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Mothers' experience of having a child with cerebral palsy. A systematic review

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ABSTRACT

Aim: To explore, synthesise and present findings of qualitative studies describing the experiences of mothers raising a child with cerebral palsy.

Design: A systematic literature review of the qualitative evidence.

Methods: A systematic search for qualitative studies published in the following databases: CINAHL (EBSCO), Medline via OVID, SCOPUS, and Google Scholar. The authors independently assessed eligibility, appraised methodological quality using the Critical Appraisal Skills Program tool for qualitative Research (CASP). An inductive thematic analysis method was adopted to synthesise major findings and to construct core concepts and themes. **Results:** Five overarching themes reflecting the experiences and perceptions of mothers raising and caring for a child with cerebral palsy are developed: 1) adapting and making sacrifices; 2) guilt and cultural blame; 3) social stigma and marginalisation; 4) physical, environmental, and financial challenges and 5) healthcare experiences.

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Introduction

Cerebral palsy (CP) is the most common permanent disability in children (Hayles et al., 2015; Patel et al., 2020) and is defined as “an umbrella term covering a group of non-progressive but often-changing motor impairment syndromes, secondary to lesions or anomalies of the brain, arising in the early stages of its development” (Mutch et al., 1992, p. 547). The range of motor disorders is large and varied and includes impairments such as limb weakness, spasticity and lack of co-ordination which can have a significant impact on a child's ability to carry out activities of daily living (Amatya & Khan, 2011). Children with cerebral palsy have long term care requirements that are different and often exceed the usual needs of typical children. Because of this, children with cerebral palsy are dependent on caregivers/parents and, most frequently mothers, for daily assistance. Health care requirements and care management of a child with cerebral palsy is often complex and involves a variety of multi-disciplinary services within a health and education framework. Co-ordination of these services, together with advocacy on the behalf of the child has a significant impact on both the physical and psychological health of a caregiver (Dambi & Jelsma, 2014).

Background

Cerebral palsy is not purely a physical disability as is commonly described; rather it is a complex neurodevelopmental disorder and the leading cause of neurological impairment in children (Rosenbaum et al., 2007). It encapsulates, not only physical impairments, but also non-physical challenges. These challenges include disorders such as epilepsy, sensory and perceptual disorders, learning, social, communication and behavioural difficulties all of which can significantly impact on the life of the child and their family (Rosenbaum et al., 2007; Rudebeck, 2020).

The daily lives of mothers with children affected by cerebral palsy are often more impacted as they are usually the primary caregiver and as such more likely to experience emotions and challenges. A recent review on parenting and caregiver experiences and needs highlighted the complex and multifaceted reality of caring for a child with cerebral palsy (Elangkovan & Shorey, 2020). In this review mothers made up most of the participant group (184 out of the 226 participants) and, although the intention was not to focus specifically on the experience of mothers, the reviewers acknowledged a dichotomy between the roles of mothers and fathers (Elangkovan & Shorey, 2020, p. 737). Other studies have demonstrated that mothers of children with disabilities experience higher stress than fathers and are at greater risk of anxiety, depression, lower psychological wellbeing, and decreased health (Crettenden et al., 2018; Resch et al., 2012; Rudebeck, 2020). Further, mothers must balance the role of parent and therapist, to provide care for a child that may require lifelong attention and rehabilitation.

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There is an abundance of quantitative literature exploring the experiences of mothers of children with cerebral palsy from a quality-of-life perspective. These studies indicate a significant negative impact on health, material, and emotional wellbeing among mothers of children with cerebral palsy (Ahmadizadeh et al., 2015; Ones et al., 2005; Ström et al., 2011). Although these quantitative approaches provide important information about children with cerebral palsy and their families, they do not allow for the rich meaningful description and subjective stories that qualitative research does.

The aim of this review is to explore the subjective experiences and individual realities of mothers raising a child with cerebral palsy, and a qualitative literature review is appropriate. This review collates and synthesises the qualitative evidence describing the experience of mothers raising a child with cerebral palsy.

Methods

Aim

To explore, synthesise and present the findings of qualitative studies describing the experiences and perceptions of mothers raising a child with Cerebral Palsy.

Design

This review was guided by the Bettany-Saltikov (2016) steps for undertaking a systematic literature review. In addition we followed the Preferred Reporting for Systematic Reviews guidelines (Page et al., 2021) and appraised the quality of included studies using the Critical Appraisals Skills Programme (Critical Appraisal Skills Programme, 2019). We used a thematic approach to synthesise and collate the findings (Thomas & Harden, 2008).

Inclusion and exclusion criteria

Studies published in English were included if they met the following criteria: a) explored the experience of mothers of children between the ages of 5–16 years with cerebral palsy; b) used a qualitative methodological study design. Studies were excluded if they: a) adopted a quantitative design b) only explored parents' experiences of home therapy programs or other specific rehabilitation interventions; c) included child participants with multiple disabilities and d) included parents of pre-school aged children only.

Search strategy

The following electronic databases were systematically searched for qualitative literature: Medline via OVID, SCOPUS, Google Scholar, EBSCO Health and CINAHL (Cumulative Index to Nursing and Allied Health Literature) via EBSCO. The search terms included *Cerebral palsy, CP, parent, caregiver, mother, guardian, experience, perception, attitude, feeling, emotion, everyday life, daily life, life with, living with*. The search terms based on PICO are illustrated in Table 1. The search was further limited to studies published in English from 2000 to 2021.

Search results

The initial search identified 73 articles for potential inclusion. Next we reviewed and screened studies by title and abstract and then the full text against the inclusion criteria. Studies using a quantitative methodology were scanned and removed. Mixed methods studies were included only if the qualitative data was relevant and easily extracted ($n = 28$ studies removed). After removing duplicates, and applying the exclusion criteria 17 articles met the inclusion criteria. The reference lists of each of the 17 articles were searched to identify new articles within the criteria but none were identified. Articles included in the

Table 1
Systematic search terms referring to PICO.

