center..."(Participant No. 3)

5.Treatment: This theme examined the various methods parents used to manage their child's medical needs and their specific worries regarding treatment. Three subthemes were identified: traditional healers, convulsions, and epilepsy. Parents often seek comprehensive solutions through traditional healers, while managing a child's epilepsy requires them to remain alert at all times.

"I'm afraid of convulsions, and you find me worried. I put an alarm on the phone at the time of treatment" (Participant No. 2).

"I took him to a woman who practiced traditional medicine because I wanted to know what he was suffering from." (Participant No. 5)

"After that, I went to a traditional healer and took medicines from her, and after that the girl became normal, she no longer had fever or diarrhea, and she began to breastfeed little by little" (Participant No. 1)

Discussion: -

This study employed a descriptive phenomenological approach to investigate the intricate life experiences of six primary caregivers of children with CP in Riyadh, Saudi Arabia. The core theme "Never give up" is the central finding, encapsulating the enduring dedication and strength caregivers demonstrate while managing their substantial responsibilities across the five main themes. The data show that caregivers face a significant physical burden, resulting in ongoing health problems such as back pain, sleep disturbances, and persistent fatigue. The study confirms international research findings by Ramezani et al. (2020) and Ephraim Kisangala et al. (2024) which show that physical strain from lifting and nighttime care responsibilities causes musculoskeletal problems and overall distress in caregivers.

The emotional burden has a major psychological impact on caregivers, reflected in subthemes of anxiety, depression, and fear. Caregivers' primary emotional challenge stems from ongoing concerns about their child's future and social interactions, as well as the need to protect their child from harm during convulsive episodes. Research by Seroke and Mkhize (2023) and Alsamiri et al. (2024) support the finding that parents experience anxiety due to worries about their child's health outcomes and need for ongoing care. The unpredictable nature of CP creates a direct link between parental mental health and the need for essential intervention strategies. The challenges facing parents theme yielded important local insights, demonstrating that parents face financial difficulties and lack sufficient support.

The high cost of private therapy forces parents to rely on less effective government services with infrequent appointments, leading to interruptions in treatment These financial obstacles and service limitations directly affect the ability to meet children's needs, for example, the need for frequent physical therapy sessions. Research conducted worldwide by Alaee et al. (2015) and Sen & Yurtsever (2007) demonstrates that specialized treatments remain inaccessible because of their high costs. A lack of support from spouses and healthcare providers (as noted by Participant No. 5) indicates weak social support networks and inadequate recognition of caregiver needs by the healthcare system. The treatment theme revealed a unique cultural aspect: parents using traditional healers alongside conventional medical care to manage convulsions and epilepsy. Some participants (e.g., Nos. 1 and 5) turned to traditional medicine in search of alternative healing solutions beyond conventional practices. Healthcare providers need to recognize parents' health beliefs, as traditional remedies are perceived to offer advantages for certain conditions (Han et al., 2022). Integrating these practices requires providers to support parents in maintaining safe, continuous care. Managing a child's epilepsy demands constant vigilance from parents, creating additional stress (as noted by Participants 2 and 6).

Limitations: -

First, the small sample size (six participants) limits the generalizability of these findings. The identified themes should be verified in future studies with larger, more diverse participant groups to establish their broader occurrence. Additionally, because this study was conducted at a single site in Riyadh using one recruitment source, the results may not be applicable to other settings or regions. Furthermore, the study relied on participants' self-reported experiences, introducing the possibility of response bias.

Implications for Practice:

Healthcare professionals should shift from providing basic emotional support to implementing family-oriented care plans and hands-on training for caregivers. Healthcare providers should teach caregivers safe lifting techniques to prevent back injuries and offer strategies to manage disrupted sleep patterns. Healthcare policymakers need to establish financial assistance programs and funding mechanisms to ensure families have access to affordable occupational and physiotherapy sessions. Developing peer support groups and caregiver education programs should be a priority to build mutual support networks and reduce social isolation. Community public-awareness initiatives are needed to foster an environment that supports families caring for children with disabilities.

Future Research:

Future studies should examine how different regions of Saudi Arabia (urban vs. rural) affect the generalizability of these findings. Longer-term, intervention-based studies should evaluate the impact of home-based nursing services and financial assistance programs on caregivers' physical and emotional strain. This research demonstrates that children with CP require strong family support, which in turn demands fundamental improvements in care services to ensure they are accessible, affordable, and culturally appropriate.

