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Caregivers' experiences of having a child with cerebral palsy. A meta-synthesis

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ABSTRACT

Aim: To synthesize qualitative research findings of caregiver experiences and challenges in caring for and raising a child with cerebral palsy.

Design: A systematic review and meta-synthesis.

Methods: Four electronic databases: CINAHL, Embase, OVID Medline, and Cochrane, were systematically searched for qualitative research papers published before December 2022. Two independent reviewers assessed eligibility and further appraised the quality of methodology using the Critical Appraisal Skills Program (CASP) tool for qualitative research. A content thematic analysis approach was used to synthesize the qualitative research findings, construct core subthemes, and synthesize themes.

Results: Sixty-seven findings were extracted from the 12 included studies. The findings were grouped into eleven sub-themes and then into five synthesized themes. The synthesized themes are 1. Need for convenient healthcare facilities, therapeutic services, and accessible public places, 2. Need for healthcare information and financial aid, 3. Psychological, and physical constraints, 4. Societal rejection and stigma, and 5. Overwhelming caring burden.

Conclusion: Caregivers face many challenges in adjusting their lifestyles to meet the needs of the child with cerebral palsy. Some adjustments reported included giving up full-time jobs and businesses to be full-time caregivers, giving up leisure activities, and confinement to one place.

Introduction

Cerebral palsy (CP) is a non-progressive neurodevelopmental disorder that affects movement, muscle tone, and motor skills due to permanent brain damage during development (Gulati & Sondhi, 2018). It can lead to abnormalities in intellectual abilities, vision, and speech (Patel, Neelakantan, Pandher, & Merrick, 2020). CP is classified into spasticity, ataxia, or dyskinesia, with spasticity being the most common form, impacting 80% of affected children and causing significant disability (Patel et al., 2020). The impairments associated with CP severely affect the quality of life, restricting their participation in age-appropriate activities, normal growth and development (Wang, Huang, & Kong, 2020).

CP has a global prevalence of three cases per 1000 live births, with higher rates among males (Vitrikas, Dalton, & Breish, 2020). Developed countries have lower CP rates than developing countries (Tunde Gbonjubola, Garba Muhammad, & Tobi Elisha, 2021). In the United States of America (USA), 2–2.5 cases per 1000 live births, while in developing countries, it's 3.5–4 cases per 1000 live births (Tunde Gbonjubola et al., 2021). South Africa's estimated CP prevalence is ten cases per 1000 live births (Donald et al., 2020). Establishing CP incidence in most developing countries is challenging due to underreporting in surveys and censuses (Marian, Magesa, & Fillipine, 2020).

CP has no cure, but its consequences can be minimized through

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continuous physiotherapy, medical treatments, and therapies (Green & Gaebler-Spira, 2019). Therapeutic management in children with CP aims to optimize their function and development within their disabilities and limitations (Wati, Purwati, & Permatasari, 2020), focusing on achieving a range of motion as a key rehabilitation goal, according to the World Health Organization (Gimigliano & Negrini, 2017; Organisation, 2021).

CP is a chronic disorder managed at home by caregivers, extending into adulthood and beyond (Vitrikas et al., 2020). Caregivers play a crucial role from diagnosis onward, necessitating recognition and involvement by clinicians in the child's healthcare (Wati et al., 2020). Parenting a child with CP demands professional preparation and education from the healthcare team (Milbrath, Crecencia Heckler de Siqueira, da GraÃsa Corso da Motta, & Coelho Amestoy, 2012). The physical deformity varies in severity, impacting parents and family significantly (Nketsia et al., 2019). Severe CP often requires multiple surgeries and extended hospitalization further emotionally and financially straining caregivers (Wati et al., 2020).

Children with CP rely on caregivers for their daily needs, leading to stress as they seek interventions and support to improve their abilities (Wati et al., 2020). Caregivers must provide complete primary caregiving, including feeding, locomotion, bathing, managing seizures, and carrying the child to medical reviews (Dantas, Pontes, de Assis, & Collet, 2012). Caring for children with CP poses significant challenges for caregivers, causing struggle, stress, and tension (Kurtuncu, Akhan, Yildiz, & Demirbag, 2015). Stressors, such as shattered plans, abandoned income-generating activities, and decreased leisure time, may deteriorate the caregiver's health (Chiluba & Moyo, 2017). Caregivers' personal, emotional, social, physical, and financial needs are usually neglected and compromised (Wang et al., 2020). CP creates uncertainty within families as they support each other in raising children living with CP (Marian et al., 2020).

Experience is subjective, shaped by individual perceptions and intentional reactions to a phenomenon (Chamond, 2017). A comprehensive review of related literature helps enhance our understanding of future caregivers' experiences with having a child living with CP (Cook, Tovin, & Kenyon, 2022). Clinicians must fully understand caregivers' needs, concerns, and emotions, offering timely support to prevent lasting adverse effects (Cook et al., 2022).

Previous reviews explored experiences of having and caring for children with CP (Elangkovan & Shorey, 2020; Smith & Blamires, 2022). Smith and colleagues focused on mothers' experiences, while Elangkovan and colleagues examined experiences and needs of parents caring for children with CP. Both reviews included children up to adolescence with different CP degrees. This review aims to understand caregivers' lived experiences and challenges while raising children with CP, ranging from birth to 12 years old, and with varying severities of CP. Caregivers include parents, grandmothers, aunts, and even siblings of the child.

This review explored the caregivers' subjective experience and challenges in caring for and raising a child with CP. This review will help clinicians understand caregivers' experiences and challenges and offer services that provide emotional support, counseling, and accurate CP-related information to meet the caregivers' needs. The review findings can be used for policy formation and further guides clinical practice.

Methods

Design

This qualitative meta-synthesis was conducted with the PICo question, 'What are the caregiver's experiences and challenges of caring for a child with CP'? The topic was registered in the PROSPERO international database (protocol number: CRD42023398493). The review was guided and directed by Purssell and McCrae (2020) steps for a systematic literature review. The review followed (Page et al., 2021) preferred reporting items for systematic review and meta-analysis (PRISMA) checklist guideline. The Critical Appraisal Skills Programme (CASP) for qualitative studies was used to assess the methodological quality of the studies (Long, French, & Brooks, 2020). A content thematic analysis approach was used to code, group, and synthesize qualitative research findings in the review (Castleberry & Nolen, 2018).