Participants	Phenomena of interest	Context
Parent* or caregiver* or mother* or * guardian*	experience* or perception* or attitude* or view* or feeling* or emotion* or 'everyday life' or 'daily life' or 'living with'	Cerebral palsy OR CP

review together with a PRISMA flow chart of the review process is shown in Fig. 1.

Critical appraisal

The quality of the 17 articles was appraised using the Critical Appraisal Skills Programme (CASP) qualitative appraisal instrument (Critical Appraisal Skills Programme, 2019). Overall, the quality of the studies was assessed to be good, and scores ranged between 16 and 18. Table 2 presents scores of included articles on each appraisal item.

Data extraction and thematic analysis

Following this, the quality appraisal data was extracted using a standardised collection form. The form included the following information: author, country, and year of publication, aim, sample size and characteristics, design and method, and main findings related to our aim. The results are summarised in Table 3.

Next, original quotes, themes, and sub themes from each of the included studies were transferred into a table to undertake coding of the text. In keeping with Thomas and Harden (2008) data was defined as any text labelled as 'results' or 'findings' Codes were created that identified the content and meanings within each study. As the inductive process continued, we looked for similarities and differences between the thematic codes to group them together into a list of themes that went beyond the content of the original studies. Through discussion, re-reading and revisiting of the data, the overarching agreed themes were generated (Table 3).

Ethics. Ethical approval was not required since this study is a systematic review.

Characteristics of included studies

The included studies were conducted in Australia ($n = 3$), $n = 2$ from Brazil, Taiwan, India, Iran, Canada and $n = 1$ from Zambia, Saudi Arabia, Spain, and Ghana. The studies used hermeneutic phenomenology ($n = 3$), interpretative descriptive ($n = 1$), grounded theory ($n = 5$), critical ethnography ($n = 1$) and the rest were reported as qualitative descriptive (7). In all the studies, the data was collected using semi-structured interviews or focus groups.

The total number of mothers across all studies was two hundred and ninety-two ($n = 292$). The mothers ranged in age from 21 years to 60+ years. Mothers' education was often not reported but among those studies that did there was wide variation ranging from no education at all to level one tertiary education. Some of the studies reported on disability using the Gross Motor Function Classification System (GMFCS) (Palisano et al., 1997). This five-level classification system describes the gross motor function of children and youth with cerebral palsy based on their self-initiated movement including sitting, walking, and wheeled mobility. The highest level of the GMFCS is five and is designated for those having the most severe mobility issues (McDowell, 2008). In this review where the study reported disability status of the child with cerebral palsy there was a wide spread of disability with GMFCS scores ranging from 1 to 5.

The data synthesis revealed five overarching themes reflecting the experiences and perceptions of mothers raising and caring for a child with cerebral palsy: 1) adapting and making sacrifices; 2) guilt and cultural blame; 3) social stigma and marginalisation;

