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# Mothers' challenges and experiences of children with cerebral palsy: a qualitative meta-synthesis

**Review**

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**Abstract:** **Objective:** To examine what challenges and experiences a mother faces in caring for children with cerebral palsy (CP). As the main caregiver of children with CP, mothers are under multiple pressures. Even though mothers' challenges and experiences of children with CP will affect their quality of life and the rehabilitation of the children, little is known about their challenges and experiences during the whole care.

**Methods:** A qualitative meta-synthesis was conducted to extract and analyze qualitative research from the PubMed, CINAHL, PsycINFO, Web of Science, Ovid and MEDLINE databases. Thirteen articles were selected and analyzed using thematic syntheses.

**Results:** From 2522 screened abstracts, 84 texts were reviewed, and 13 studies met the inclusion criteria. Mothers' challenges and experiences of children with CP include 4 themes, both positive and negative.

**Conclusions**: The mothers of children with CP suffer from physical burden, as well as psychological pressure, in the care experience; social and healthcare support are their main challenges. Interventions to help them face the difficulties and adapt to the role of caregivers as soon as possible should target multiple aspects in order to maximize effectiveness, to promote the healthy growth of children with CP.

**Keywords:** *challenges • children with cerebral palsy • experience • meta-synthesis • mothers*

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## 1. Introduction

Cerebral palsy (CP) refers to a group of disorders involving the development of movement and posture, causing activity limitation that is attributed to non-progressive disturbances that occurred in the developing fetus or infant brain. They are often accompanied by disturbances of sensation, cognition, communication, perception, behavior, or by a seizure disorder.[1] Consequently, these constraints may lead to dysfunction in self-care and make children dependent on others for their activities of daily living.[2]

CP is the most common cause of physical disability in early childhood. According to the Surveillance of Cerebral Palsy in Europe (SCPE), the overall prevalence of CP decreased from 1.90/1000 live births to 1.77/1000 live births; it shows a significant reduction in the prevalence of children with CP of birth weight 1500–2499 g.[3]

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Although the reduction in percentage of CP prevalence from 1980 to 2003 is encouraging, CP as a lifetime condition can be a traumatic event for the family.[4]

The treatment and rehabilitation of children with CP is a long-term process. Furthermore, the impact of the functional limitations becomes more apparent and severe as the child ages.[5] Although children with CP may be a source of joy to the parents, their special needs may add to the emotional, physical, and financial strain in caring for them. There is much evidence to show that mothers, who, as the primary caregivers for children with CP, suffer from higher levels of fatigue and depression, and lower quality of life compared to the mothers with healthy children.[6–8] Khayatzadeh Mahani et al.[9] found that social restrictions and decreased marital satisfaction were among the difficulties faced by mothers of children with CP. There is no doubt that these conditions will lead to a significantly worsened quality of life of mothers.

Generally, parenting practices are known to significantly contribute to child health; their health and well-being are therefore of great importance to support them in caring for their children.[10] Quantitative studies have increasingly been carried out on this topic from different angles and phrases, and, therefore, executing a qualitative meta-synthesis could be useful for obtaining an integrating and systematic synthesis of the study, which could help guide practice and future research. In addition, carrying out a meta-synthesis from this perspective can help detect vital aspects of the challenges and experiences of the mothers of children with CP that are currently not found and addressed. Healthcare services and professional medical staff will be able to develop interventions better, in order to help mothers with their true needs and expectations, with this knowledge.

The aim of this meta-synthesis was to draw together the findings of qualitative research into a composition of mothers' challenges and experiences of children with CP. The findings of qualitative studies relevant to mothers' challenges and experiences were collected and synthesized carefully to gain a better understanding of mothers' challenges and experience of children with CP. Based on the results, we proposed some suggestions for healthcare services and professional medical staff that would help provide psychological, physical, and social support to mothers, create an equal and convenient social environment for families of children with CP, and promote healthy growth of children.

# 2. Methods

## 2.1. Meta-synthesis

A meta-synthesis draws on the subjective and interpretive nature of existing qualitative research to construct more complete and plausible understandings of reality than what is currently available from the existing literature.[11] There are several approaches to qualitative synthesis; in this instance, the meta-synthesis procedures proposed by Paterson et al.[12] was applied to respond inductively to the study questions and to integrate the new knowledge. This method seeks to systematically review the literature and to produce an interpretive synthesis of the results of other qualitative studies. The data, coding, and analysis were undertaken by 2 researchers. First, coding was performed to develop the concepts. In this process, memos were noted down, as well as theoretical concepts about coding and the relationships between them. Throughout the process, a series of concepts emerged. Through team comparison and discussion, sub-themes were then created as categorical elements, which were then grouped into categories. A data matrix was created for each category to analyze the properties and relationships between them, transforming these categories until more precise codes were obtained to classify and reorder the information. Finally, the results of the study were synthesized to explain the central categories and subcategories, to provide a theoretical explanation for the study topic. Meta-synthesis offers more than the aggregation of various characteristics that shape a phenomenon, as it provides a description or full explanation of this phenomenon and distinguishes the similarities and differences between the ideas surrounding an experience.[13] It involves the process of comparing, translating, and analyzing the original results, which leads to the generation of new interpretations.[14]

To provide rigor and validity in the interpretation of texts, 2 researchers worked simultaneously to analyze the texts, identify the topics, and trace their development. Furthermore, in order to seek external consensus and improve the quality of the results, the results were discussed with another researcher.