Inclusion and exclusion criteria

Only empirical peer reviewed published literature in English on the phenomena in question, published before December 2022 were in included in the review.

Search strategy

The literature search was conducted in December 2022 for research studies published before the date. Four electronic databases were searched systematically for qualitative literature with the assistance of a professional librarian. The databases were CINAHL, Embase, OVID Medline, and Cochrane. The search terms were selected from the MESH term list ("Caregivers", "Parents", "Fathers", "Mothers", "family ", 'experience', 'caregiver burden', 'challenges', 'perception', 'cerebral palsy', 'child', 'disabled children', 'mobility limitation', 'interview', personal narrative", "qualitative research") and were used in the search in various combination with Boolean operators "AND" and "OR".

Ethical consideration

Ethical approval was not required since this study is a meta-synthesis.

Search results

The initial literature search produced 641 research papers from the electronic databases and Google Scholar. Two independent reviewers (OO & OO) assessed the articles' eligibility based on the inclusion and exclusion criteria. Subsequently, we screened studies by title, abstract, and full text based on the inclusion criteria. Duplicated articles ($n = 29$) were removed. After removing duplicates, irrelevant articles ($n = 572$) were removed based on title and abstract. Full texts ($n = 40$) were downloaded and screened. Articles that did not meet criteria ($n = 28$) were removed. Finally, 12 articles published between 2013 and 2022 were included in the review, and their reference lists were searched to identify new articles meeting the criteria, but none were identified. The reviewers then discussed the findings and reached an agreement. There were no differing judgments between the two reviewers that needed the opinion of the third reviewer. Fig. 1 is the PRISMA flow diagram displaying the screening process.

Critical appraisal

Critical appraisal is a vital stage in synthesizing systematic reviews of evidence (Long et al., 2020). The quality of the 12 articles was evaluated using the CASP checklist (Long et al., 2020). Yes (Y), Unclear (U), and No (N) were used to appraise the studies. In each article, >2/3 questions were answered yes, indicating a low risk of bias (Mays & Pope, 2020). Overall, the studies were of good quality (Table 1).

Data extraction and synthesis

The quality of data was extracted and assessed using a standardized collection form. The form included appraisal information such as author, year, country, sample size, children's age and degree of CP, methodology, data collection tool, analysis, and findings related to our aim. Table 2 is the summary results of extracted data. During the data extraction, both reviewers (OO & OO) worked together, reading the studies to find key concepts. The articles were assigned codes using

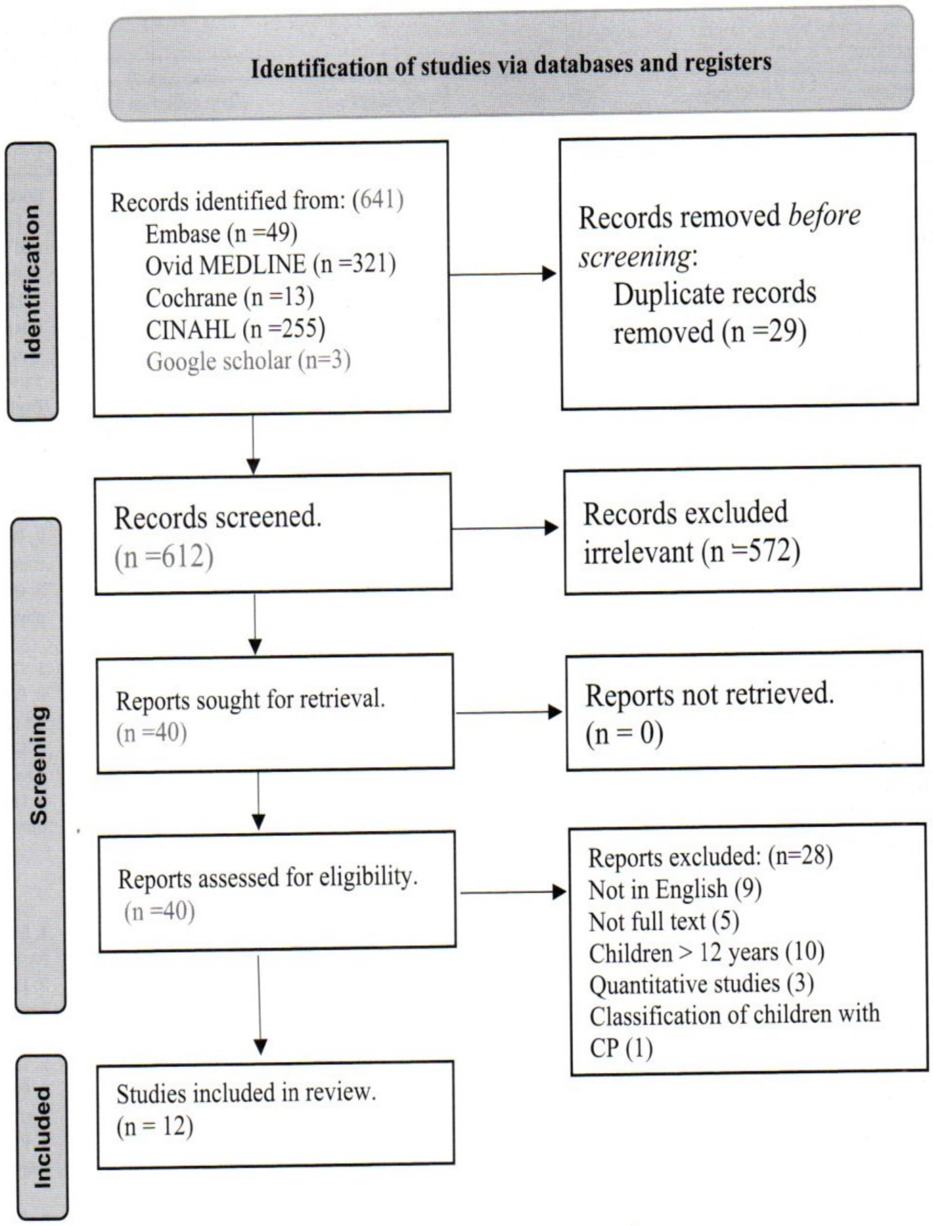

Fig. 1. Flow chart.