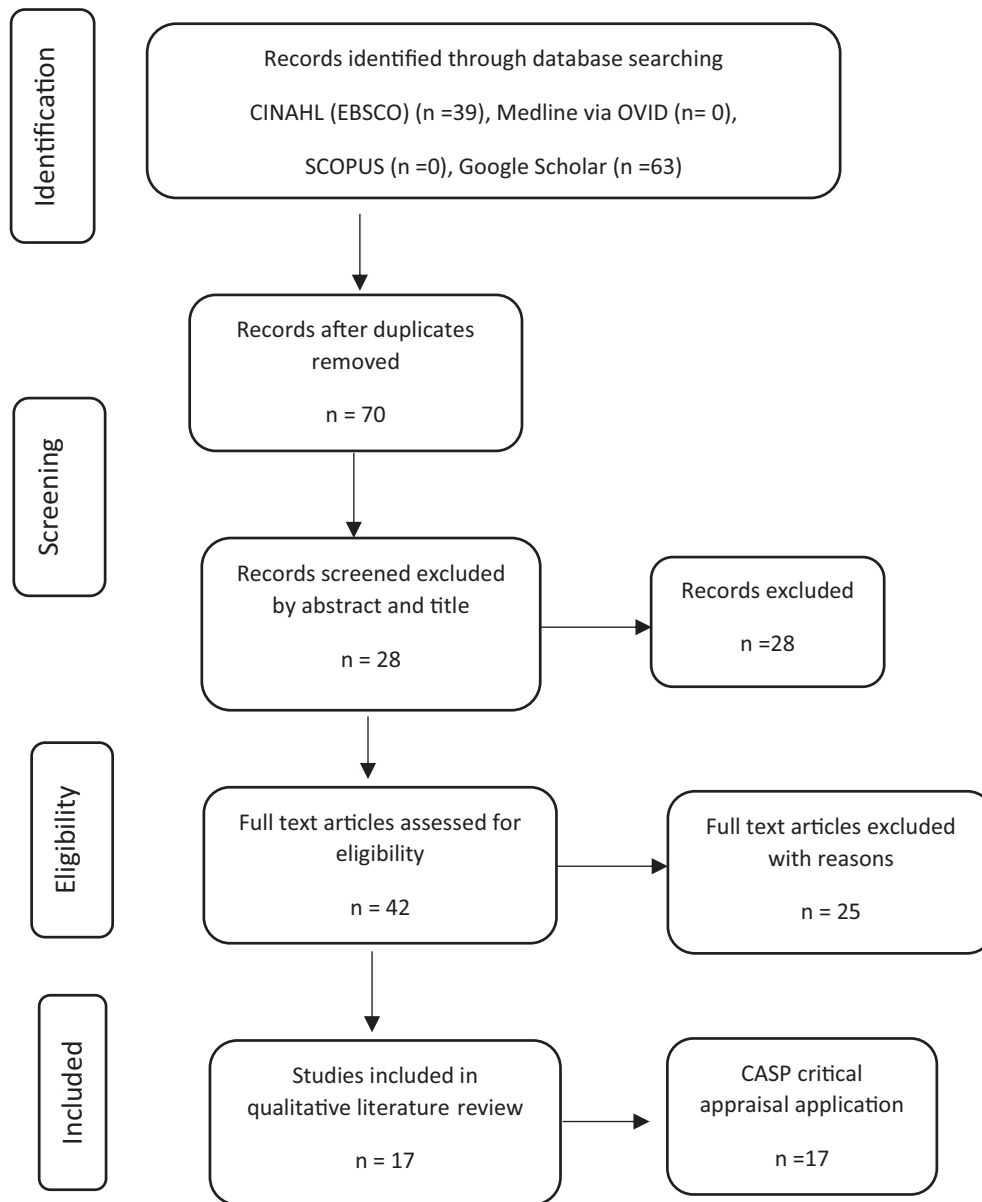


Fig. 1. Flowchart describing the search and exclusion process following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) model.

4) physical, environmental, and financial challenges and 5) healthcare experiences. Original quotes are provided for illustration of the key themes.

Theme 1 – Adapting and making sacrifices

Mothers assumed the role of key caregiver and therefore held the most responsibility and burden of caring for the children with cerebral palsy (Huang et al., 2010; Milbrath et al., 2008; Vadivelan et al., 2020). They experienced significant changes within their lives that required them to adapt and make adjustments and sacrifices (Milbrath et al., 2008; Mokhtari & Abootorabi, 2019). Some of these sacrifices included leaving their jobs, or reducing hours, changing their lifestyle, or adapting to a new daily routine that enabled the time and space to care for their child with cerebral palsy.

I had to quit my job to take care of him, because there was nobody who could take care of him (Milbrath et al., 2008, p. 429).

Mother's sacrifice and inability to maintain employment not only placed financial pressure on the family, it also negatively impacted the mother's identity.

I'm a drama teacher by training...and it was who I am in every facet...and then of course I had Nicole and everything just stopped like that overnight. It's affected my work and my identity...I'm Nicole's mum not myself. (Mother of Nicole aged 4 years, GMFCS Level IV) (Davis et al., 2010, p. 69).

Mothers also described how caring for their child with cerebral palsy was 'time consuming' and how daily cares such as showering required a balancing of time and adapting priorities. These necessary adaptations meant that the mother experienced limits to freedom and resulted in a sense of separation from family and others in the community.

The child is always with me. What can I do; my biggest problem is that there is nobody to keep the child for me to have a time for

Table 2
Critical appraisal of included studies.

Article	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total
Afonso, T., et al. (2020)	2	2	2	2	2	0	2	2	2	2	18
Alaee, N., et al. (2014)	2	2	2	2	2	0	0	2	2	2	16
Davis, E., et al. (2009)	2	2	2	2	2	0	2	2	2	2	18
Davis, E., et al. (2008)	2	2	2	2	2	0	2	2	2	2	18
Fernandez-Alcantara, M., et al. (2015)	2	2	2	2	2	0	2	2	2	2	18
Hayles, E., et al. (2015)	2	2	2	2	2	0	2	2	2	2	18
Huang, Y. P., et al. (2010)	2	2	2	2	2	0	2	2	2	2	18
Huang, Y. P., et al. (2011)	2	2	2	2	2	0	2	2	2	2	18
Milbrath, V. M., et al. (2008)	2	2	2	2	2	0	2	2	2	2	18
Mohamed Madi, S., et al. (2019)	2	2	2	2	2	0	2	2	2	2	18
Mokhtari, M., & Abootorabi, F. (2019)	2	2	2	2	2	0	0	2	2	2	16
Nimbalkar, S., et al. (2014)	2	2	1	2	2	0	2	2	2	2	17
Nyante, G. G. and Carpenter, C. (2019)	2	2	2	2	2	0	2	2	2	2	18
Reid, A., et al. (2011)	2	2	1	2	2	1	2	2	2	2	18
Singogo, C., et al. (2015)	2	2	1	2	2	0	2	2	2	2	17
Vadivelan, K., et al. (2020)	2	2	2	2	2	0	2	2	2	2	18
Whittingham, K., et al. (2013)	2	2	1	2	2	0	2	2	2	2	17

myself. I really feel that there is a chain on my hands and feet. With the child with me, I can do nothing. (Alaee, et al., 2015, p. 2150).

Despite this sense of being tied down and carrying the burden of managing the care of their child with cerebral palsy, mothers recognised and understood they were integral to their child's world. They realised that ultimately their ability to adapt and assume this key caregiver role was crucial despite the impact it had on many aspects of their own life. One of the most significant impacts was on the marital relationship, where mothers lost support from their husbands and thus had to adapt to the burden of becoming the sole caregiver (Huang et al., 2010). In several studies mothers reported frequent fighting with their spouse, lack of support from their husbands, issues of substance abuse, domestic violence (Mohamed et al., 2019; Mokhtari & Abootorabi, 2019), and rejection by their partners (Huang et al., 2011; Singogo et al., 2015; Vadivelan et al., 2020). For some, acknowledging the shift in the marital relationship was not always filled with negative experiences but instead with an understanding that adapting to a new way of life was necessary.

There's a different kind of grief because you recognize that things are never going to be the way you planned them to be. And the things that you may have planned for you and your spouse are no longer going to be that way either... (Reid et al., 2011, p. 174).

