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Understanding the State of Research Evidence Involving Parents of Children with Cerebral Palsy in the Arab Contexts: A Scoping Review

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Abstract

Raising a child with cerebral palsy (CP) can be both rewarding and challenging. Family caregivers, typically parents, play an important role in supporting and caring for children with CP. Research on CP family caregiving is growing, but Arab parental caregiving appears absent from this body of work. The objective was to map the scope of the existing literature about parents of children with CP in Arab contexts to identify gaps in knowledge and guide future research. This scoping review was conducted following the JBI methodology. Five major health-related databases (MEDLINE, CINAHL, EMBASE, Global Health, APA Psycinfo) and two general search engines and directories (Google Scholar and Ulrichsweb) were searched. We selected peer-reviewed studies that included parents of children with CP in Arab countries, regardless of publication date or study design. The search included literature published in Arabic and English. We identified ten studies that met our criteria and were published between 2013 and 2022. Across all studies, mothers were the most reported primary caregivers. Four studies reported tasks performed by parental caregivers, including but not limited to transferring, dressing, transportation, and feeding. The included studies explored the financial, social, and information needs of the parents. Studies focused primarily on caregiver burden or other negative consequences of caregiving. Parents in one study only reported increased resilience as a positive consequence. In addition, no studies included interventions. Research on parental caregiving in the Arab context is limited. Further studies are necessary to explore the unique needs and experiences of Arab CP caregivers.

Keywords: Arab countries; Caregiver; Cerebral palsy; Children; Parents; Scoping review.

INTRODUCTION

Cerebral palsy (CP) is a neurological disorder primarily affecting body movement and muscle coordination. The cause of CP is a non-progressive brain injury or malformation appearing while a child's brain is developing (Mutch *et al.,* 2008). One of the most common neurodevelopmental disorders is CP(Mohammed *et al.*, 2021), with a prevalence rate of 2 to 2.5 per 1,000 live births, equating to more than 17 million cases worldwide(Oskoui *et al.*, 2013). Children with CP experience several signs and symptoms, including muscle stiffness, exaggerated movements, abnormal gait, and joint contractures, which may lead to limitations in daily activities, reduced participation in meaningful life roles, and poor emotional well-being and quality of life (Mushta *et al.*, 2022).The impact of CP extends beyond the affected children, significantly influencing their parents' lives(Park *et al.*, 2019). Parents are primarily responsible for supporting their children's overall development and health by fulfilling physiological and emotional needs while providing adequate material resources for a child to develop and grow (Elangkovan *et al.*, 2020).

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Globally, parents of children with CP, particularly mothers, are integral to securing opportunities for their children to participate meaningfully in daily life activities (Vadivelan *et al.*, 2020) and remain functioning at home and school (Elangkovan *et al.*, 2020). Parental caregiving tasks can range in scope and degree of control (Schulz *et al.*, 2010), including scheduled (e.g. help with activities of daily living) vs. emergent tasks (e.g. interaction with medical personnel). The responsibilities of parents of children with CP can also vary from instrumental (e.g., transportation, shopping, home maintenance) to highly personal assistance, such as bathing and toileting, to more general social and emotional support. While some of these activities follow a distinct pattern and may be predicted and normal for parents, many are not, which may make parents feel stressed and lack confidence (Elangkovan *et al.*, 2020; Schulz *et al.*, 2010). Parents of children with CP often report poor physical and psychological health outcomes due to their caregiving responsibilities and may need more knowledge about managing their children's complex needs (R. Mohammed *et al.*, 2021) and specialized support services (Almasri *et al.*, 2011; Cheshire *et al.*, 2010; Jamali *et al.*, 2020).

Two recent reviews of family caregiving research highlight the increasing global interest in understanding the experiences of parents of children with CP. The first review, published in 2020, focused on the parenting experiences and needs of parental caregivers of children with CP (Elangkovan *et al.*, 2020). This review included 17 qualitative studies, mostly conducted in the United States (n=4), Iran (n=3), and Australia (n=2), and published between 1988 and 2019. The findings highlight the complex and multifaceted reality of caring for a child with CP. In particular, the authors reported that raising a child with CP adds additional challenges to parents' lives, especially if they are parents of other neurotypical children who also need time and attention. The review authors also identified the needs of parents who care for children with CP, including assistance in maintaining a balanced family life and co-parenting. Mothers were typically the primary caregiving role, with fathers taking on the responsibility of being the sole breadwinners.