Table 1
Methodological quality appraisal of included studies ($n = 12$).

Article codes	Author	Question 1	Question 2	Question 3	Question 4	Question 5	Question 6	Question 7	Question 8	Question 9	Question 10
(A1)	Alaee et al., (2015)	Y	Y	Y	Y	Y	Y	NS	Y	Y	Y
(A2)	Ballantyne et al., (2019)	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
(A3)	Dalvand et al., (2015)	Y	Y	Y	U	Y	U	Y	Y	Y	Y
(A4)	Dezoti et al., (2015)	Y	Y	Y	Y	U	U	U	Y	Y	Y
(A5)	Kruijsen-Terpstra, et al., (2016)	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
(A6)	Madzhie et al., (2022)	Y	Y	Y	Y	Y	U	U	Y	Y	Y
(A7)	Mokhtari & Abootorabi., (2019)	Y	Y	Y	Y	Y	N	U	Y	Y	Y
(A8)	Ni et al., (2022)	Y	Y	Y	Y	Y	Y	Y	Y	U	Y
(A9)	Nimbalkar et al., (2014)	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
(A10)	Taylor et al., (2022)	Y	Y	Y	U	Y	N	Y	Y	Y	Y
(A11)	Vadivelan et al., (2020)	Y	Y	y	Y	Y	Y	Y	Y	U	Y
(A12)	Whittingham et al., (2013)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

CASP checklist:1. Was there a clear statement of the aims of the research? 2. Is a qualitative methodology appropriate? 3. Was the research design appropriate to address the aims of the research? 4. Was the recruitment strategy appropriate to the aims of the research? 5. Was the data collected in a way that addressed the research issue? 6. Has the relationship between the researcher and participants been adequately considered? 7. Have ethical issues been taken into consideration? 8. Was the data analysis sufficiently rigorous? 9. Is there a clear statement of findings? 10. How valuable is the research?

Appraisal results: Y, Yes: U, Unclear, N, No:

Table 2
Summary table of data extraction.

Author (year) country and article codes	Participants	Participants' educational and employment status	Children age and degree of CP	Methodology	Data collection and analysis	Key Findings
Alaee et al. (2015) **Iran** **(A1)**	$N = 17$ Mothers (n = 12) Fathers (($n = 5$).	**Education level** <High school ($n = 3$) High school (n = 7) Tertiary (n = 7) **Employment** Unemployed ($n = 10$) Part-time (n = 2) Full-time ($n = 5$) were fathers	<12 years **Degree of CP** Mild ($n = 5$) Mod (n = 4) Severe ($n = 7$)	Qualitative phenomenological studies	In-depth structured interviews-Content analysis	**Social challenges** 1. Inadequate facilities and services 2. Unsupportive interactions 3. Limitation of parents' social relations 4. Social seclusion of the child and parent **Psych emotional challenges** 1. Intrapersonal conflicts 2. Being worried 3. Sense of loneliness
Ballantyne et al. (2019) **Canada** **(A2)**	$N = 18$ Mothers ($n = 13$) fathers (n = 5)	**Education level** High school ($n = 4$) Tertiary ($n = 14$) **Employment** Not employed (n = 7) Employed ($n = 11$)	6 months to 11 years **Degree of CP** **Not reported**	Qualitative descriptive design	Semi-structured interviews/Thematic analysis	1. Wanting to know what to expect 2. Feeling supported in their transition 3. Getting there emotionally and physically
Dalvand et al. (2015) **Iran** **(A3)**	$N = 16$ Mothers (n = 16)	**Education level** Illiterate (n = 12) High school ($n = 3$) Tertiary (n = 12) **Employment** Not employed (n = 12) Part-time ($n = 2$) Full time(n = 2)	Birth - 12 years **Degree of CP** GMFCS 1(n = 1) 11(n = 3) 111(n = 4) IV(n = 3) V(n = 5)	Qualitative content analysis designs	Semi-structured interviews/Thematic analysis	1. Coping with self-care problems, 2. Efforts to gain treatment follow-up, 3. Coping with the challenges of educational care 4. Limited parental personal leisure time.
Dezoti et al. (2015) **Brazil** **(A4)**	$N = 19$ Caregivers ($n = 19$)	**Not specified**	Birth –12 years **Degree of CP** **Not reported.**	Descriptive qualitative designs	Semi-structures interviews/Thematic analysis	1. Experience of the family in caring for a child with cerebral palsy 2. Frail social support concerning family bonds
Kruijsen-Terpstra, et al. (2016) **Netherlands** **(A5)**	$N = 21$ Caregivers ($n = 21$)	**Not specified**	2-4 years **Degree of CP** **Not reported.**	A qualitative design	Semi-structured interviews/Thematic analysis	1. Information 2. Communication 3. Partnership between parents and therapists 4. Process of parental empowerment
Madzhie et al. (2022) **South Africa** **(A6)**	N = 12 Mothers (n = 12)	**Not specified**	3–5 years **Degree of CP** **Not reported.**	A qualitative phenomenological design	Semi-structured interviews/Thematic analysis	**Social challenges** 1. Lack of facilities and services 2. Financial problems 3. Inability of parents to have a social life 4. Unsupportive environment 5. Social conflicts **Psychological challenges** 1. Being worried 2. Stress 3. Loneliness and isolation
Mokhtari and Abootorabi (2019) **Iran** **(A7)**	$N = 8$ Mothers (n = 8)	**Education level** None had tertiary education. **Employment** Unemployed ($n = 8$)	2–12 years **Degree of CP** Mod (n = 4) Severe (n = 4)	Hermeneutic phenomenological designs	Semi-structured interviews/Thematic Analysis	1. Life world existential: lived body. 2. Life world existential: lived relationships. 3. Life world existential: lived time. 4. Life world existential: lived space.
Ni et al. (2022) **China** **(A8)**	N = 18 Mothers (n = 13) Fathers (n = 5)	**Education level** High school (n = 3) Tertiary ($n = 15$) **Employment** Unemployed ($n = 6$) Self-employed(n = 4) Employed (n = 8)	1.5–6 years **Degree of CP** Quadriplegia (n = 5) Spastic (n = 3) Diplegia ($n = 6$) Hemiplegia (n = 4)	Descriptive qualitative designs	Semi-structured interviews/Thematic analysis	1. Overall responsibility, 2. Being alone 3. Exhausted by caring. 4. Being a prisoner for life 5. Uncertainty regarding the future.
Nimbalkar et al. (2014) **India** **(A9)**	N = 13 Mothers (n = 11) Grandmother (n = 1) Father (n = 1)	**Education level** **Not specified** **Employment** Unemployed (n = 11) Employed (n = 2)	<12 years **Degree of CP** **Not reported.**	Qualitative research designs	Semi-structured interviews/Thematic assisted by a software	1. Social problems experienced by the parents. 2. Problems experienced in caring for the child 3. Financial problems experienced by the parents. 4. Health problems experienced by