Theme 2. Guilt and cultural blame

Shame, humiliation, and a sense of personal failure are feelings commonly described by the mothers in the studies reviewed. Mothers reported feeling guilty and blamed themselves for their child's diagnosis (Milbrath et al., 2008). In several studies, the sense of personal guilt and culpability surrounding having a child with cerebral palsy was interpreted through a spiritual lens and seen as punishment from God (Milbrath et al., 2008; Mohamed Madi et al., 2019; Nyante & Carpenter, 2019).

Maybe I have done something wrong sometime; perhaps I have committed sins and God is taking revenge (Alaee et al., 2015, p. 2151).

Culture and spiritual beliefs influenced and impacted on the guilt and blame mothers felt and was also reflected in the attitudes and responses from others. It was not uncommon to experience negative attitudes from family, friends, and people within their communities (Mohamed Madi et al., 2019; Mokhtari & Abootorabi, 2019; Nimbalkar et al., 2014; Nyante & Carpenter, 2019; Singogo et al., 2015; Vadivelan et al., 2020). Mothers described how having a disabled child was viewed as a social disharmony and that blame was placed on them for not producing a 'normal' healthy child.

My husband's family does not like me and the fact that I have a child with cerebral palsy. They have been trying to force my husband to leave me and marry someone else ... My friends say all sorts of things and refer to my child as a mentally ill child and that my husband wants to leave me because of that, they are big snakes in the grass.' (Singogo et al., 2015, p. 3).

In some instances, husbands and the husbands' family felt embarrassed by a child with cerebral palsy and struggled to accept the situation. This ability to accept and interpret a diagnosis of cerebral palsy was sometimes influenced by culture and traditional beliefs. For example in Taiwan having a child with cerebral palsy was deemed a disruption to ancestry and a disgrace to the family (Huang et al., 2011) and in Ghana the child was labelled as an animal, for example a snake (Nyante & Carpenter, 2019). Even among studies where the cultural and spiritual interpretation of a child with cerebral palsy was not as prominent, the social stigma and marginalisation of these mothers was a strong thread.

Mothers also felt stressed and guilt about their other children and recognised how siblings' lives were also impacted by the adjustments and adaptations that accompanied living with a sibling with cerebral palsy.

Certainly (older child) paid a price ... 'cause we didn't play ... we didn't go to things, or if we did go to things it was always such a big deal ... it was a lot of work to load up and unload ... it's not as carefree (Reid et al., 2011, p. 175).

Often siblings were expected to help with caregiving responsibilities and required to take on more responsibility around the house. Mothers felt additional stress when the healthy sibling reacted in a jealous and angry way to these expectations (Huang et al., 2011; Nimbalkar et al., 2014) and/or experienced guilt and stress about not being able to provide the same care and attention to their other children (Vadivelan et al., 2020).

Theme 3. Social stigma and marginalisation

Mothers reported feeling as though their lives had become very different since having their child with cerebral palsy and described feeling unsupported by key people, socially rejected, and discriminated against (Davis et al., 2010; Mokhtari & Abootorabi, 2019; Nimbalkar et al., 2014; Singogo et al., 2015; Vadivelan et al., 2020).

My friends laugh at me. He is a very difficult child, if I go with him to church, we spend the whole time outside, so I have stopped going to church, not even town. Unless I'm in dire need then I ask my mother to help look after him ... (Singogo et al., 2015, p. 3).

The stigma imposed by friends and society led to a sense of isolation and resulted in difficulties with maintaining their own interests and social connections. Many expressed difficulty making contributions to conversations when socialising, which ultimately resulted in them either withdrawing socially or limiting their socialising to a few close family members (usually their own mothers or other female family members) and/or other mothers of children with cerebral palsy (if they knew any) with whom they could feel safe and supported (Davis

Table 3
Summary table. Characteristics of the studies included in the review.