The second review, published in 2022, was also a qualitative meta-synthesis of 17 studies addressing the lived experiences of mothers of children with CP (Smith *et al.*, 2022). The included studies were mostly conducted in Australia, Brazil, Taiwan, India, Iran, and Canada. The review presented an overview of the challenges faced by mothers raising a child with CP, highlighting experiences of marginalization, guilt, and cultural blame. The review emphasized the need for education and awareness across all communities and settings to prevent the negative impact of stigma on the lives of mothers and their children. Each of these reviews provided valuable insights into CP parental caregiving, although they were both narrow in scope of methodology and focus. For instance, both reviews included qualitative studies mostly conducted in Western countries (e.g., the United States and Australia). An in-depth synthesis of Arab parental CP caregiver needs and experiences, including caregiving tasks, challenges, and consequences, and interventions targeting this caregiver population, is not available in the literature.

Socio-cultural and healthcare environments profoundly influence parental caregivers' caring role, experience, and support needs for children with CP (Chamond, 2017). The Arab region (a geographic and political region of 22 countries located in the Middle East and North Africa that share a common history, language, and culture) has unique cultural values and social norms that can shape the perception of CP, coping mechanisms of families, and provision of health and social care (Mushta *et al.*, 2019, 2022). In many Arab societies, traditional gender roles remain deeply ingrained, with distinct expectations for men and women within the family and community. These roles can significantly influence attitudes toward caring for children with disabilities. Cultural norms may dictate different standards of acceptable behaviour for men and women in these situations, which can impact the level of support and care provided to the child. Understanding these cultural dynamics is crucial for effectively addressing the needs of children with disabilities and ensuring they receive appropriate care and support within their families and communities. Also, policymakers and practitioners can better address families' needs by considering factors such as gender roles and cultural beliefs about child-rearing practices (Cook *et al.*, 2022). This knowledge may promote positive outcomes for children and families in the region because involving Arab households in research ensures that their perspectives shape research priorities, facilitating meaningful engagement and participation in addressing their unique needs.

Review question

Following a Population, Concept, Context (PCC) mnemonic recommended by Joanna Briggs Institute (JBI) for the conduct of scoping reviews (Peters MDJ *et al.*, 2020), the main question was: What is the current state of evidence about CP parental caregiving research in Arab contexts? Specifically, we were interested in mapping the evidence relative to the characteristics of caregivers that have been included in caregiving studies, caregiver needs, tasks, challenges, and consequences of caregiving, and interventions targeting this caregiver population.

METHODS

This scoping review was conducted using the JBI methodology for scoping reviews (Peters MDJ *et al.*, 2020). We registered our protocol in the Open Science Framework on 27 February 2023. For the full protocol, see – https://osf.io/9dc25/. This review was reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist (Tricco *et al.*, 2018).

Inclusion criteria

Participants: We included studies that focus on adult (≥18 years old) parent caregivers of children (<18 years old) with CP. In our original protocol, we had planned to include studies focusing on family caregivers (i.e., parents, grandparents, siblings). However, a preliminary search of existing evidence (Mushta *et al.,* 2019, 2022)indicated that parents (not other family members) are typically the primary family caregivers of children with disabilities in the Arab context. Therefore, this review focuses on biological parental caregiving to provide a comprehensive synthesis of insights specific to this predominant caregiver role. We excluded studies focusing on formal caregivers (e.g., healthcare providers), paid caregivers (e.g., personal support workers), other family caregivers (e.g., siblings, grandparents, etc.), and caregivers of adults/older adults. We also excluded studies with mixed caregiving populations, in which data from parents of children with CP were not reported separately.

Concept*:* We included any study focused on assessing the physical or psychological health of parents of children with CP, providing interventions, and/or exploring their experiences and support needs. We excluded any medical or rehabilitation assessment, intervention, or experience focused only on children with CP.

Context: No time limits were placed on the search to enable an understanding of the state of research evidence involving parent caregivers of children with CP in the Arab context. We included studies conducted in Arab countries in the Eastern Mediterranean region, including Iraq, Egypt, Syria, Jordan, Lebanon, Palestine, Qatar, Bahrain, Saudi Arabia, the United Arab Emirates, Oman, Somalia, Sudan, Mauritania, the Comoros Islands, Djibouti, Algeria, Morocco, Libya, Tunisia, Kuwait, and Yemen (Almukhaini *et al.*, 2022). We included studies published in English and Arabic languages. Full-text studies published in other languages were excluded due to a lack of resources for full translation.