(*continued on next page*)

Table 2 (*continued*)

Author (year) country and article codes	Participants	Participants' educational and employment status	Children age and degree of CP	Methodology	Data collection and analysis	Key Findings
						the parents 5. Child's future 6. Perception of the Society towards the Child 7. Response of caregivers (caregiver coping mechanisms) 8. Support obtained by the caregivers from others **9.** Support and health care services 10. Differences between participants attending rural clinic and participants attending an urban clinic
Taylor et al. (2022) **Australia** **(A10)**	N = 11 Mothers (n = 11)	**Education level** Not specified **Employment** Unemployed (n = 6) Employed (n = 5)	1–12 years **Degree of CP** GMFCS 1–11 (n = 2) II-III (n = 2) IV-V(n = 2) IV(n = 3) Ataxic(n = 2)	Qualitative descriptive designs	Semi-structures telephone interviews/ Thematic analysis	1. Child-centered world, 2. Making decisions, 3. Knowing their child, 4. Seeking and receiving support
Vadivelan et al. (2020) **India** **(A11)**	N = 10 Mothers (n = 10).	**Not specified**	2–10 years **Degree of CP** **Not reported.**	Qualitative exploration designs.	Semi-structured interviews/Thematic analysis.	1. Lack of knowledge 2. Lack of spousal support 3. Compromised care for other children 4. Lack of support by extended family 5. Social discrimination against the child and the family 6. No physical support from community members 7. Lack of accessible public transport 8. Lack of flexible timings in the workplace 9. Insufficient disability support by the government 10. Lack of buffers for health expenditure 11. Lack of support groups and information support
Whittingham et al. (2013) **Australia** **(A12)**	N = 8 Mothers (n = 6) Fathers (n = 2)	**Education level** Tertiary (n = 8) **Employment** Not specified	2–12 years **Degree of CP** GMFCS 1(n = 3) 11(n = 2) IV(n = 1) V(n = 2)	Descriptive qualitative designs	Semi-structured interviews/Thematic analysis	1. Grief 2. Worries for the future. 3. Diagnosis both a challenge and a relief 4. Hospitalization and treatment a challenge 5. Challenges coping with others-social rejection. 6. Be honest and give a plan of action

letter A and a number to undertake the coding and grouping of the findings as represented in all the tables. The coding and grouping of findings were guided by Smith's Interpretative phenomenological analysis (Smith, 2008). Codes were assigned into first order constructs that will identify the meaning and content within each study about caregivers' experiences and challenges. The first-order constructs were findings from original studies based on participants lived experiences. The second-order constructs were the authors' original interpretations of participants' accounts. It is essential to preserve the original text's meaning during data extraction (Yadav, 2022). Using the original author's language, the researcher maintained the initial studies' meaning. After completing the extraction process, the researchers read and reread the first-order constructs and then developed the subthemes based on similarity in meaning to keep up with Thomas and colleagues' specifications (Thomas & Harden, 2008). These subthemes were synthesized to produce a complete set of narrative-synthesized themes. The synthesized themes were developed based on researchers' interpretations of the participants' experiences presented in the second-order constructs. In this stage, both reviewers engaged in intense discussions to ensure the synthesized themes were valid.

Results

Characteristics of studies included

The 12 studies were conducted in various developed and developing countries, including Asia ($n = 6$), Europe ($n = 3$), Oceania ($n = 2$), and Africa ($n = 1$) as represented in Table 2. The participants were 171 caregivers. The children had varied degrees of CP classified using Gross Motor Function Classification System (GMFCS). Half of the research studies did not report the degree of CP. Most participants were mothers and were unemployed. Some had part-time jobs, and fathers had permanent jobs. Participants' educational background was not reported, but among those studies that reported, their educational background varied from no education at all, some had high school education, and some had tertiary qualifications.

Most studies used qualitative descriptive designs ($n = 5$), hermeneutic phenomenology designs ($n = 3$), qualitative research designs ($n = 2$), qualitative explorative designs ($n = 1$), and qualitative content analysis designs ($n = 1$) as represented in Table 2. Data were collected using in-depth semi-structured interviews until data saturation was reached. Interviews mainly were face-to-face, with only one study that used telephonic interviews. Data were analyzed using thematic analysis and one assisted by software.

Synthesized findings

Sixty-seven findings were extracted from the 12 included studies. The findings were grouped into eleven sub-themes and five synthesized themes illustrated in Table 3. The synthesized themes are: 1. Need for convenient healthcare facilities, therapeutic services, and accessible public places, 2. Need for healthcare information and financial aid, 3. Psychological and physical constraints, 4. Societal rejection and stigma, and 5. Overwhelming caring burden.

Theme 1: need for convenient healthcare facilities, therapeutic services, and accessible public places

Holistic care management of children with CP requires convenient access to adequate, funded healthcare facilities and accessible public places. Care for children with CP involves therapeutic services under specialized therapists and medication, yet insufficient facilities offer such services. There are also limited specialized therapists to provide professional therapeutic care to the children, which exposes caregivers to long waiting hours. Caregivers are subjected to the use of more expensive private facilities. In rural areas, it is tough to access healthcare facilities, public transport, and other public places because of wheelchair use by the children, which forces caregivers to use private vehicles.