## 2.2. Inclusion and exclusion criteria

To guide the systematic search of the literature, the following predetermined inclusion and exclusion criteria were applied, taking into account for preparing the aims of the meta-synthesis (Table 1).

## 2.3. Search strategy

A comprehensive and systematic approach was used to locate the relevant published research studies in the area of mothers' challenges and experiences of children with CP. Two researchers searched 6 electronic databases for literature: PubMed, Cumulative Index to Nursing and

Allied Health Literature (CINAHL), PsycINFO, Web of Science, Ovid, and the Medical Literature Analysis and Retrieval System Online (MEDLINE). Referencing lists of the selected articles were also reviewed through the snowballing technique, for the purpose of obtaining other related items. Then, the appropriate keywords were used: "mother," "children," "cerebral palsy," "qualitative study." The search strategies using PubMed as an example can be seen in Figure 1.

The available literature appeared in February 2021. One researcher imported all records into EndNote reference management software to exclude duplicates. Two researchers screened the titles and abstracts of all records independently to identify studies that appeared to be potentially related to mothers' challenges and experiences of children with CP. When there is a disagreement, another researcher joined the discussion and decided to include or exclude. then obtained the full

| Inclusion criteria | Exclusion criteria |
|---|---|
| Mothers were aged 18 years or above, Children with CP were aged between 0-18 years | |
| Qualitative studies focus on: | |
| Psychological, physical, social challenges faced by mothers of children with CP. | Other caregivers' and health personnel's experience of the mother role |
| Mothers' experiences from first learning of the diagnosis to the whole caring process. | Review articles, official reports, book reviews, theoretical articles, dissertations, conference abstracts, and editorials |
| Mothers' change and growth in the caring experience. | |

*Note:* CP, cerebral palsy.

**Table 1.** Inclusion and exclusion criteria applied to the literature search.

**#1** "Mothers"[Mesh] OR "Parents" [Mesh] OR "caregivers"[Mesh] OR "family"[Mesh])OR mother*[Title/Abstract] OR caregiver*[Title/Abstract] OR carer*[Title/Abstract]
**#2** "Child"[Mesh] OR " Disabled children"[Mesh] OR "Infant" [Mesh] OR "Adolescent" [Mesh]) OR Child*[Title/Abstract] OR Child with a disab*[Title/Abstract] OR Teenager*[Title/Abstract]
**#3** "Cerebral Palsy"[Mesh] OR CP[Title/Abstract]
**#4** "Interviews as topic"[Mesh] OR "Focus groups"[Mesh] OR "Narration"[Mesh] OR "Qualitative research"[Mesh] OR Interview[Title/Abstract] OR "Focus" group[Title/Abstract] OR qualitative study[Title/Abstract] OR qualitative studies[Title/Abstract] OR semi-structured[Title/Abstract] OR unstructured[Title/Abstract] OR structures[Title/Abstract] OR informal[Title/Abstract] OR in-depth[Title/Abstract] OR face-to-face[Title/Abstract] OR grounded theory[Title/Abstract] OR phenomenology[Title/Abstract]
**#5** #1 AND #2 AND #3 AND #4

**Figure 1.** Search strategies for PubMed.

text of these articles for review, and thirteen of these met the inclusion criteria.[15–27] This process can be seen in Figure 2, and a summary of the included articles can be seen in (Table 2).

## 2.4. Quality assessment

The included papers were critically appraised according to the Critical Appraisal Skills Program (CASP) checklist for qualitative research. The CASP is a 10-question tool with "Yes," "No," or "Can't Tell" responses, including 2 initial selection questions on the aims and congruence of the qualitative methodology, and 8 questions about design, sampling, data collection, reflexivity among researcher-participants, ethical considerations, data rigor, clarity of findings, and applicability of results. The checklist allows qualitative research evidence to be appraised systematically, guiding the reviewer about the results, their validity, and their transferability. The methodological quality of identified studies was assessed independently by 3 researchers, then researchers got together to discuss discrepancies in scores awarded; where discrepancies could not be resolved, they were discussed with another researcher. The results can be seen in Table 2. They were all included in the analysis.