First author and year	Country of origin	Research Question/Aim	Methodological design and data collection	Sample and sample size	Findings relevant to the review
Afonso, T., Silva, S. S. d. C., & Pontes, F. A. R. (2020)	Brazil	To explore past experiences and future expectations arising from mothering a child with CP?	Semi demographic inventory, GMFCS interviews grounded theory, interviews	13 mothers	<ol style="list-style-type: none"> 1) Importance of acquired learning 2) The maturation processes 3) The suffering experienced 4) The perceptions about happiness and the challenges to be overcome. Mothers perceived themselves accomplished with the construction of intense learning about the care required in cerebral palsy <p>Future –feeling relate to the perception of the child's lack of adaptive competence Past – a set of experiences leads to a maturation process which tolerance and patience are evident.</p> <p>four subcategories</p>
Alaee, N., Shahboulaghi, F. M., Khankeh, H., & Mohammad Khan Kermanshahi, S (2014)	Iran	Aim of study to explore the needs and challenges of parents in caring and supporting their child with cerebral palsy	Semi structured interviews	12 mothers 5 fathers	<ol style="list-style-type: none"> 1) inadequate facilities and services 2) unsupportive interactions 3) limitation of parents' social relations, 4) social seclusion of the child and parent in the category of social challenges, and three subcategories, "intrapersonal conflicts," "being worried," and "sense of loneliness," in the category of psychoemotional challenges.
Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., Davern, M., & Reddihough, D (2009)	Australia	To explore impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. To explore if impact changes from childhood to adolescence	Grounded theory semi-structured interviews	24 mothers 13 fathers	<ol style="list-style-type: none"> 1) No differences in parental QOL among subgroups (i.e. mothers and fathers, age groups, GMFCS levels) 2) Parental QOL ranged across a wide spectrum. 3) Caring for a child with Cerebral Palsy affects a parent's physical well-being, social well-being, freedom & independence, family well-being & financial stability. 4) Parents indicated that they often feel unsupported by the services they access.
Davis, E., Shelly, A., Waters, E., Mackinnon, A., Reddihough, D., Boyd, R., Kerr, G., & Graham, H. (2008)	Australia	Aim of study to identify domains of QOL for adolescents with cerebral palsy (CP) from adolescent and parent perspectives to guide the development of an adolescent version	Grounded theory semi-structured interviews	21 mothers 2 fathers 17 adolescents	<p>Fifteen QOL domains were identified including;</p> <ol style="list-style-type: none"> 1) health issues in adolescence 2) participation 3) education 4) specific cerebral palsy-related issues (pain and discomfort, communication), 5) family issues practical issues (financial resources) 6) changes associated with adolescence (sexuality, independence). <p>Parents experience</p>
Fernandez-Alcantara, M., Garcia-Caro, M. P., Laynez-Rubio, C., Perez-Marfil, M. N., Marti-Garcia, C., Benitez-Feliponi, A., Berrocal-Castellano, M., & Cruz-Quintana, F. (2015)	Spain	To identify feelings of loss in parents of children with infantile cerebral palsy.	Grounded theory semi-structured interviews	24 parents 15 mothers 9 fathers	<ol style="list-style-type: none"> 1) Loss of the ideal child (more complex in the first stage of diagnosis and when cerebral palsy is more severe), Shock, hope, traumatic experience. 2) Acceptance of child <p>Parents experience health care for their child as a process of</p> <ol style="list-style-type: none"> 1) Making the most of their body and their life. 2) Learning as you go 3) Navigating the systems meeting needs through partnership 4) Being empowered or disempowered 5) finding a balance <p>Suggestions made on how to modify the system to improve experience</p> <p>Four shared meaning revealed:</p>
Hayles, E., Harvey, D., Plummer, D., & Jones, A. (2015)	Australia	How to parents living in a rural area of Australia experience health care for their children with Cerebral Palsy? What to parents think are important aspects of their child's health care? How do parents want their healthcare needs met?	Grounded theory focus group interview	11 mothers 2 fathers	<ol style="list-style-type: none"> 1) Making the most of their body and their life. 2) Learning as you go 3) Navigating the systems meeting needs through partnership 4) Being empowered or disempowered 5) finding a balance <p>Suggestions made on how to modify the system to improve experience</p> <p>Four shared meaning revealed:</p>
Huang, Y. P., Kellett, U. M., & St John, W. (2010).	Taiwan	Cerebral palsy: experiences of mothers after learning their child's diagnosis.	Hermeneutic phenomenology interviews	15 mothers	<ol style="list-style-type: none"> 1) Feeling out of control and powerless 2) Mistrusting health professionals 3) Release and confirmation

Table 3 (continued)

First author and year	Country of origin	Research Question/Aim	Methodological design and data collection	Sample and sample size	Findings relevant to the review
Huang, Y. P., Kellett, U. M., & St John, W. (2011).	Taiwan	Aim to study Taiwanese mothers' challenging experiences when a disabled child is born into their families in the context of Chinese culture	Hermeneutic phenomenology interviews	15 mothers	4) Feeling blame for not following traditional practices Shared meanings revealed four modes of being concerned: <ol style="list-style-type: none">(1) experiencing burden as a sole primary caregiver;(2) managing the challenges by balancing demands;(3) being marginalised by others(4) encountering limited or no professional support.
Milbrath, V. M., Cecagno, D., Soares, D. C., Amestoy, S. C., & Heckler de Siqueira, H. C. (2008).	Brazil	What is the adaptive processes experienced by a woman motivated by the birth of a child with Cerebral Palsy?	Descriptive exploratory	6 mothers	Two key themes: <ol style="list-style-type: none">1) Experiencing being a woman--mother of a child with cerebral palsy2) Supporting networks necessary to the woman--mother of a child with special needs.
Mohamed Madi, S., Mandy, A., & Aranda, K. (2019)	Saudi Arabia	To explore the perceptions of disability among Saudi mothers and to understand the implication of the meaning for the mothers of children with disability.	Critical ethnographic focus groups and follow-up interviews	6 mothers	Three primary themes were identified that specifically influenced and affected the mothers' experiences: <ol style="list-style-type: none">1) culture and religion,2) motherhood and disability3) community stigma and discrimination.
Mokhtari, M., & Abootorabi, F. (2019)	Iran	Lived Experiences of Mothers of Children with Cerebral Palsy in Iran: A Phenomenological Study	Hermeneutic phenomenology interviews	8 mothers	Themes identified <ol style="list-style-type: none">1) feelings2) self-expectation3) levels of relations4) levels of support. Conclusions: mothers are uncertain about the future. Facilities for rehab and treatment (insufficient & inadequate) and levels of satisfaction with caring systems (dissatisfaction with government agencies/-satisfaction with private treatment centres)
Nimbalkar, S., Raithatha, S., Shah, R., & Panchal, D. A. (2014)	India	To explore the psychosocial problems faced by the parents of children with cerebral palsy (Cerebral Palsy in rural and urban settings).	Focus groups	1 grandmother 1 father 11 mothers	Psychosocial problems experienced by the parents identified as; <ol style="list-style-type: none">1) Disturbed social relationships2) Health problems3) Financial problems4) Moments of happiness5) Worries about future of the child6) Need for more support services7) Lack of adequate number of trained physiotherapists
Nyante, G. G., Carpenter, C. (2019)	Ghana	The experience of carers of children with cerebral palsy living in rural areas of Ghana who have received no rehabilitation services: A qualitative study	Descriptive phenomenology semi-structured interviews	12 carers 8 mothers 1 father 2 grandmothers 1 cousin	Two themes: <ol style="list-style-type: none">1. Developing personal beliefs to support the caregiving role (3 sub-themes)2. Demands that shape the experience of caring (3 subthemes)
Reid, A., Imrie, H., Brouwer, E., Clutton, S., Evans, J., Russell, D., & Bartlett, D. (2011)	Canada	If I knew then what I know now": parents' reflections on raising a child with cerebral palsy	Interpretive description interviews	7 mothers 2 fathers	<ol style="list-style-type: none">1) Results informed the development of tips for parents and children to enhance their families experience and interactions with healthcare providers, educators and others.2) Parents elaborated upon what was helpful and what could be changed to improve their children's and families experience s through support, advocacy and education at different levels
Singogo, C., Mweshi, M., & Rhoda, A. (2015)	Zambia	Explore the challenges experienced by mothers caring for children with cerebral palsy in Zambia.	Exploratory interviews	16 mothers	Themes: <ol style="list-style-type: none">1) physical challenges2) social isolation3) perceived causes of cerebral palsy4) physical access challenges5) marital problems