Conclusion: -

This study provides a detailed qualitative insight into Saudi parents' experiences caring for children with CP. It highlights their strong determination ("Never Give Up") while also revealing their struggles with persistent physical and emotional challenges, as well as inadequate financial and institutional support.

References: -

1. Alaee, N., Shahboulaghi, F. M., Khankeh, H., &Kermanshahi, S. M. K. (2015). Psychological challenges for parents of children with cerebral palsy: A qualitative study. Journal of Child and Family Studies, 24(7), 2174. https://doi.org/10.1007/s10826- 014-0016-3
2. Alsamiri, Y. A., Alaghdaf, A. A., Alsawalem, I. M., Allouash, B. A., &Alfaidi, S. D. (2024). Mothers of children with disabilities: exploring lived experiences, challenges, and divorce risk. Frontiers in Psychology, 15. https://doi.org/10.3389/fpsyg.2024.1399419
3. Al Salloum, N. J., & Abdelaziz, I. A. (2022). Prevalence, types, and outcomes of cerebral palsy at a tertiary center in Jeddah, Saudi Arabia. Cureus, 14(8), e27599. https://doi.org/10.7759/cureus.27599
4. Andrews, C., Namaganda, L. H., Imms, C., Eliasson, A.-C., Asige, E., Godfrey Wanjala, Kakooza-Mwesige, A., &Forssberg, H. (2022). Participation of children and young people with cerebral palsy in activities of daily living in rural Uganda. 65(2), 274–284. https://doi.org/10.1111/dmcn.15323
5. Arzani, M., Jahromi, S. R., Ghorbani, Z., Vahabizad, F., Martelletti, P., Ghaemi, A., Sacco, S., &Togha, M. (2020). Gut-brain Axis and migraine headache: a comprehensive review. The Journal of Headache and Pain, 21(1). https://doi.org/10.1186/s10194-020-1078-9
6. Braun, V., & Clarke, V. (2006). Using Thematic Analysis in Psychology. Qualitative Research in Psychology, 3(2), 77–101. https://doi.org/10.1191/1478088706qp063oa
7. Chen, C., Bailey, C., Baikie, G., Dalziel, K., & Hua, X. (2023). Parents of children with disability: mental health outcomes and utilisation of mental health services. Disability and Health Journal, 16(4), 101506–101506. https://doi.org/10.1016/j.dhjo.2023.101506
8. Creswell, J. W., & Poth, C. N. (2007). Qualitative inquiry and research design: Choosing among five approaches (2nd ed.). Sage Publications
9. DeMauro, S. B., McDonald, S. A., Heyne, R. J., Vohr, B. R., Duncan, A. F., Newman, J. E., Das, A., & Hintz, S. R. (2024). Increasing Prevalence of Cerebral Palsy Among Two-year Old Children Born at <27 Weeks of Gestation: A Cohort Study. The Journal of Pediatrics, 113944–113944. https://doi.org/10.1016/j.jpeds.2024.113944
10. Ephraim Kisangala, Etheldreda Leinyuy Mbivnjo, Edward, Barrett, B., Godfrey Zari Rukundo, Namisango, E., & Heslin, M. (2024). Health and economic impact of caregiving on informal caregivers of people with chronic diseases in sub-Saharan Africa: A systematic review. PLOS Global Public Health, 4(12), e0004061–e0004061. https://doi.org/10.1371/journal.pgph.0004061
11. Ghazawy, E. R., Mohammed, E. S., Mahfouz, E. M., &Abdelrehim, M. G. (2020). Determinants of caregiver burden of persons with disabilities in a rural district in Egypt. BMC Public Health, 20(1). https://doi.org/10.1186/s12889-020-09266-4
12. Han, J. E., Kim, J., Kim, K. H., Lee, J. Y., & Sung, S. H. (2022). Traditional Korean Medicine Usage and Perception: a comparative study between the general population and the disabilities. Journal of pharmacopuncture, 25(1), 24–36. https://doi.org/10.3831/KPI.2022.25.1.24
13. Hassan, N. (2023). Social Stigma and Psychological Burden among Caregivers of Children with Cerebral Palsy. Journal of Medical Research and Reviews, 1(2), 1–1. https://doi.org/10.5455/jmrr.20230712094757
14. Holloway, I., & Galvin, K. (2017). Qualitative research in nursing and healthcare (4th ed.). Wiley. https://www.books.google.co.id/books?id=EKu
15. Kinney, M. O., Chester, V., Tromans, S., Alexander, R. T., Angus-Leppan, H., Bagary, M., Cock, H., Devapriam, J., Hassiotis, A., Mula, M., Reuber, M., Ring, H., Roy, A., Scheepers, M., & Shankar, R. (2020). Epilepsy, anti-seizure medication, intellectual disability and challenging behaviour – Everyone's business, no one's priority. Seizure, 81, 111–116. https://doi.org/10.1016/j.seizure.2020.07.018
16. Lakhani, A., Ali, T. S., Kramer-Roy, D., & Ashraf, D. (2024). Informal social support for families with children with an intellectual disability in Karachi, Pakistan: A qualitative exploratory study design. Heliyon, 10(20), e39221. https://doi.org/10.1016/j.heliyon.2024.e39221
17. Mercan, S., Ateş, M. A., & Uçan, Ö. (2020). Quality of life among persons with intellectual and physical disability in northwestern Turkey. Çukurova Medical Journal, 45(4), 1482-1492. https://doi.org/10.17826/cumj.735333