# 3. Results

Two researchers summarized themes and subthemes after they completed the full-text reading of the included articles independently through a staged coding process,[28] and one researcher organized group discussion to improve suitability of each theme and subtheme. We also extracted original data excerpts from articles (e.g., participant quotes, stories), to help illustrate our own meta-synthetic findings. Through meta-synthesis, the mothers' challenges and experiences of children with CP were revealed. The recurring themes were the following: negative emotions, burden and challenges, social support and security, and actively growing and expectation. These issues are further divided into subthemes that improve our understanding of the phenomenon. The main results are described below and can be seen in Table 3.

## 3.1. Theme 1: Negative emotions

The care of a child with CP is a source of tension for mothers; they experienced many negative emotions, accompanying different phases of care, including shock, denial, sadness, anxiety, fear, guilt, and even suicidal thoughts.

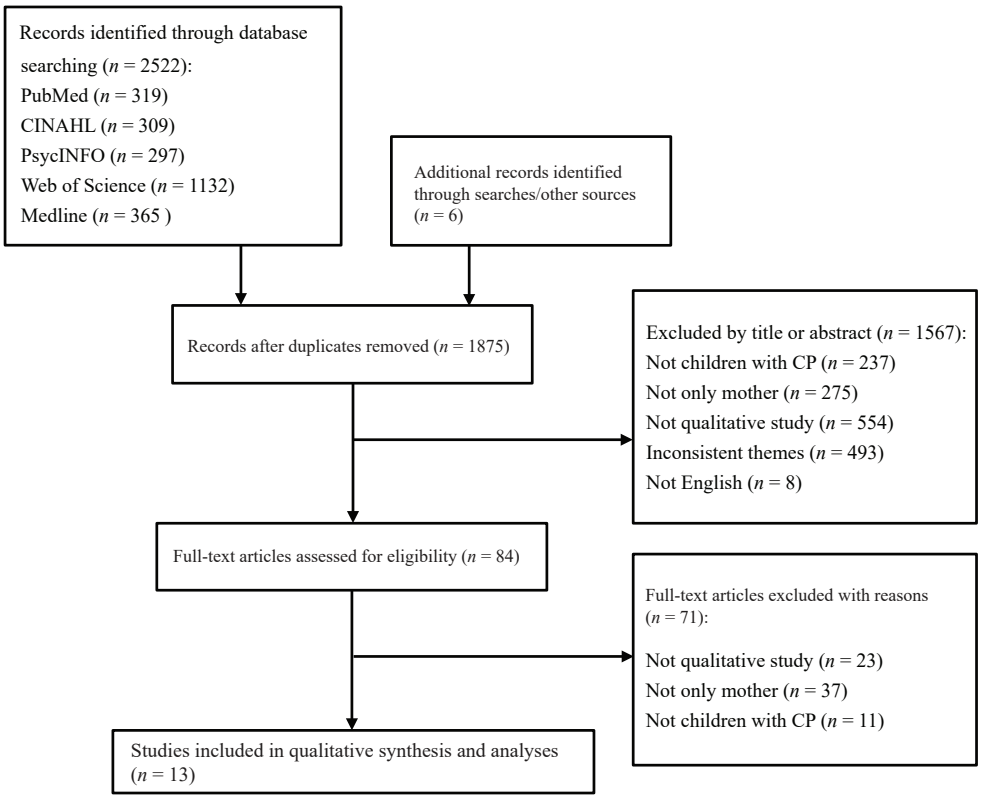



**Figure 2.** Flow diagram for selection process.
*Note*: CINAHL, Cumulative Index to Nursing and Allied Health Literature; CP, cerebral palsy.