(continued on next page)

Table 3 (continued)

First author and year	Country of origin	Research Question/Aim	Methodological design and data collection	Sample and sample size	Findings relevant to the review
Vadivelan, K., Sekar, P., Sruthi, S. S., & Gopichandran, V. (2020)	India	To explore the burden of caregivers of children with cerebral palsy: an intersectional analysis of gender, poverty, stigma, and public policy	Exploratory interviews-thematic content analysis	10 mothers	6) challenges with the health care system Stressors identified were: 1) 1)physical-aches/pains, abusive husband, lack of community support- accessibility barriers 2) emotional- guilt blame-emotional abuse-worry 3) social- blame, discrimination, lack of inclusive spaces, lack of social support groups 4) Financial- unable to work, lack of job options, insufficient welfare support 5) Informational- lack of knowledge about caregiving options.
Whittingham, K., Wee, D., Sanders, M. R., & Boyd, R. (2013)	Canada	Sorrow, coping and resiliency: parents of children with cerebral palsy share their experiences.	Focus groups and web based cross sectional survey	6 mothers 2 fathers and 94 parents did the survey (the adapted burke questionnaire on chronic sorrow)	1) Some parent found diagnosis distressing while others found it a relief 2) At time parents found medical and allied health intervention particularly challenging 3) Authors conclude that the chronic sorrow theory is a useful way of understanding experiences of parents of children with cerebral palsy 4) Parents may experience delayed intense chronic sorrow symptoms following a triggering event and this is normal.

et al., 2010; Mokhtari & Abootorabi, 2019; Nimbalkar et al., 2014; Singogo et al., 2015). Mothers reported having a reduced ability to participate in social gatherings that required leaving their house such as attending weddings or going on holiday. The challenges and the public discrimination that ensued when taking part in these activities meant they often just stayed at home (Mohamed Madi et al., 2019; Nyante & Carpenter, 2019). However, this resulted in a sense of loss about previous freedoms and a longing to resume their previous lives prior to caring for their child with cerebral palsy (Afonso et al., 2021; Davis et al., 2010).

Well, it impacts on everything because there is nothing that you can do spontaneously. I guess I miss that at times (Davis et al., 2010, p. 68).

There was a sense of powerlessness over these attitudes and mothers felt helpless to protect their child and felt hurt about the way people and society viewed them.

To tell you the truth, I don't accept society's attitude toward my daughter. Their attitude makes my daughter feel bad. At the same time, I can't control people's attitudes, and I feel powerless. The word "handicapped" hurts my feelings. It hurts me a lot. (M2) (Mohamed Madi et al., 2019, p. 8).

Overall, the consistent lack of understanding and support from friends, families and community was a major cause of both psychological and physical stress for mothers who felt alone and solely responsible for meeting all aspects of their child's needs (Mokhtari & Abootorabi, 2019; Vadivelan et al., 2020). In the few studies where these social supports were stronger and more positive it was clear that this played a significant role in helping mothers to cope and adapt to the complexity of mothering their child with cerebral palsy. Hayles et al. (2015) and Reid et al. (2011) highlighted the power of informal networks with other

parents for support, information sharing, problem solving and guidance and regarded the opportunity to build new links with like-minded parents as being a positive experience.

Theme 4. Physical, environmental, and financial challenges

Mothers described numerous challenges that impacted on their experience of raising and caring for a child with cerebral palsy. Three key subthemes that contributed to this experience were: physical, environmental, and financial.

Physical

Mothers experience with physical challenges was frequently a direct result of caregiving responsibilities such as lifting, carrying, and physically caring for their child with cerebral palsy (Mokhtari & Abootorabi, 2019; Nimbalkar et al., 2014; Nyante & Carpenter, 2019; Reid et al., 2011; Singogo et al., 2015; Vadivelan et al., 2020). Physical ailments such as shoulder and back pain and generalised body aches from carrying their child long distances to and from appointments were commonly reported issues in places like India, Zambia, Ghana and Iran (Mokhtari & Abootorabi, 2019; Nimbalkar et al., 2014; Nyante & Carpenter, 2019; Singogo et al., 2015; Vadivelan et al., 2020). The lack of access to equipment such as hoists and wheelchairs created a more physically demanding situation for the mothers in these countries. Other tasks, such as changing nappies, bathing and dressing children with spasticity and musculoskeletal dysfunction were described as increasingly demanding as the child grew and became heavier. This was common across all the studies regardless of setting.

I've got to lift him in the car. I've got to lift his wheelchair in the car ... He's 38.9 k. The chair's 44 k. So there's lots of things ... It's just how it is and it's just that we have to do this. (Hayles et al., 2015, p. 1147).

The significant physical strength and ability required of the mother impacted many aspects of their life and created new challenges as the child developed into a teenager and beyond. The need to stay physically strong to manage their child's care was a significant burden where words like 'hardship', 'tiring' and 'difficult' described the unrelenting nature of the care required.