18. National Institute of Neurological Disorders and Stroke. (2025). Cerebral Palsy. Www.ninds.nih.gov. https://www.ninds.nih.gov/health-information/disorders/cerebral-palsy
19. Negussie Boti Sidamo, Sultan Hussen Hebo, Kassahun, A. B., & Endris, B. O. (2025). Exploring family caregiver burdens and coping mechanisms for patients with comorbid neglected tropical diseases and mental illness in Southern Ethiopia: insights from qualitative findings. Frontiers in Tropical Diseases, 6. https://doi.org/10.3389/fitd.2025.1475955
20. 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: The Journal of Health Care Organization, Provision, and Financing, 59, 004695802211215. https://doi.org/10.1177/00469580221121510
21. Nowak, S. A. (2025). V. Braun, V. Clarke, Thematic Analysis. A Practical Guide Londyn: SAGE Publications Ltd, 2022, 376 s. Neofilolog, 64/2, 470–474. https://doi.org/10.14746/n.2024.64.2.15
22. O'Connor, B., Kerr, C., Shields, N., Adair, B., &Imms, C. (2019). Steering towards collaborative assessment: a qualitative study of parents' experiences of evidence-based assessment practices for their child with cerebral palsy. Disability and Rehabilitation, 43(4), 458–467. https://doi.org/10.1080/09638288.2019.1629652
23. Park, E., & Kim, J. (2020). Activity limitation in children with cerebral palsy and parenting stress, depression, and self-esteem: A structural equation model. Pediatrics International, 62(4), 459–466. https://doi.org/10.1111/ped.14177
24. Ramezani, M., Eghlidi, J., Pourghayoomi, E., & Mohammadi, S. (2020). Caring-Related Chronic Low Back Pain and Associated Factors among Mothers of Children with Cerebral Palsy. Rehabilitation Research and Practice, 2020, 1–6. https://doi.org/10.1155/2020/8854435
25. Seroke, S., & Mkhize, S. W. (2023). Psychosocial experiences of mothers caring for children with cerebral palsy in the eThekwini district. Health SA Gesondheid, 28. https://doi.org/10.4102/hsag.v28i0.2072
26. Sen, E., & Yurtsever, S. (2007). Difficulties experienced by families with disabled children. Journal for Specialists in Pediatric Nursing, 12(4), 238–252. https://doi.org/ 10.1111/j.1744-6155.2007.00119.x
27. Shadab Shahali, Mahmoud Tavousi, Sadighi, J., Ramin Mozafari Kermani, & Rostami, R. (2024). Health challenges faced by parents of children with disabilities: a scoping review. BMC Pediatrics, 24(1). https://doi.org/10.1186/s12887-024-05104-3
28. Speziale, H. S., Streubert, H. J., & Carpenter, D. R. (2011). Qualitative research in nursing: Advancing the humanistic imperative (5th ed.). Wolters Kluwer Health/Lippincott Williams & Wilkins. https://www.books.google.co.id/books?id=xNByh3B1Wt0C
29. Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care, 19(6), 349–357. https://doi.org/10.1093/intqhc/mzm042
30. van Manen, M. (2017). But Is It Phenomenology? Qualitative Health Research, 27(6), 775–779. https://doi.org/10.1177/1049732317699570
31. Watkins, L. V., Linehan, C., Brandt, C., Snoeijen-Schouwenaars, F., McGowan, P., & Shankar, R. (2022). Epilepsy in adults with neurodevelopmental disability - what every neurologist should know. Epileptic Disorders, 24(1), 9–25. https://doi.org/10.1684/epd.2021.1366