Sub-theme 1: shortage of facilities and limited access to medical services

The caregivers are dissatisfied with government facilities. Many countries have a shortage of rehabilitation, respite services and daycare centers for children with CP. Caregivers experienced long waiting hours and limited skilled therapists. Most children with CP are confined in wheelchairs, making it difficult to access public transport when going for doctors' appointments and poses a major challenge for caregivers. Wheelchairs are a barrier in some private and public places, such as stairs, uneven surfaces, or entrances without access ramps. There is a lack of proper toilets for children with disabilities in some country's public places, recreational and medical centers, which makes it very hard for caregivers to move around with the children, threatening and confining the caregivers' lived space.

> *"With the pain I have in my joints, I can't even sit the child on the usual toilets, it is too big so that my child completely falls in it"*(Alaee, Shahboulaghi, Khankeh, & Mohammad Khan Kermanshahi, 2015).

> *"Travelling on public bus with my child is a problem. The buses are overcrowded. If I leave even one bus to take the next one, I will miss the physiotherapy appointment"*(Vadivelan, Sekar, Sruthi, & Gopichandran, 2020).

Sub-theme 2: inadequate support from the government

Management of CP requires continuous physical, speech, and occupational therapies, which are sometimes inadequate. Caregivers experience costly travel expenses for therapy services at the health facility. India, through the social welfare department, provides disability grants although insufficient.

> *"The disability card provides 1500 rupees every month, but it's not enough for even the health care expenses"* (Vadivelan et al., 2020).

Table 3
Coding and grouping table.

Article codes	Research findings	Sub-themes	Synthesized themes
Alaee et al. (2015) (A1) Ballantyne et al. (2019) (A2) Dalvand et al. (2015) (A3) Dezoti et al. (2015) (A4) Kruijsen-Terpstra, et al. (2016) (A5) Madzhie et al. (2022) (A6) Mokhtari and Abootorabi (2019) (A7) Ni et al. (2022) (A8) Nimbalkar et al. (2014) (A9) Taylor et al. (2022) (A10) Vadivelan et al. (2020) (A11) Whittingham et al. (2013) (A12)	Inadequate facilities and services (A1) Lack of facilities and services (A6) Lifeworld existential: lived space (A7) Support and health care services (A9) Differences between participants attending the rural clinic and Participants attending the urban clinic (A9) Lack of accessible public transport (A11)	Shortage of facilities and limited access to medical services.	Need for convenient healthcare facilities, therapeutic services, and accessible public places
	Insufficient disability support by the government (A11) Lack of buffers for health expenditures (A11)	Inadequate support from the government	
	Wanting to know what to expect (A2) Information (A5) Communication (A5) The partnership between parents and therapists (A5) Process of parental empowerment (A5) Hospitalization and treatment are a challenge (A12). Be honest and give a plan of action (A12)	Needs for professional advice and information exchange	Need of healthcare information and financial aid
	Financial problem (A6) Financial problems experienced by the parents (A9)	Financial needs for the care of the child with CP	
	Exhausted by caring (A8) Health problems experienced by the parents (A9)	Physical pains	Psychological and physical constraints
	Being worried (A1) (A6) Lifeworld existential: lived time (A7) Uncertainty regarding the future (A8) Child's future (A9) Worries for the future (A12) Diagnosis is both a challenge and a relief (A12)	Uncertainty	
	Intrapersonal conflicts (A1) Sense of loneliness (A1) Getting there	loneliness and self-trapped	

(*continued on next page*)

Table 3 (*continued*)

Article codes	Research findings	Sub-themes	Synthesized themes
	emotionally and physically (A2)		
	Experience of the family in caring for a child with cerebral palsy (A4)		
	Loneliness and isolation (A6)		
	Stress (A6)		
	Lifeworld existential: lived body (A7)		
	Being a prisoner for life (A8)		
	Being alone (A8)		
	Grief (A12)		
	Social seclusion of the child and parent (A1)	Discrimination and lack of participation in social events	
	Live world existential: lived relationships (A7)		Societal rejection and stigma
	Social problems experienced by the parents (A9)		
	Perception of society towards the child (A9)		
	Social discrimination against the child and the family (A11)		
	No physical support from community members (A11)		
	Unsupportive interactions (A1)		
	Limitation of parents' social relations (A1)	Unmet social support needs	
	Feeling supported in their transition (A2)		
	Frail social support concerning family bonds (A4)		
	The inability of parents to have a social life (A6)		
	Unsupportive environments (A6)		
	Social Conflicts (A6)		
	Support obtained by the caregivers from others (A9)		
	Seeking and receiving support (A10)		
	Lack of flexible timings in the workplace (A11)		
	Lack of social support groups and information support (A11)		
	Lack of spousal support (A11)		
	Lack of support from extended family (A11)		
	Challenges coping with others-social rejection (A12)		

Table 3 (*continued*)

Article codes	Research findings	Sub-themes	Synthesized themes
	Coping with self-care problems, (A3)	CP-specific caring challenges and adjustments	Overwhelming caring burden
	Efforts to gain treatment follow-up, (A3)		
	Coping with challenges of educational care, (A3)		
	Limited parental personal leisure time (A3)		
	Problems experienced in caring for the child (A9)		
	Child-centered world, (A10)		
	Making decisions (A10)		
	Knowing their child (A10		
	Overall responsibility (A8)	Stress from siblings	
	Response of caregivers (caregiver coping mechanism) (A9)		
	Compromised care for other children (A11)		

Theme 2: need for healthcare information and financial aid

The burden of caring combined with limited CP-related care knowledge leads to continuous psychological, physical, and financial constraints for caregivers. Caring for children with CP is overwhelming and emotional, resulting in caregivers' negative emotional feelings and physical pain. Caring for a child with CP requires huge finances, professional preparation, and education from healthcare professionals.

Sub-theme 1: needs for professional advises and information exchange

This theme explains that caregivers mostly manage the disabled children at their home hence needs professional advice and clear CP-related information from clinicians. The diagnosis on its own comes as a shock. Caregivers needs clear and honest CP-related information, pathology, care plan, and available treatment options. Clinicians were sometimes economical with information or gave too much information in a short time which caused frustration to the carers. Some caregivers had to search for information on the internet. Care partnership between caregivers and healthcare workers is necessary for caregiver empowerment purposes.