Sometimes she [13-year old daughter] will soil herself with urine and faeces, so I have to get her clean. It is not an easy task bathing her because she is now heavy and tall. I sometimes struggle with her for more than an hour trying to clean her (Nyante & Carpenter, 2019, p. 819).

Environmental. Environmental factors were identified by mothers as a barrier to their child being able to be an active community member—these included a lack of ramps, lifts and sidewalks, the lack of inclusive spaces and disability friendly transport (Mohamed Madi et al., 2019; Singogo et al., 2015; Vadivelan et al., 2020). Mothers felt anger and frustration about the poor design of facilities that limited their child's participation in society and in the typical activities of being a child such as going to school.

I have difficulty going for outings, such as going shopping or dining, because of inaccessibility of the community. Able people don't consider the disabled in the building structures (Mohamed Madi et al., 2019, p. 8).

Mothers cited environmental and structural issues as the key driver in creating isolation and segregation (Mohamed Madi et al., 2019) and described how geographical limitations of rural living, impacted accessibility when having to attend appointments.

Financial. Financial demands imposed on families is a significant cause of stress for mothers and their families, all of whom report heavy health related expenses which they often must fund themselves (Vadivelan et al., 2020, Alae et al., 2014, Nimbalkar et al., 2014, Davis et al., 2009). Nimbalkar et al. (2014) concluded that to meet all the financial needs (e.g., privately funded equipment, spiritual interventions, and appropriate transport), compromises were made in other aspects of life. Along with these ongoing costs, paid work was impacted through having to miss days due to attending hospital appointments during working hours.

I pawn my old jewellery for a sudden need for money as I face many financial issues related to my child's care.....I do not want to compromise on the care for my child, whatever the financial situation maybe (Vadivelan et al., 2020, p. 6).

Many mothers reported having to leave their paid employment for good so that they could adequately care for their child, while also having to make sacrifices and finding different ways of managing the financial burden (Nimbalkar et al., 2014, Davis et al., 2008,).

Theme 5 Healthcare experiences

Mothers of children with cerebral palsy encounter significant interaction, input and information from healthcare services. One of the strong themes in the literature highlights the importance of what, how and when information was shared with them. Receiving information "by chance" and the need to be personally proactive to get their child the access to the services needed was a common experience (Davis et al., 2010; Hayles et al., 2015 ; Reid et al., 2011). Mothers wanted improved access to services and for health professionals to be honest with them, give them accurate and individualised information, develop a plan of action, and treat them as an equal team member (Davis et al., 2010; Whittingham et al., 2013).

A really individual and tailored approach, according to what the family's needs are... as well as what our emotional state is... (Whittingham et al., 2013, p. 1451).

Mothers reported that their feeling of empowerment was compromised by inaccurate and inconsistent information about cerebral palsy from health professionals (Nyante & Carpenter, 2019; Reid et al., 2011). This lack of information and support contributed to difficulties with balancing the needs of the child and the family. Hayles et al. (2015) revealed that mothers wanted their child to do the best they could in life, and it was important to them, that their child was seen as a child first and as having a disability second. Mothers reported how they felt empowered by increasing their ability to meet their child's needs, but this was dependent on a good working relationship with health professionals and health services. When this didn't happen, mothers felt unheard and disempowered (Hayles et al., 2015; Singogo et al., 2015). Two separate Taiwanese studies (Huang et al., 2010; Huang et al., 2011) reported on mothers' mistrust in health professionals' ability to provide timely and accurate diagnosis and ensure that optimal treatment was received. In addition, these authors revealed how mothers' experienced dissatisfaction when health professionals showed their impatience, lack of sympathy and unwillingness to communicate with them to provide the best individualised care of their child.

I could only wait outside the rehabilitation room as he thought I might disturb the therapy. The therapist just let her choose what she wanted to practice. I couldn't say to him that my daughter already knows how to do it.....the session took half an hour, but it took us more than two hours to travel there and back home (Huang et al., 2011, p. 193).

Mothers indicated that navigating the health system was difficult due to its complex nature. With its multitude of systems, differences in eligibility, accessibility and availability and the raft of policies, procedures, and funding to be navigated it was a steep learning curve for most (Hayles et al., 2015; Reid et al., 2011). However, the more they knew about their child's needs and the services available, the easier it was to find the most appropriate and available care. This enabled them to have choice and the opportunity to make decisions that fitted best for them and their child.

It always comes down to the parents need more information. If there is something available that may be beneficial to our child, or it may not be, we still want to know what it is so we can make a decision (Hayles et al., 2015, p. 1144).

Mothers of children that were less physically disabled reported that their children had even less access to services because they weren't considered a priority (Hayles et al., 2015; Reid et al., 2011). Hayles et al.'s (2015) study found that regardless of their child's age or level of disability, mothers had to deal with an ongoing cycle of evolving needs. Each healthcare experience had a cumulative effect on their subsequent experiences which resulted in a "learning as you go" approach to managing care for a child with cerebral palsy.

Discussion

This literature review aimed to identify and synthesise the evidence regarding the experience of mothers caring for school aged children with cerebral palsy. The studies reviewed represent the voices of mothers across a variety of settings and illustrate the influence of both society, culture, and community.

The literature highlighted the observation that as mothers assume the role of primary caregiver of their child with cerebral palsy, they experience significant impacts on their time, freedom, and identity. They must learn to adapt and make sacrifices to provide care for their child and this impacts on their relationships (often marital) and wellbeing.

These findings resonate with previous research that describes the significant role, responsibility, and time requirements of caregiving activities for mothers of a child with cerebral palsy and the consequent negative impact on daily life and mental health (Byrne et al., 2010; Rassafiani et al., 2012; Sawyer et al., 2011). Financial challenges and the inability to work due to carer responsibilities was a significant finding and has been reported elsewhere as having an adverse effect on quality of life of mothers (Ahmadzadeh et al., 2015). Healthcare professionals need to be aware that mothers spend a considerable amount of time caring for their child with cerebral palsy and the impact that this has on many aspects of their life.