| Author/year | Location of study | Aim | Sample | Data methods | Core finding | Quality appraisal (%) |
|---|---|---|---|---|---|---|
| Vadivelan et al.[15] | Tertiary Care Center, Tamil Nadu | To understand the physical, psychosocial, financial, and other stressors among caregivers of children with CP | 10 mothers of children with CP | Thematic content analysis, semi-structured interview | 5 main themes<br>• Individual stressors<br>• Interpersonal stressors<br>• Community stressors<br>• Environmental stressors<br>• Health system and policy stressors | 80 |
| Mokhtari and Abootora.[16] | Saba Private Rehabilitation Center, Lran | To investigate the experiences of Iranian mothers of children suffering from CP | 8 mothers of children with CP | Hermeneutic phenomenology, semi-structured interviews | 4 main themes<br>• Life world existential: Lived body<br>• Life world existential: Lived space<br>• Life world existential: Lived time<br>• Life world existential: Lived relationship | 60 |
| Marian et al.[17] | Hospital, Namibia | To reveal the experience of mothers of children born with CP | 12 mothers of children with CP | Phenomenological, explorative and contextual design, In-depth interviews | 4 main themes<br>• The emotional experiences of mothers<br>• Social Support<br>• Community acceptance | 60 |
| Mohamed Madi and Mandy.[18] | Medical City, Saudi Arabia | To explore the perceptions of disability among mothers of children with CP | 6 mothers of children with CP | Ethnographic, focus groups | 3 main themes<br>• Culture and religion<br>• Motherhood and disability<br>• Community stigma and discrimination | 60 |
| Kurtuncu et al.[19] | Rehabilitation Center, Turkey | To determine the difficulties experienced by mothers of children with CP and their needs | 15 mothers of children with CP | Phenomenological approach, semi-structured interviews | 9 main themes<br>• Difficult to accept diagnosis<br>• Family relationship<br>• Relationships between children<br>• Care difficulties<br>• Educational difficulties<br>• Worries About the future<br>• Expectations for the future<br>• Availability of social support<br>• Sexual life | 60 |
| Dalvand et al.[20] | Participants' homes/ clinics/school/ community, Iran | To explore occupations of mothers of children with CP | 16 mothers of children with CP | Content analysis methodology, semi-structured interviews | 4 main themes<br>• Coping with self-care problems<br>• Efforts to gain treatment follow-up<br>• Coping challenges of educational care<br>• Limited parental personal leisure time | 60 |
| Dehghan et al.[21] | Clinics, Iran | To explore the experience of social participation of mothers of children with CP | 14 mothers of children with CP | Content analysis method, semi-structured interviews. | 3 main themes<br>• Polarization of positive and negative feelings<br>• Challenges to mothers' social activity<br>• Striving to engage in society | 60 |

(*Continued*)

**Table 2.** Continued

| Author/year | Location of study | Aim | Sample | Data methods | Core finding | Quality appraisal (%) |
|---|---|---|---|---|---|---|
| Glasscock,[22] | Clinics, USA | To describe the lived experience of being the mother of a child with CP | 15 mothers of children with CP | Phenomenological methods, audiotaped interviews. | 4 main themes<br>• Caregiver burden<br>• Family/social support<br>• Women's/mothers' roles<br>• Socioeconomics | 70 |
| Huang et al.[23] | Hospital, Taiwan, China | To describe challenging caregiving experiences for mothers providing care for children with CP | 15 mothers of children with CP | Hermeneutic phenomenological approach, in-depth interviews and journaling methods | 4 main themes<br>• Experiencing burden as a sole primary caregiver<br>• Managing the challenges by balancing demands<br>• Being marginalized by others<br>• Encountering limited or no professional support | 80 |
| Singogo et al.[24] | Townships, Zambia. | To explore the challenges of mothers who cared for children with CP | 16 mothers of children with CP | Exploratory methodology, semi-structured individual interviews. | 5 main themes<br>• Physical challenges experienced by the mothers<br>• Social isolation<br>• Perceived causes of CP<br>• Physical access challenges<br>• Marital problems and challenges with the health care system | 70 |
| Milbrath et al.[25] | Care Institution, Brazil | To get to know the adaptation process experienced by a woman, motivated by the birth of a child with CP | 6 mothers of children with CP | Descriptive and exploratory methodology, semi-structured interview. | 2 main themes<br>• Experiencing being a woman-mother of a child with CP<br>• Supporting networks necessary to the woman-mother of a child with special needs | 50 |
| Power et al.[26] | Clinic, Irish | To study the effect of the child's communication difficulties on the mother's life | 3 mothers of children with CP | Grounded theory, semi-structured interview. | 5 main themes<br>• Hardships experienced by the mother<br>• Emotional investment in the child's communication progress<br>• Laboring to get the child's communication going<br>• Being consumed with the child's communication<br>• Hardships experienced by the child | 60 |
| Huang et al.[27] | Hospital, Taiwan, China | To describe mothers' experience of learning that their child has been diagnosed with CP | 15 mothers of children with CP | Phenomenological methodology, in-depth interviews and journaling methods. | 4 main themes<br>• Feeling out of control and powerless<br>• Mistrusting healthcare professionals<br>• Release and confirmation<br>• Feeling blamed for not following traditional practices | 80 |

*Note:* CP, cerebral palsy.

**Table 2.** Characteristics of included studies.

| Themes | Subthemes |
|---|---|
| Negative emotions | Shock and denial |
| | Guilt and blame |
| | Worry and sadness |
| | Anxious and uncertain |
| | Unfair for children |
| | Dilemma |
| | Helplessness |
| Burden and challenges | Physical challenges |
| | Financial burden |
| | Limited social participation |
| | Career choices |
| Social support | Family support |
| | Marital problems |
| | Social support |
| | Education problems |
| | Social discrimination |
| | Environment challenges |
| Actively growing and expectation | Self-regulation |
| | Return to society |
| | Accept and release |
| | Coordination and investment |