Types of sources*:* This scoping review considered quantitative, qualitative, and mixed methods study designs for inclusion. We excluded conference and protocol papers, abstracts, systematic and non-systematic literature reviews, opinion pieces, dissertation theses, and letters to the editor.

Search strategy

A peer-reviewed search strategy (McGowan *et al.*, 2016) was developed in consultation with a health sciences librarian with expertise in systematic reviews (AR). As planned in our original protocol, we searched six commonly used databases in the health sciences– MEDINE (Ovid), EMBASE (Ovid), CINAHL (EBSCO), APA PsycInfo (Ovid), Global Health (Ovid), and Google Scholar (using Publish or Perish). In addition to these initially identified databases, we included the Ulrich's Periodicals Directory (Ulrichsweb.com) databases (UPDD) as a means of searching Arabic language publications explicitly. Because UPDD provides a directory search in English, we were able to located titles that might not otherwise have been included. Our electronic searches were all conducted in English to locate articles published from the inception of the database or journal. The last search was undertaken on February 20, 2023. The full search strategy for each information source is presented in Appendix I. Search strategies varied across databases to reflect slightly different content and subject terms. In cases where the databases were small (e.g. GlobalHealth) and screening would be very efficient, additional terms were not added.

Study selection

Following the search, we uploaded the search results from each electronic database to Covidence systematic review software (Veritas Health Innovation, Melbourne, Australia), and duplicates were removed. We performed two phases of screening: titles and abstracts, followed by full texts. Initially, we piloted the screening process on 3 studies to ensure the inclusion/exclusion criteria were clear and effective in selecting studies. Following the pilot test, the remaining titles and abstracts were screened by two reviewers independently. Then, we downloaded the full texts for all potentially relevant articles for further screening. The full texts of selected citations were assessed in detail against the inclusion criteria by two reviewers independently. Any disagreements between the two reviewers at each stage of the study selection process were resolved through discussion, without the need for a third reviewer. The inter-rater reliability score was (1) For the title and abstract screening, the reviewers achieved an 84% agreement rate. Cohen’s Kappa was calculated to account for chance agreement, yielding a value of 0.61, indicating substantial agreement. (2) For the full-text review, the reviewers achieved a 100% agreement rate. Cohen’s Kappa for the full-text review was 1, indicating almost perfect agreement.

Data extraction

We used a data-charting form adapted from JBI for data extraction (Peters MDJ *et al.,* 2020) – see Appendix II. This form was pilot-tested on 3 studies to ensure the data extraction was both comprehensive and feasible. Two reviewers independently completed data extraction. Conflicts were resolved through discussion. We extracted the following information from each article: study details (author, year, publication title, journal name, country in which the study was conducted, study purpose/aim/objective/question, design, methods, theoretical underpinnings); characteristics of caregivers (number of parental caregivers included, age, gender, relationship to care-recipient, and income); caregiver tasks described (yes/no, description); caregiver needs described (yes/no, description); care recipients' characteristics (age, gender, and level of disability); if an intervention was delivered (yes/no, delivery format); description of the assessment tool/measure.

Data analysis and presentation

The quantitative data was carried out in IBM SPSS Statistics for Windows, Version 28.0 (IBM Corp, Armonk, NY). We used descriptive statistics (frequency, percentage, mean, and standard deviation) to describe the characteristics of studies, caregivers, and care recipients, type of studies, sample size, age, gender, relationship to care recipient, and income). Furthermore, a content analysis approach, recommended by JBI (Peters MDJ *et al.*, 2020) was implemented to analyze qualitative data. Three reviewers familiarized themselves with the articles, systematically searched for descriptions/concepts, identified key themes across the studies, and sent them to the rest of the authors for approval. We presented the extracted data and findings in tabular format in a manner that aligns with the objective of this scoping review. A narrative summary accompanies the findings and describes how the results relate to the review's objective and questions.

RESULTS

Description of included studies

The initial search retrieved 87 records. After removing the duplicates (n =22), 65 titles and abstracts were screened based on the inclusion criteria, and 51 were excluded at this stage. The remaining 14 citations progressed to full-text screening, where four citations were excluded. Ten records were retained for data extraction and included in the review. The PRISMA-ScR flow diagram in Figure 1 presents the search and selection of articles for the scoping review.