> *"Yeah, that [i.e., information on the way children with CP can function in society] is what I really missed! You enter a world that you know nothing whatsoever about. You leave the hospital with the child, and they tell you 'Well, keep track of its development'*(Kruijsen-Terpstra et al., 2016*).*

> *"A really individual and tailored approach, according to what the family's needs are... as well as what our emotional state is..."*(Whittingham, Wee, Sanders, & Boyd, 2013*).*

Sub-theme 2: financial needs for the care of the child

Money is needed in the upbringing and caring of a child with CP to cater for expensive medications, therapies, and transportation of the child to care facilities. Disabled children are special needs children. Most children use diapers daily, another financial burden for the caregivers. Caregivers had to make life compromises to match the child's financial needs and neglected other children due to financial constraints.

> *"The medication for children with CP are expensive although I try to buy some of the medication but some are so expensive that I am not able to buy them for my child, sometimes I end up using the money that I should use to support my first child with, so that I can buy some medication"*(Madzhie, Mphephu, Baloyi, & Chueng, 2022).

> *"I have a lahri (business on a handcart), so when I have to get the child for physiotherapy, I have to face a loss. Customers go back and business suffers"*(Nimbalkar, Raithatha, Shah, & Panchal, 2014).

Theme 3: psychological and physical constraints

Caring for children with CP is overwhelming and emotional resulting in caregivers' negative emotional feelings and physical pains. The caregiving role is devastating and stressful, coupled with chronic sorrow. Caregivers have generalized body pains due to their everyday caring roles. The caregiving role is devastating and stressful coupled with chronic sorrow. They live in uncertainty about the future of their child. Caregivers of children with CP have mixed emotions ranging from neutral, negative, and positive from taking care of the disabled child.

Sub-theme 1: physical pains

The category explains caregivers' generalized body pains resulting from the caring burden. Caregivers had a decline in their physical health. Some caregivers experienced pains in their shoulder, wrists and backaches resulting from carrying and lifting the children and walking long distances for child's medical reviews.

> *"Every time I go to the hospital with my child in my arms to do rehabilitation treatment, I take care of the child by myself, and I feel like I cannot hold them anymore; when I take care of the child for a long time, my shoulders, waist, and back are very painful"*(Ni, Ding, Wu, Zhang, & Liu, 2022).

> *"There is no suitable wheelchair and transportation, I have to carry my son everywhere. Now I feel pain with my wrist"* (Ni et al., 2022).

Subtheme 2: uncertainty

Caregiving role is devastating and stressful coupled with chronic sorrow, and uncertainty about the future of the child. Caregivers are worried and concerned about the child's health, education and how to provide and sustain the child in the future. Caregivers live in worry of who would take care of their children in their absence.

> *"When we died tomorrow, who will take care of this child, her brother or sister can't. if she could walk some steps and almost do her daily living activities, we would have less worry"*(Alaee et al., 2015)

> *"My child's cerebral palsy symptoms are very serious, and he recovered slowly. I see no hope. What should I do in my future life?"* (Ni et al., 2022).

Subtheme 3: loneliness and self-trapped

Caregivers experienced sense of loneliness, feeling isolated, self-blame, sadness, and helplessness, combined with lost opportunities due to caregiving roles and lack of support. Caregivers felt isolated with inability to attend social events or visit other people. Some caregivers are finally accepting, leaning upon spiritual beliefs, and finding ways of handling the child's disability and regaining their self-worth.

> *"I usually do not attend social events, even if I attend I will make sure I stay far from other people so that they do not see my child and notice the child's condition"* (Madzhie et al., 2022)

> *"When asked about her opinion about cerebral palsy, she blamed herself for the diagnosis and showed significant distress when speaking about the future"*(Dezoti, Cosvoski Alexandre, de Souza Freire, Alves das Mercês, & de Azevedo Mazza, 2015).

> *"I used to work in the company, but now I quit my job at home to take care of my daughter, now I have given up on my hobbies. I can't go everywhere. I've been with him, I do not have time and energy to do anything else"* (Ni et al., 2022)

Theme 4: societal rejection and stigma

Unawareness of the disorder subjected caregivers and children with CP to family and societal rejection, blame, and stigma because of the child's physical disability, depriving them of outdoor activities and recreational spaces. Lack of understanding and acceptance of the disorder by family members and society makes the caregivers and child prone to societal rejection. Caregivers received varying levels of support from family and healthcare workers. The caregivers and children have limited involvement in social activities and gatherings because of the child's physical limitations.

Sub-theme 1: discrimination and lack of participation in social events

Caregivers experienced discrimination and were deprived of social activities due to the children's physical disability. Caregivers cannot participate in social gatherings such as marriages, and celebrations as they are full-time caring for the child. They are also faced with environmental obstacles because they are confined to wheelchairs which makes it hard for them to move around with the children. Others look down upon caregivers and their children with CP. Caregivers are abandoned, and mostly live in isolation leading to limited interaction with others.

> *"I always sit somewhere far from the view of others. I feel my mother-in-law and sister-in-law don't want me to be in their group because of my child who is not normal"*(Alaee et al., 2015).

> *"I feel very low esteem by the way people around us look at us. I face a lot of problems while traveling by bus and interact with people"*(Vadivelan et al., 2020).

Sub-theme 2: unmet social support needs

The category describes the varied levels of support that caregivers received. Society does not clearly understand CP and unaware of the caregiver's challenges and needs. Caregivers experienced unnecessary and irrelevant questioning and explaining, which put a lot of strain on them. Most caregivers lack family and societal support, resulting in broken families. Some caregivers got support from family, peers, and healthcare professionals even though sometimes the support is weak.

> *"When you have other families, who have already gone through what you're going through, just listening to their stories is enough to guide you into possibly the right direction"* (Ballantyne et al., 2019).

> *"So no, no family support. As I said, my friends are all at different stages, and their kids didn't have the issue, I didn't get that much support"* (Taylor, Kong, Foster, Badawi, & Novak, 2022).

Theme 5: overwhelming caring burden

Caregivers are faced with all-day intense caring roles, and responsibilities due to the child's physical limitations and muscle spasticity. The children have self-care limitations and depend on the caregivers. Caregivers are overwhelmed because they care for the entire family members. Caregivers neglect their physical, emotional, and social well-being and that of other family members.