**Table 3.** Themes and subthemes.

The mothers of children with CP said that they were shocked and denied when they first learned of the diagnosis.[17,25] Most of the families went to many hospitals to check the diagnosis, because they were in denial. It may destroy their hope of being a mother of a healthy child once they accept that their child has CP.[19,27] Affected by religion and culture, mothers had misunderstood about the perceived causes of CP. Some mothers thought that the reason their child developed CP is because they did not successfully give birth to their child and did not sufficiently nurture their bodies during pregnancy; they felt guilty and blamed themselves.[16,18,19,24,27] Permanent brain damage from CP meant that there was no hope of being cured, which made mothers feel uneasy and devastated for their child's future, and they don't know who's going to look after the child if something happens to them.[19,27] For some mothers, separation from children was an issue because children lack independence and need help. Mothers feel anxious when their children are not with them.[27] The deterioration of the child's condition causes the mother grief, especially when the mother compares their child to a healthy child, the mother feels guilty and unfair to the child.[21] During rehabilitation, mothers reported that maintaining a balance between being protective and promoting independence was a challenge for them.[23] Every time the mothers see their child injured during the rehabilitation training, they are in a dilemma. Moreover, the mothers articulated concerns over how stigma could affect their children's self-esteem and result in psychological damage.[18] Sometimes, mothers experienced a sense of helplessness when confiding the burden on their shoulders, and that nobody could help.

## 3.2. Theme 2: Burden and challenges

Mothers identified as primary caregiver stressors, that daily caring is difficult and exhausting for them. Because children with CP are unable to walk, the mother takes care of all their needs and they have to be carried continuously, and help them do their daily activities. They reported that they felt worn out.[15,16,19,24] Most of the mothers have >1 child, and they need to take care of every child's daily life. Mothers said that caregiving affects their well-being and quality of life.[16,22] How the mothers did their best for their child differed from person to person, but all showed a desire to do as much as they could to help their child reach its full potential and highest self-care.

Mothers said that they experienced financial difficulties.[15,19,22] Family incomes were not adequate to cover children's rehabilitation costs and the mothers' health expenses. Mothers who gave up work to spend more time with their child lost their financial resources and coupled with it was inadequate medical insurance support, all of which resulted in financial burden.[26]

Mothers play a major role in the care; they need to spend a lot of time in childcare activities. Long-term care not only increases the mother's negative emotions, physical burden and financial burden, but also affects personal leisure time and space.[16,20] Sometimes a child's behavior problems or strange performance may also limit the mother's social participation.[16,21] The limited social participation further reduces the support from friends and aggravates social marginalization. Furthermore, most of the mothers in the included studies chose to leave the job market and give up their careers to better take care of their children with CP. As is common, mothers work part-time not full-time, to spend more time caring for their children with CP. Choosing between personal values and accompanying their children is one of the challenges they have to face. The Mother's challenges and experiences, affected by the birth of a child with CP, were described as being due to sudden event; their life and work changed completely.[25]

## 3.3. Theme 3: Social support and security

Social support refers to the functions performed for the individual by significant (i.e., primary) others, as well as supplied by secondary group members. The most frequently mentioned functions are emotional,

informational, and instrumental assistance. Substantial evidence shows that social support is positively and causally related to mental health, physical health, and longevity.[29,30] This theme indicates the main concerns that the mother experienced: lack of support from family and society, marital problems, inadequate or inappropriate facilities and services, and society's attitude towards the mothers and children with CP.

Mothers believe that children with a disability are a special group in society and draw attention from others. It inevitably leads to exclusion and isolation from society, and the attitudes of ordinary people, which affects their mental health and social participation.[17,21] Most mothers have experienced family incompatibility and disapproval; the family sees children as a burden and shame.[18,23,27] Some mothers not only lost support from family, but also from their husbands;[15,24] they said it was upsetting when the husband would yell at the child and can't accept them; the sexual relationship in the marriage was also affected.[19] Even worse than that was that family tensions were compounded by sibling rivalry when the child with CP needs was favored.[19] The study shows that mothers' lack of support from family, friends, and community members will result in their isolation by society.[15,24]

Most of the mothers said that they had difficulty in receiving education for their children. They said it is unfair to reject and exclude CP children going to school, since they lack self-care skills.[17,22] As for the mothers whose children were educated, they complained that they suffered social stigma and discrimination from teachers, but were eager to be equal to the others.[15,18,19,22] At the same time, without family support, mothers have to spend most of their time accompanying their children by themselves. Some mothers can't help children do homework because of limited ability.[20]

Mothers feel dissatisfied and a loss of trust in the healthcare professionals due to the delay in diagnosis and their impatientattitude.[18,22,27] The worst thing that mothers have experienced is the shortage of therapists and the lack of medical support, which will cause them anxiety. Nearly all mothers experienced physical access problems. Due to the lack of assistive devices for transferring them from one place to another at home or outdoors, children with CP need significant help from their mother. This means that the inadequate facilities increases the burden on the mother.[15,17,21,22] Being faced with inappropriate environments, like narrow sidewalks, barriers, and lack of elevators, mothers have experienced a lot of inconvenience in caring for their children with CP; they felt powerless and worried about their child's safety when society failed to provide a disability-friendly environment and ignored their needs.[17,21,24]

### 3.4. Theme 4: Actively growing and expectation

The subjects' roles are mothers as well as women.[22] When their children were diagnosed, they are required to adapt to the role of the mother of children with CP as soon as possible. The theme shows that the mother can handle various difficult tasks and achieve positive growth during the caring process. Their views on the future of their children have also improved, even though they were anxious at first. As mothers, they saw their child grow as an individual and become adult in society.