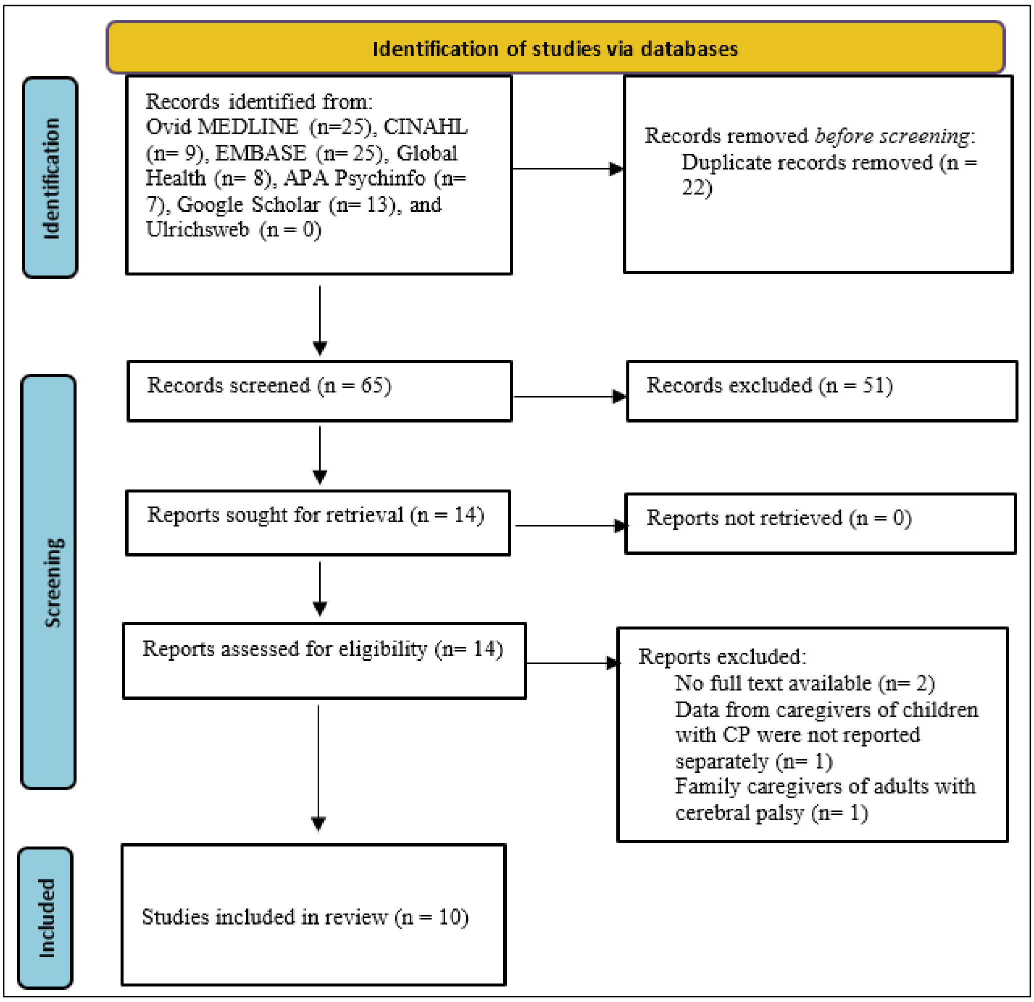

Figure 1: Search results and study selection and inclusion process (Page *et al.*, 2021)

The key characteristics of the included studies are summarized in Table 1. All studies (n=10, 100%) were published between 2013 and 2022. Studies were conducted across four Arabic countries, including Saudi Arabia (n=4, 40%), Jordan (n=4, 40%), Sudan (n=1, 10%) and Palestine (n=1, 10%). Studies were published in 10 different journals across the disciplines of Nursing, Rehabilitation, Neurosciences, Public Health, Dentistry, and Physiotherapy. In terms of study designs, seven studies (70%) were quantitative (Al-Gamal, 2013; Al-Gamal *et al.*, 2013; Alghamdi *et al.*, 2021; Almasri *et al.*, 2014; Mohammed *et al.*, 2016; Tahayneh1 *et al.*, 2020; Wyne *et al.*, 2017) and three studies (30%) were qualitative (Alwhaibi *et al.*, 2022; Mohamed Madi *et al.*, 2019; Nazzal *et al.*, , 2018), one of the qualitative studies was previously mentioned in two other reviews (Elangkovan *et al.*, 2020; Smith *et al.*, 2022), Questionnaires (n=8) and focus groups/interviews (n=2) were the most identified data collection methods. One study reported the use of the social model of disability (Mohamed Madi *et al.*, 2019) as a theoretical framework.