Mothers also described how family and members of their community judged them and held them responsible for the child's disability. (Mohamed Madi et al., 2019; Mokhtari & Abootorabi, 2019; Nimbalkar et al., 2014; Nyante & Carpenter, 2019; Singogo et al., 2015; Vadivelan et al., 2020). This was particularly prominent in the Asian studies where the parents in law clearly communicated a lack of acceptance and disappointment about the disabled child (Huang et al., 2010; Huang et al., 2011). In Chinese culture a disabled child is deemed disruptive to the natural order of the parent child relationship where the expectation is that they will be rewarded for their parenting and that the child will 'give back' to them what they have given (Holroyd, 2003). A disabled child is viewed as not being able to live a useful life and is considered 'shameful'. Mothers in our review experienced a sense of personal failure, shame, and guilt for their child's diagnosis. This sense of blame was frequently related to cultural and spiritual beliefs where mothers believed that cerebral palsy was a divine intervention, a challenge or a punishment sent by God. This philosophical view about disability has been explored in other studies (Daudji et al., 2011; Park et al., 2009; Raman et al., 2010) and highlights the need for health professionals to recognise the role that spirituality and culture plays in mothers' perceptions and future expectations of their child's disability. Health professionals must be made aware that among some cultures, the mothers shame and guilt may result in a fear of disclosing challenges to outsiders and thus a reluctance to seek support from external services (Ravindran & Myers, 2012).

Our review shows that lack of understanding and stigmatisation from friends, family and the community is a significant source of stress (Alaee et al., 2015; Mohamed Madi et al., 2019; Nyante & Carpenter, 2019). Stigma discrimination and social isolation are commonly described experiences in the literature among mothers of children with disabilities and, like the mothers from our review, create a sense of exclusion from the communities in which they live (Inan Budak et al., 2018). Lack of knowledge of disability as well as misunderstandings and social constructions concerning the cause of disability all contribute to harmful beliefs. There is good evidence that support groups or networks have empowering benefits including enabling connections and providing support and reassurance about the day to day challenges of having a child with cerebral palsy (Law et al., 2001). However, it is clear from our review that context does matter, with only the Canadian and Australian mothers describing information sharing and informal networks as a means of providing support and improving their ability to manage caring for their child with cerebral palsy.

The mothers experienced physical challenges as a direct result of caregiving, particularly related to tasks such as toileting, changing nappies and bathing. Elankovan and Shorey (2020) similarly reported a theme of physical challenges in their review of the literature and pointed out the importance of recognising how variation of physical challenges would likely relate to complexity and severity of cerebral palsy. The studies in our review, like those of Elankovan and Shorey (2020), did not always specify Gross Motor Function Classification System (GMFCS) (Wood & Rosenbaum, 2000). The needs of mothers of children with cerebral palsy will be different depending on this level of functional ability and therefore it is possible that the nuances of the challenges based on cerebral palsy complexity are not as visible or generalisable in our review.

There is strong evidence that financial challenges played a key role and contributed to mothers' ability to promote and maintain their child's health and wellbeing (Vadivelan et al., 2020, Alaee et al., 2014, Nimbalkar et al., 2014, Davis et al., 2009). Although these challenges varied between geographical locations due to the widely varied government and social support systems available, the root of the issues were similar and highlight the challenges at a system level that permeate across all geographical settings. Mothers described their experiences with healthcare services in both positive and negative ways. Inconsistent or inaccurate information, disrespectful and dismissive attitudes and lack of an individualised approach contributed to mothers' negative healthcare experiences. This is consistent with other recent studies (Mohd Nordin et al., 2019; Strunk, 2010). Mothers in our review gained a sense of confidence and control when they were armed with information and as they developed the skills and knowledge surrounding how to manage their child's care. Health professionals have an important role to play ensuring that mothers feel positive and empowered and that they have the tools needed to understand and competently navigate the complex social, financial and health systems within their country (Alaee et al., 2015). This includes support with communication, advocacy, information exchange direct care and emotional support.

Limitations of the review

There are some limitations worth noting. Although the studies reviewed represent a wide ethnic and geographical spread, we only included studies in English, and this may have excluded relevant qualitative studies that could have provided a more representative overview. We were primarily interested in studies that looked at the experience from a broad perspective and therefore did not include studies that focused on rehabilitation practices. This could have potentially limited a more in-depth description of mother's experience of caregiving. Some of the studies included both fathers, mothers, and other caregivers' experiences and although these are important and relevant to raising a child with cerebral palsy we felt it was important to highlight the mothers experience as the primary caregiver.

Another limitation is the mere inclusion criteria of the review which was done to provide a meaningful focused review eg. exclusion of quantitative studies, randomised controlled trials, younger children, children with multiple disabilities and adolescents.

Conclusion

This qualitative literature review provides an overview of the experiences of mothers raising a child with cerebral palsy and the significant burden of care, marginalisation and challenges they face while doing this. It sheds light on how guilt and cultural blame creates an additional barrier for them in their day-to-day life and that education is needed across a broad range of settings and among all communities to ensure that stigma and ignorance does not negatively impact on the lives of mothers and their children.

Implications for Clinical Practice: This review highlights the need for support networks, collaborate healthcare relationships, clear and accurate information and adequate government and financial support. By understanding mothers' experiences more deeply, there is an opportunity to guide the changes needed for improvement and provide a more meaningful picture into what this experience looks like.

Future research

Research is needed to inform both education and health systems, assist with changing societal attitudes to include inclusion and acceptance, develop interventions to support carers and inform new strategies for rehabilitation.

Declaration of Competing Interest

None to declare.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pedn.2022.01.014>.

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