Mothers try to adjust themselves by using supporting networks as a mechanism to facilitate their adaptive responses.[17] The family sees a child with CP as normal, and they do not hide them anymore. More and more people's attitudes have changed about mothers of children with CP, and because of that, mothers of children with CP can fit in society.[16,21] They said that social participation can reduce their levels of mental distress and help them to move their focus from their child to themselves for a short time.[21] Mothers said communication and shared experiences with peers is also a good way to release pressure and encourage one another.[17]

Mothers reported that they could not accept the truth that their children are undergoing CP, but they are glad to say that they are past that now.[16,19] They realized that overprotection could result in their children losing the possibility of developing skills that would enable them to live independently in the future.[23] Therefore, they try to establish a good relationship with medical staff and trust them, developing their children's self-care skills through cooperating with medical treatment and performing rehearsed rehabilitation exercises. For the children with CP who have difficulty communicating, mothers put emotional investment in the child's communication process.[26] To promote their children's participation in society, mothers tried to reconstruct good situations like going out everywhere with the child; they strive to create opportunities for children, to avoid being isolated by society.[17,26] Some mothers have also become a playmate with their children.[20] After long-term care, mothers have the aspiration for their children's future and wish that their children might be able to lead a healthy life like an ordinary child.[16,18]

## 4. Discussion

The aim of this study was to develop a meta-synthesis about mothers' challenges and experiences of children with CP. Thirteen studies were analyzed and resulted in 4 main themes. We believe that mothers of children with CP have various challenges and difficulties that are

due to lacking of knowledge and support, and that the main emotional experience is negative. We also found that some mothers have gained a positive experience in responding to challenges, and most of the mothers are eager to get support and assistance from family and society. Based on the results, we propose the following suggestions for improving the mothers' care experience of children with CP and helping them to cope with challenges.

Studies have shown that parents who give long-term care for children with disabilities will be easy to cause severe mental stress and psychological complications.[31] Children with CP have low self-care ability, mothers as the main caregiver are not only facing financial and physical burden, but also suffering psychological pressure, which may probably result in negative emotions.[32] Negative emotions are reliably associated with poorer health.[33] Therefore, it is important to take appropriate intervention to assist mothers to regulate and manage their emotions from various phases. Healthcare services and professionals should set up a trusting relationship with the mothers to help them accept the fact that the CP was diagnosed, then explain the cause of the CP, to reduce mothers' feeling of guilt, and introduce the main treatment and rehabilitation plan, to relieve their worry and uncertainty. The evidence supports mindfulness training as one of the cognitive psychology methods, which can reduce one's anxiety and worry.[34] It is an effective way to reduce the mothers' negative stress and stress-related health outcomes.

Since CP children's brain is damaged or there is a non-progressive brain injury, it is often accompanied by behavioral abnormalities and epilepsy.[35] The negative aspect of this disease is that it not only requires the family to have predictive ability, but also caring skills. Notably, changes in healthcare systems have caused almost all children to remain at home in the care of their families rather than in institutions such as the hospital or clinic.[2] Mothers need to acquire the skills and knowledge to provide them with rehabilitation training. However, the results show that mothers have a lack of ability, which will make caring more difficult. Mothers require more attention, support, and special assistance from the government; they hope to have more chance to learn the knowledge and skills from medical staff. It is therefore critical that intervention should be implemented to address the mothers' such issues. Elaboration of educational technology in health and developing educational workshops through group dynamics has proven to be an effective way to improve family disease knowledge.[36,37]

Caring for children with CP is characterized by long duration, high intensity, and high cost. The results show that parents faced economic, social, career and environmental challenges during the care process. A family-centered approach to the management of children with CP should be taken, because the mother's care alone may reduce both the child's rehabilitation and mother's quality of life.[38] We suggest that the healthcare system share and cut the burden of mothers by providing financial support, establishing care centers, setting up family healthcare centers, and create a convenient social environment, as well as reduce the environmental barrier, which could further help decrease the physical stress that mothers experience while taking care of their children.[39]

This study found that mothers experience increasing psychological, physical, and financial burden of caregiving over time, and that mothers learn to adapt and accommodate to the role and reap the benefits of growth, which complements the wear-and-tear model of caregiving and the adaptation model.[40] We believe that being guided by the 2 competing conceptual models will help advance our understanding of the impact of children with CP on the family. Furthermore, it is crucial to develop interventions that focus primarily on the psychological wellbeing of the mothers rather than addressing this as a secondary aim.