Table 1: Characteristics of included studies

Citation	**Title**	**Journal name**	**Country**	**Purpose**	**Design**	**Data collection method(s)**	**Theoretical framework**
Al-Gamal, 2013	Quality of life and anticipatory grieving among parents living with a child with cerebral palsy	International Journal of Nursing Practice	Jordan	To describe the quality of life and anticipatory grieving among Jordanian parents living with a child with CP.	Cross-sectional	Questionnaire	NR
Al-Gamal *et al.*, 2013	Psychological distress and perceived support among Jordanian parents living with a child with cerebral palsy: a cross-sectional study	Scandinavian Journal of Caring Sciences	Jordan	To provide insight into the psychological distress and perceived support among Jordanian parents living with a child with CP.	Cross-sectional	Questionnaire	NR
Alghamdi *et al.*, 2021	Cross-cultural adaptation of the Arabic version of Self-Care Domain of Child Engagement in Daily Life and Ease of Caregiving for Children measures	Research in Developmental Disabilities	Saudi Arabia	To cross-culturally adapt the Self-Care Domain of Child Engagement in Daily Life and the Ease of Caregiving for Children to Arabic language and Saudi culture and to examine the reliability of the Arabic version of both measures	Cross-sectional	Questionnaire	NR
Almasri *et al.*, 2014	Psychometric properties of the Arabic Family Support Scale for families of children and youth with cerebral palsy in Jordan.	Journal of Intellectual and Developmental Disability	Jordan	To (a) describe the process of translation and cultural validation of the Arabic Family Support Scale (A-FSS; Dunst *et al.*,1984), (b) examine the psychometric properties of the A-FSS on a sample of Jordanian families of children and youth with CP, and (c) identify and quantify sources of support for Jordanian parents of children with CP.	Cross-sectional	Questionnaire	NR
Alwhaibi *et al.*, 2022	Factors affecting mothers' adherence to home exercise programs designed for their children with cerebral palsy	International Journal of Environmental Research and Public Health	Saudi Arabia	To find out what factors influence Saudi mothers' compliance with their children with CP's Home Exercise Program (HEP)	Qualitative	Questionnaire	NR

Citation	**Title**	**Journal name**	**Country**	**Purpose**	**Design**	**Data collection method(s)**	**Theoretical framework**
Mohamed Madi *et al.*, 2019	The perception of disability among mothers living with a child with cerebral palsy in Saudi Arabia	Global Qualitative Nursing Research	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.	Qualitative	Focus group interviews	The social model of
Mohammed *et al.*, 2016	Quality of life of cerebral palsy patients and their caregivers: A cross-sectional study in a rehabilitation center Khartoum-Sudan	Journal of Neurosciences in Rural Practice	Sudan	To measure the QoL of CP patients and their caregivers and determine the factors affecting both of them	Cross-sectional	Questionnaire	NR
Nazzal *et al.*, 2018	Lived experiences of Jordanian mothers caring for a child with a disability	Disability and Rehabilitation	Jordan	To explore the perspectives, challenges and adaptations of Jordanian mothers living with a child with disability.	Qualitative	Individual interviews	NR
Tahayneh *et al.*, 2020	Factors affecting mother' s adherence towards cerebral palsy home exercise program among children at Hebron and Bethlehem, Palestine	International Journal of Pharmaceutical Research	Palestine	To investigate the factors associated with mothers' adherence towards CP home exercise program among children at Hebron and Bethlehem city.	Cross-sectional	Questionnaire	NR
Wyne *et al.*, 2017	Oral health comprehension in parents of Saudi cerebral palsy children	Saudi Dental Journal	Saudi Arabia	To determine oral health comprehension among parents of CP children.	Cross-sectional	Questionnaire	NR

NR, Not reported.

Description of demographic and clinical characteristics of caregivers and their care recipients with CP