Sub-theme 1: CP specific caring challenges and adjustment

Caregivers experience higher caring demands related to the development of children with CP. Most of the children with CP depend entirely on their caregivers. Caregivers must assist with the child's self-care such as dressing, undressing, bathing, feeding, toiletry services, carrying and lifting children, forcing caregivers to have limited personal leisure time. Caregivers experienced feeding difficulties because of the children's abnormal muscle tone, making mealtimes stressful. Caregivers must continue with rehabilitation exercises even at home, further keeping them busy.

> *"We've tried all the feeding methods. We've tried disguising, we've tried bribing. We've had picnics. We've had psychologists in to try and she just will not eat other types of food. We have tried everything under the sun. Also, a lot of it has just been self-taught, just for my husband and I-just learning ourselves"(*Taylor et al., 2022*).*

> *"I go to school with him, and during breaks, I take him to the bathroom, I feed him, and move him about, and assist him to sit in his chair. I put him in his pram because there are few caregivers in schools; if one day I cannot go, then he cannot go, either. Because they are not well cared for and the positioning is incorrect, if I was sure that they would look after him the way I do, then I would not have to go, and waste so much time"(*Dalvand et al., 2015*).*

Sub-theme 2: stress from siblings

Caring for children with CP increases caregivers' daily chores and stress. Caregivers care for all family members, such as siblings of the disabled child. The overload of responsibilities resulted in caregivers neglecting other family members. Caregivers experienced persistent complaints from siblings of disabled children.

> *"She (mother) works at hospital where she is taking her child for treatment and pays money for the same. Mummy did not do anything for my betterment"(*Nimbalkar et al., 2014*).*

Discussion

The review focused on caregivers of children under 12 with CP, exploring their experiences and challenges. It identified five themes related to emotional, physical, financial constraints, and uncertainty about the child's future. Financial constraints were a recurring issue, supported by a previous review (Smith & Blamires, 2022). Caregivers' adaptation was emphasized throughout the child's development, requiring love, empathy, and patience (Elangkovan & Shorey, 2020). Integrating the new reality of caring for a child with a disability involved physical, emotional, and financial adaptation (Freitag, Milbrath, & Motta, 2020).

CP management requires lifelong multidisciplinary care, physiotherapy, comorbidity management, and therapies (Donald et al., 2015; Richards & Malouin, 2013). However, caregivers experienced inadequate facilities, therapeutic services, and social welfare support. Respite care services, daycare centers, wheelchair accessibility, and appropriate toilets for disabled children are lacking. Access to medical facilities is restricted, with shortage of skilled therapists, and long waiting lists in public centers. Some caregivers resort to costly private rehabilitation centers, further straining their finances (Bergeron, Vincent, & Boucher, 2012). Alaee, Mohammadi-Shahboulaghi, Khankeh, and Mohammad Khan Kermanshahi (2013) also confirmed insufficient pharmacotherapy, rehabilitation facilities, and CP-related information for caregivers. Governmental agencies' performance is unsatisfactory, particularly affecting rural caregivers who must travel long distances for limited physiotherapy time.

Caregivers face financial challenges related to high therapy, and travel expenses. Government support is crucial. Pretorius and Steadman (2018) assert that disability funds often fail to cover children's basic needs. In a Bangladesh study, Nuri, Aldersey, and Ghahari (2019) highlighted the unmet financial and rehabilitation needs of families with disabled children. Policymakers must prioritize supporting affected families and subsidizing CP-related healthcare costs. Raising children with CP restricts caregivers from working, adversely affecting their quality of life (Smith & Blamires, 2022). Many caregivers abandon their businesses and jobs to become full-time carers, leading to excessive financial burden for their families. Medications, are often unavailable in hospitals, incur high costs, exceeding most families' incomes. Caregivers make sacrifices to meet the financial needs of the children's care. McNally and Mannan (2013) indicated that the treating and caring for a child with CP can be financially burdensome.

Parents of children with CP face challenges due to physical deformity, and hospitalization is emotionally draining for the entire family. Caregivers rely on healthcare providers for CP-related information, seeking guidance on managing the child at home. Milbrath et al. (2012) emphasized the need for parental empowerment through education, and emotional support from the healthcare team. The ethical principle of autonomy acknowledges the right to information sharing about available treatment options, enabling well-informed decision making (Scher & Kozlowska, 2018). Findings showed mixed caregiver feelings about the quality of information shared by healthcare providers, with some satisfied and others not.

Clinicians withhold vital information about CP, distressing caregivers who have limited knowledge and need clear information (Marian et al., 2020). Limited information leads to fear and uncertainty about the child's future, leaving caregivers with unanswered questions. Seeking answers on their own adds stress, causing hopelessness and helplessness. Kruijsen-Terpstra et al. (2014) reported that caregivers seek CP-specific information to prepare for the child's future. Continuous and transparent communication between clinicians and caregivers is essential for coping and adjusting to their new caregiving role (Aydin & Nur, 2012).

Clear communication is crucial through a partnership between caregivers, the healthcare team, and the caregiver's involvement in their children's therapy. This partnership enhances parental decision-making and goal setting for the child's intervention. Family-centered-care approach, promoting collaboration between service providers and caregivers, is widely acknowledged in the literature (Arango, 2011). However achieving this in practice faces challenges (Abraham & Moretz, 2012). A true partnership in care and access to information empower caregivers to gain control and enhance their caring role.

Some children with CP have self-care limitations, leading to complete primary caregiving by caregivers. This dependence on caregivers can cause intrapersonal conflicts and a loss of passion for life as they are constantly with the child. Overdependence induces stress, chronic sorrow, and isolation from community activities. Consequently, caregivers experience a poor quality of life and a desire to escape their caring role. Caregivers of disabled children commonly reported poor sleep quality, body aches, and backaches (Yilmaz, Erkin, & İZKİ, A. A., 2013). They also experience guilt, sorrow, anger, hopelessness, and self-blame (Huang, Kellett, & St John, 2012). Additionally, caregivers have fear and anxiety about future care for their children when they become weak and old, as caring roles consume energy and time, reducing personal freedom (Kim & Kim, 2019).