### 4.1. Strengths and limitations

This review focuses on mothers' challenges and experiences in caring for the children with CP, without involving fathers or other caregivers. The diagnosis of CP is a traumatic event for family; future research is required to explore the individual experiences and challenges of different family members.

Although great efforts were made to identify all relevant articles, there may be articles that were missed. Even though we attempted to include evidence of the challenges and experiences of mothers worldwide, 8 of 13 articles were from Asia, 2 of 13 articles were from Africa, and 1 article each from Europe, North America, and South America. It would be better to have a more even distribution worldwide.

## 5. Conclusions

Caring for children with CP is demanding and challenging, which may affect all the aspects of a mother's life may be affected by it. This study provides a more holistic view of mothers' challenges and experiences of children with CP. In this qualitative review, we found that the challenges of mothers of children with CP included emotional, physical, and social aspects, the mothers experienced negative and positive impacts, and all of them can be profound. We know that the primary needs of mothers are family and social support, community equality, and shared form of the healthcare system, based on the

results. Therefore, health care professionals who plan to provide services must endeavor to improve the current situation, while also finding innovative and feasible ways to meet the needs of mothers. Future research needs to explore how to improve mothers' coping skills in care and how to develop a family-centered rehabilitation program for caregivers of children with CP.

## Ethical approval

Ethical issues are not involved in this paper.

## Conflicts of interest

All contributing authors declare no conflicts of interest.

### References


1. Aisen ML, Kerkovich D, Mast J, et al. Cerebral palsy: clinical care and neurological rehabilitation. *Lancet Neurol*. 2010;10:844–852.
2. Davis E, Shelly A, Waters E, et al. The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. *Child Care Health Dev*. 2010;36:300.
3. Sellier E, Platt MJ, Andersen GL, et al. Decreasing prevalence in cerebral palsy: a multi-site European population-based study, 1980 to 2003. *Dev Med Child Neurol*. 2016;58:85–92.
4. Fernández-Alcántara M, García-Caro MP, Laynez-Rubio C, et al. Feelings of loss in parents of children with infantile cerebral palsy. *Disabil Health J*. 2015;8:93–101.
5. Dambi JM, Jelsma J, Mlambo T. Caring for a child with cerebral palsy: the experience of Zimbabwean mothers. *Afr J Disabil*. 2015;4:168.
6. Garip Y, Ozel S, Tuncer OB, Kilinc G, Seckin F, Arasil T. Fatigue in the mothers of children with cerebral palsy. *Disabil Rehabil*. 2017;39:757–762.
7. Glinac A, Matović L, Delalić A, Mešalić L. Quality of life in mothers of children with cerebral palsy. *Acta Clin Croat*. 2017;56:299–307.
8. Lee MH, Matthews AK, Park C. Determinants of health-related quality of life among mothers of children with cerebral palsy. *J Pediatric Nurs*. 2019;44:1–8.
9. Khayatzadeh Mahani M, Rostami HR, Nejad SJ. Investigation of quality of life determinants among mothers of children with pervasive developmental disorders in Iran. *Hong Kong J Occup Ther*. 2013;23:14–19.
10. Barfoot J, Meredith P, Ziviani J, Whittingham K. Parent-child interactions and children with cerebral palsy: an exploratory study, investigating emotional availability, functional ability, and parent distress. *Child Care Health Dev*. 2017;43:812–822.
11. Atkins S, Lewin S, Smith H, Engel M, Fretheim A, Volmink J. Conducting a meta-ethnography of qualitative literature: lessons learnt. *BMC Med Res Methodol*. 2008;8:21.
12. Paterson BL, Thorne SE, Canam C, Jillings C. Meta-study of qualitative health research: a practical guide to meta-analysis and meta-synthesis. Vol. 3. California, USA: Sage; 2001.
13. Sandelowski M, Docherty S, Emden C. Qualitative meta synthesis: issues and techniques. *Res Nurs Health*. 1997;20:365–371.
14. Zimmer L. Qualitative meta-synthesis: a question of dialoguing with texts. *J Adv Nurs*. 2006;53:311–318.
15. Vadivelan K, Sekar P, Sruthi SS, Gopichandran V. Burden of caregivers of children with cerebral palsy: an intersectional analysis of gender, poverty, stigma, and public policy. *BMC Public Health*. 2020;20:645.
16. Mokhtari M, Abootorabi F. Lived experiences of mothers of children with cerebral palsy in Iran: a phenomenological study. *Child Youth Serv*. 2019;40:224–244.
17. Marian S, Magesa E, Fillipine N. Experiences of mothers of children born with cerebral palsy in Oshana Region, Namibia. *Glob J Health Sci*. 2020;12:1–72.
18. Mohamed Madi S, Mandy A. The perception of disability among mothers living with a child with cerebral palsy in Saudi Arabia. *Glob Qual Nurs Res*. 2019;6:2333393619844096.
19. Kurtuncu M, Akhan LU, Yildi H, Demirbag BC. Experiences shared through the interviews from fifteen mothers of children with cerebral palsy. *Sex Disabil*. 2015;33:349–363.
20. Dalvand H, Hosseini SA, Rassafiani M, Samadi SA, Khankeh HR, Kelly G. Co-occupations: the caregiving challenges of mothers of children with cerebral palsy. *Br J Occup Ther*. 2015;78:450–459.
21. Dehghan L, Dalvandi A, Rassafiani M, Hosseini SA, Dalvand H, Baptiste S. Social participation experiences of mothers of children with cerebral palsy in an Iranian context. *Aust Occup Ther J*. 2015;62:410–419.
22. Glasscock R. A phenomenological study of the experience of being a mother of a child with cerebral palsy. *Pediatr Nurs*. 2000;26:407.