The characteristics of caregivers and their care recipients with CP are summarized in Table 2. Across studies, sample sizes of caregivers ranged between 6 and 230 participants (Almasri *et al.*, 2014; Mohamed Madi *et al.*, 2019), while the number of care recipients ranged between 6 and 200 children with CP (Al-Gamal, 2013; Al-Gamal *et al.*, 2013; Mohamed Madi *et al.*, 2019). Most caregivers were young adult mothers (n=778/1070 participants), with mean age ranging between 33 and 39.5 years old. Reported across eight studies (Al-Gamal, 2013; Al-Gamal *et al.*, 2013; Alghamdi *et al.*, 2021; Almasri *et al.*, 2014; Alwhaibi *et al.*, 2022; Mohammed *et al.*, 2016; Nazzal *et al.*, 2018; Wyne *et al.*, 2017), care recipients were predominantly male children with CP (n=529/916), with mean age ranging between 2.2 and 10.3 years old. Six studies reported the income of caregivers (Al-Gamal, 2013; Al-Gamal *et al.*, 2013; Alghamdi *et al.*, 2021; Almasri *et al.*, 2014; Alwhaibi *et al.*, 2022; Tahayneh1 *et al.*, 2020), ranging between $564.98 and $3918.83 per month, corresponding to below-average incomes in the respective countries. To ensure consistency and comparability across the studies, we reported income using the Canadian dollar. Five studies (Al-Gamal, 2013; Al-Gamal *et al*, 2013; Alghamdi *et al.*, 2021; Almasri *et al.*, 2014; Mohammed *et al.*, 2016) reported the level of disability of care recipients according to the Gross Motor Functional Classification System (GMFCS), with mixed distribution across all levels. Most children (n=172) were classified as GMFCS level V (Al-Gamal, 2013; Al-Gamal *et al.*, 2013; Alghamdi *et al.*, 2021; Almasri *et al.*, 2014; Mohammed *et al.*, 2016). The GMFCS is a standardized tool that categorizes children with CP into different levels based on their motor abilities, ranging from level I to level V (Mushta *et al.*, 2019).

Description of needs of parents of children with CP in Arab contexts

In terms of needs, most studies (n=7) identified the support needs of families, emphasizing an overall lack of support. Support needs were categorized as emotional, physical, material/instrumental, and informational (Kyzar *et al.*, 2012). Assistance that improves psychosocial functioning and well-being, such as reducing stress or increasing positive emotions, is referred to as emotional support. Support for accessing financial services and completing family tasks is referred to as material or instrumental support. Physical support helps improve a person's health and daily living skills. Informational support involves providing information to guide the family’s decision-making. The studies indicated the necessity for Arab families of children with CP to be equipped with comprehensive information related to their child's health condition (including oral health), how to access diverse services and the importance of implementing home exercises. Furthermore, many parent caregivers report the need for emotional support and a lack of support from other family members (e.g., unreliable/unsupportive fathers or extended family) or society (Al-Gamal, 2013; Mohamed Madi *et al.*, 2019; Mohammed *et al.*, 2016; Nazzal *et al.*, 2018). One study reported that parents need support related to accessing financial services (Nazzal *et al.*, 2018). No physical support needs were reported, nor were any parent-caregiver support interventions evaluated across the 10 included studies. However, the included studies indicated that it is imperative to advocate for the provision of multidisciplinary support and services centered around the family's needs, and policies that adequately support parents of children with CP (Al-Gamal *et al.*, 2013; Almasri *et al.*, 2014; Alwhaibi *et al.*, 2022; Mohamed Madi *et al.*, 2019; Wyne *et al.*, 2017).

Table 2: Characteristics of caregivers and their care-recipients with CP

Citation	**Caregiver characteristics**							**Care-recipient characteristics**		
	Sample size	**Mean age (SD)**	**Relationship with care-recipient n (%)**	**Caregiver tasks**	**Income (Mean/ range)**	**Caregiver needs**	**Caregiving consequences**	**Mean age (SD)**	**Gender n (%)**	**GMFCS n (%)**
Al-Gamal 2013	204	34.7 (7.33)	Mothers: 134 (65.69) Fathers: 70 (34.31)	Heavy lifting and turning, bathing, helping the child use a toilet, getting the child to sleep, dressing, and assisting the child to move	$576.86	Social support	personal sacrifice, sadness, burden, and lower quality of life.	4.6 (NR)	Girls: 79 (38.7) Boys: 125 (61.27)	Level 1: 36 (18.2) Level 2: 46 (23.2) Level 3: 34 (17.2) Level 4: 26 (13.1) Level 5: 56 (28.3)
Al-Gamal *et al.*, 2013	210	34.7 (7.33)	Mothers: 134 (63.81) Fathers: 70 (36.19)	NR	$576.85	Policy to provide support for parents and to develop family-centered services, and multi-professional support	Stress, nervousness, depression, low parental social support	4.6 (NR)	Girls: 79 (38.7) Boys: 125 (61.27)	Level 1: 36 (18.2) Level 2: 46 (23.2) Level 3: 34 (17.2) Level 4: 26 (13.1) Level 5: 56 (28.3)
Alghamdi *et al.*, 2021	36	34 (7.1)	Mothers: 25 (69.44) Fathers: 11 (30.56)	Child’ s mobility, positioning, and self-care	<$1068.87- $2137.38: 6; $2137.74- $3206.25: 5; $3206.61- $3918.83: 3	NR	NR	6 (2.7)	Girls: 12 (40) Boys: 18 (60)	Level 1: 6 (20) Level 2: 4 (13.33) Level 3: 3 (10) Level 4: 4 (13.33) Level 5: 13 (43.33)
Almasri *et al.*, 2014	230	36(12.2)	Mothers: 115 (50) Fathers: 115 (50)	NR	<$564.98/ month: 53 $564.98–1129.97/month: 44 $1129.97–$1,993.28/ month: 10 > $1883.28/ month: 7	providing information regarding child health conditions and access to different types of services, and advocate the provision of services within the FCS model	NR	4.6 (4.4)	Girls: 54 (47) Boys: 61 (53)	Level 1: 19 (16.5) Level 2: 15(13) Level 3: 24 (20.9) Level 4: 32 (27.7) Level 5: 25 (21.7)