Feeding difficulties and mealtimes cause stress for caregivers. CP-related motor dysfunction affects chewing and swallowing muscles, leading to dysphagia (Taylor, Zhang, Foster, Novak, & Badawi, 2018). Caregivers fear that their children might aspirate and choke while feeding. A skilled multi-professional team is vital to improve children's nutritional intake and growth. However, seeking feeding specialists can be challenging (Adams et al., 2012), leaving caregivers to make daily decisions independently. This can lead to caregiver stress (Arvedson, 2013). Managing feeding difficulties requires careful planning and collaboration between caregivers and clinicians (Andrew, Parr, & Sullivan, 2012).

Caregivers face challenging emotional experiences in coping with and accepting their child's disability, alongside the difficulties of medical interventions. However, support from family, healthcare practitioners, friends, and positive stories from peers bring hope and cushions these emotions. Even minor improvements in children with CP are deeply appreciated by caregiver (Huang et al., 2012). Some caregivers find satisfaction in their care for children with CP and consider themselves special caregivers.

Caregivers of disabled children face societal discrimination, stigma, and exclusion from social events. They are rejected, humiliated, and judged by others, including relatives. Disabled children often lack acceptance from healthy peers, leading caregivers to feel insecure and hide their children to avoid unwelcome interactions. Families of disabled children face more negative social responses compared to families with normal children (Huang et al., 2012). As a result, parents of children with CP may feel abandoned, discriminated against, and limit their interactions with others, seeking solace with parents facing similar situations or isolating themselves altogether.

Stigma discredits and devalues individuals within a social context (Yang et al., 2007), leading to persistent suffering and emotional trauma (Kakuma et al., 2010). Lack of understanding about CP affects family and social relationships, subjecting caregivers to ridicule and hurtful comments. Society's ignorance about the unique needs of caregivers and children with CP results in discrimination (Neely-Barnes, Graff, Roberts, Hall, & Hankins, 2010).

Society lacks understanding of caregivers raising children with CP. Some family members struggle to accept disabled children, hindering their support. Children with sensorimotor disorders need temporary recreation and, relief, yet caregivers lack financial, physical, and psychosocial support (Scime, Bartlett, Brunton, & Palisano, 2017). Support from family, peers and clinicians is crucial during occupational therapy, diagnosis, and caregiving (Huang, Kellett, & St John, 2010). Non-supportive spouses and family members contribute to caregivers' increased stress levels. Family-centered care giving is linked to reduced stress (Aydin & Nur, 2012). The government's support for caregivers and disabled children is limited, lacking support groups and welfare information.

Families and society sometimes provide excellent support to caregivers, particularly, fathers and grandparents. However, some individuals lacked knowledge about CP, leading to irritating and excessive questioning for caregivers. Many studies emphasized social support as crucial for caregivers of children with CP in numerous studies (Cook et al., 2022; Wijesinghe, Cunningham, Fonseka, Hewage, & Østbye, 2015). Peers, families, and clinicians play a vital role in meeting caregivers' emotional, practical, and informational needs. Establishing peer-supportive programs would enable caregivers to share information, coping mechanisms, emotional support.

Caregivers neglect other family members, particularly other children, and spouses, due to overwhelming caregiving responsibilities. Providing equal attention to non-CP children becomes challenging. Self-care is emphasized for caregivers of children with CP (Kurtuncu et al., 2015). They must continue rehabilitation exercises and medical treatments at home including managing crucial antiepileptic drugs timings and doses for co-morbidities like seizures. The children's needs keep caregivers constantly busy.

Rezaie and Kendi (2020) acknowledged that family caregivers accept the caring role for children with CP in their daily lives. Caregivers often accompany the children to school daily, assisting with homework and addressing manual skills challenges. This increased responsibility reduces their freedom and consumes substantial energy and time, negatively impacting their daily life and mental health (Byrne, Hurley, Daly, & Cunningham, 2010; Singogo, Mweshi, & Rhoda, 2015). The lack of support and overwhelming responsibilities leads to exhaustion, making caregivers feel like prisoners in their own lives.

The review discovered a high demand for care in the development of children with CP, impacting the family's social context. Hildingsson and Thomas (2014) also highlighted the significant effects on mothers' marital relationships and well-being due to the caring role. Seeking help in caregiving was deemed beneficial (Wijesinghe et al., 2015). Children with CP desire to play and interact with others, but their physical disability often hinders toy manipulation (Vitrikas et al., 2020). Caregivers play with the children requiring extra tolerance. Smith (2009) supported the importance of play for children's development and positive affect.

Caregivers faced challenges and negative emotions while dealing with the child's disability, but some eventually accepted and coped with it, regaining their self-worth. They displayed resilience and even shared their skills with other caregivers for support. Like others, they stayed strong and positive, using various coping strategies to remain optimistic.

Limitations

Including studies only written in English is an essential limitation because relevant qualitative studies in other languages may still need to be included to make a valuable contribution to our review.

Implications for practice and policy

The review emphasizes the importance of recognizing caregivers' demanding and vulnerable situations. Clinicians should foster care collaboration and partnership, integrating a patient-family-centered care approach for children with CP. Policymakers must support families of disabled children through disability funds and healthcare subsidies. Nursing interventions should provide emotional support, counseling, and accurate information about CP. Accessible healthcare facilities should be established, and caregiver peer support groups can offer information, and emotional support. Establishment of respite care services is essential which will offer temporary relief to caregivers and improve family functioning. Public awareness campaigns are essential to promote acceptance and emotional support for caregivers and individuals living with disabilities.

Conclusion

Caring for a child with CP is daunting, tiresome, emotionally, and physically painful. Caregivers face challenges adjusting their lifestyles to meet the child's needs suffering from societal stigma and discrimination. They give up careers and leisure activities, leading to frustration, loneliness, and shattered future goals. Developing creative coping strategies to address these complex issues and provide adequate support for caregivers is essential.

CRediT authorship contribution statement

Maggie Dumsile Dlamini: Conceptualization, Methodology, Formal analysis, Writing – original draft, Writing – review & editing. **Ying-Ju Chang:** Conceptualization, Methodology, Formal analysis, Writing – review & editing, Supervision. **Tram Thi Bich Nguyen:** Methodology, Formal analysis, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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