23. Huang YP, Kellett U, St. John W. Being concerned: caregiving for Taiwanese mothers of a child with cerebral palsy. *J Clin Nurs*. 2012;21:189–197.
24. Singogo C, Mweshi M, Rhoda A. Challenges experienced by mothers caring for children with cerebral palsy in Zambia. *S Afr J Physiother*. 2015;71:274.
25. Milbrath VM, Cecagno D, Soares D, Amestoy SC. Being a woman, mother to a child with cerebral palsy. *Acta Paul Enferm*. 2008;21:427–431.
26. Power R, McManus V, Fourie R. Hardship, dedication and investment: an exploration of Irish mothers commitment to communicating with their children with cerebral palsy. *J Psychiatr Ment Health Nurs*. 2009;16:531–538.
27. Huang YP, Kellett UM, St John W. Cerebral palsy: experiences of mothers after learning their child's diagnosis. *J Adv Nurs*. 2010;66:1213–1221.
28. Corbin J, Strauss A. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. California, USA: Sage Publications; 2014.
29. Umberson D, Montez JK. Social relationships and health: a flashpoint for health policy. *J Health Soc Behav*. 2010;51:54–66.
30. Wills TA, Ainette MG, Baum A, et al. Social networks and social support. In: A. Baum, T. A. Revenson, & J. Singer (Eds.), *Handbook of Health Psychology*. New York, USA: Psychology Press. 2012:465.
31. Prakash V, Patel AM, Hariohm K, Palisano RJ. Higher levels of caregiver strain, perceived by Indian mothers of children and young adults with cerebral palsy, who have limited self-mobility. *Phys Occup Ther Pediatr*. 2017;37:64–73.
32. Whittingham K, Wee D, Sanders MR, Boyd R. Sorrow, coping, and resiliency: parents of children with cerebral palsy share their experiences. *Disabil Rehabil*. 2013;35:1447–1452.
33. Stellar JE, John-Henderson N, Anderson CL, Gordon AM, McNeil GD, Keltner D. Positive affect and markers of inflammation: discrete positive emotions predict lower levels of inflammatory cytokines. *Emotion*. 2015;15:129–133.
34. Lindsay EK, Creswell JD. Mechanisms of mindfulness training: monitor and acceptance theory (MAT). *Clin Psychol Rev*. 2017;51:48–59.
35. Bax M, Goldstein M, Rosenbaum P, et al. Proposed definition and classification of cerebral palsy, April 2005. *Dev Med Child Neurol*. 2005;47:571–576.
36. Santos PDSD, Santos ZMSA, Diógenes LMMB, Caldas JMP, Rodrigues KAF, Carneiro RF. Qualification of the family caregiver to the application of educational technology in health. *Rev Bras Enferm*. 2018;71:1135–1143.
37. Nascimento MHM, Teixeira E. Educational technology to mediate care of the "kangaroo family" in the neonatal unit. *Rev Bras Enferm*. 2018;71(suppl 3):1290–1297.
38. Almasri NA, An M, Palisano RJ. Parents' perception of receiving family-centered care for their children with physical disabilities: a meta-analysis. *Phys Occup Ther Pediatr*. 2018;38:427–443.
39. Lawal H, Anyebe EE, Obiako OR, Garba SN. Socio-economic challenges of parents of children with neurological disorders: a hospital-based study in North West Nigeria. *Int J Nurs Midwifery*. 2014;6:58–66.
40. Kim Y, Given BA. Quality of life of family caregivers of cancer survivors: across the trajectory of the illness. *Cancer*. 2008;112:2556–2568.