Citation	**Caregiver characteristics**							**Care-recipient characteristics**		
	Sample size	**Mean age (SD)**	**Relationship with care-recipient n (%)**	**Caregiver tasks**	**Income (Mean/ range)**	**Caregiver needs**	**Caregiving consequences**	**Mean age (SD)**	**Gender n (%)**	**GMFCS n (%)**
Alwhaibi *et al.*, 2022	113	33.6	Mothers: 113 (100)	Provide a home exercise program for their children	<$1783.3: 23 $1783.31-$3566.62: 35	Awareness workshops for mothers about the importance of home exercise programs	NR	5.8 (3)	Girls: 44 (40.4) Boys: 65 (59.6)	NR
Mohamed Madi *et al.*, 2019	6	NR	Mothers: 6 (100)	NR	NR	Need for clinicians to listen to the mothers to consider their beliefs and the impact of these beliefs on their experiences	Maternal anxiety; resilience if mothers believe their child's disability is from God; stigma from community; blamed, shamed, stigmatized, and socially isolated due to their child's disability	10.3 (NR)	NR	NR
Mohammed *et al.*, 2016	65	34.2 (10.2)	Mothers: 60 (92.31) Fathers: 1 (1.54) Grandmothers: 4 (6.15)	Moving, feeding, bathing, playing, chatting, going out together, watching television and in few instances teaching	NR	NR	Reduced quality of life	7.5(2.9)	Girls: 24 (36.9) Boys: 41 (63.1)	Level 1: 6 (9.2) Level 2: 3(4.6) Level 3: 17 (26.2) Level 4: 17 (26.2) Level 5: 22 (33.8)
Nazzal *et al.*, 2018	7	39.5(6.8)	Mothers: 7 (100)	NR	NR	Financial, Social, Emotional	Increased perceived stigma, fear for the future, increased perceived care-giving burden and, adaptations to the child’ s disability	10.2 (3.5)	Girls: 4 (57.1) Boys: 3 (42.9)	NR
Tahayneh *et al.*, 2020	48	33 (10.1)	Mothers: 48 (100)	NR	<$400: 6 $401-$999: 22 >$1000: 18	NR	NR	2.2 (0.65)	NR	NR
Wyne *et al.*, 2017	157	34(7.3)	Mothers: 136 (86.62) Fathers: 21 (13.38)	NR	NR	Oral health education in several areas	NR	6.7 (2.7)	Girls: 67 (42.7) Boys: 90 (57.3)	NR

NR, Not reported; SD, Standard deviation; GMFCS, The Gross Motor Function Classification System

Description of caregiving tasks of parents of children with CP in Arab contexts

Information regarding caregiving tasks was reported across four studies (40%) (Al-Gamal, 2013; Alghamdi *et al.*, 2021; Alwhaibi *et al.*, 2022; Mohammed *et al.*, 2016). These tasks included transferring, dressing, washing/bathing, mobility (and transportation), cooking, feeding, toileting, housekeeping, playing, teaching, oral care, providing a home exercise program, and shopping. The most common tasks reported were transferring (3/4 studies), dressing (3/4 studies) and washing/bathing (3/4 studies).

Description of consequences of caregiving among parents of children with CP in Arab contexts

Five studies reported information about the consequences of parental caregiving of children with CP (Al-Gamal, 2013; Al-Gamal *et al.*, 2013; Mohamed Madi *et al.*, 2019; Mohammed *et al.*, 2016; Nazzal *et al.*, 2018). Parents in these studies reported how their physical and psychological health was affected by their child's diagnosis. For example, some parents (particularly mothers) experienced chronic pain, stress, depression, and/or reduced quality of life due to the heavy care burden of having a child with CP (Al-Gamal, 2013; Al-Gamal *et al.*, 2013; Mohamed Madi *et al.*, 2019; Nazzal *et al.*, 2018). Parents in one study reported an increase in resilience as a positive consequence associated with caregiving (Mohamed Madi *et al.*, 2019).

Description of caregiving experiences of parents of children with CP in Arab contexts

Relative to caregiving experiences, two of the three qualitative studies explored the experiences of mothers of children with CP (Mohamed Madi *et al.*, 2019; Nazzal *et al.*, 2018). Across the findings of the two studies, five common themes emerged that shed light on the challenges faced by these mothers. The themes include mothers experiencing challenges related to the diagnosis and acceptance of their child's condition, stigmatization and negative societal attitudes, limited access to specialized healthcare services, financial burdens, and inadequate support systems. The available evidence highlights how cultural factors play a significant role in shaping the experiences of mothers. Specifically, traditional beliefs, misconceptions, and cultural norms influence parents' perceptions of CP, impacting their acceptance, help-seeking behaviours, and treatment choices. For instance, in the study by Madi *et al.*, 2019 the mothers believed that the causes of CP are "Evil Eye" and "Jinn" (i.e., invisible spirits that inhabit the earth, capable of assuming various forms and influencing humankind for either good or evil).

"I believe what happened to my son was a strong ayn (evil eye) that hit his health. I felt it one day when I had a large gathering in my house and one of the ladies without saying Masha'Allah (God protect you from envy), said, "You have a pretty child." (Mohamed Madi *et al.*, 2019)

In the hope of finding a cure for their children, some mothers sought to utilize all treatment options, including healing through the Quran (the holy book in Islam) (Mohamed Madi *et al.*, 2019) The authors suggested that health and social care providers need to consider caregivers' beliefs and the effects of these beliefs on their caregiving experience.

Stigma and societal pressure often result in feelings of isolation, emotional distress, and a lack of understanding and support from the wider community. In fact, the studies show that both children with CP and their parents experience stigma, affecting the family dynamics and quality of life. For example, mothers were commonly blamed for their children's disability (Mohamed Madi *et al.*, 2019; Nazzal *et al.*, 2018)

"My mother-in-law blamed me for not having a healthy child. Society blames the mother. In the beginning, my mother and my aunts told me to admit him to disabled centers and to leave him till he became independent, but I refused" (Mohamed Madi *et al.*, 2019)

"When my son goes out, children in the neighborhood start laughing at him often calling him 'crippled,' or 'disabled.' These voices keep resounding in my head and it hurts deep down to hear people calling my child as such." (Nazzal *et al.*, 2018)

DISCUSSION

We conducted this scoping review to understand the existing literature concerning the needs and experiences, caregivers' characteristics included in caregiving studies, caregiver needs, tasks, challenges, and consequences of caregiving, and interventions targeting parents of children with CP in Arab countries. This exploration is motivated by the recognition that family life is intricately influenced by historical, social, and cultural contexts (26). To our knowledge, this is the first scoping review with a specific focus on Arab parental caregiving of children with CP. We found 10 out of 87 potential studies provided information about the parent role in caring for children with CP in the Arab region, reflecting limited consideration of this important topic within the domain of caregiver research. Nevertheless, all the included studies were published in the last decade, which may reflect an emerging interest in this topic. The findings of this review shed light on several key aspects related to parental experiences (primarily mothers), support needs, and challenges in the context of CP within the Arab region.

Key findings and future research recommendations

Despite increasing awareness of the importance of exploring parental experiences and perspectives across many societies (Jansen-Van Vuuren *et al.*, 2021;

Ni *et al.*, 2022), we found little targeted exploration of the experiences of Arab parents of children with CP. Specifically, our review showed that CP caregiving literature in Arab countries has focused primarily on the experiences and perspectives of young adult mothers raising a child with CP (Mohamed Madi *et al.*, 2019; Nazzal *et al.*, 2018). Fathers' experiences and perceptions of their role in parenting a child with CP are under-researched, thereby limiting understanding of their role. This knowledge gap could be attributed to the traditional caregiving role in Arab families, where there is a gender predominance of mothers as the primary caregivers (Elangkovan *et al.*, 2020; Vadivelan *et al.*, 2020) and cultural factors that reinforce these gender roles (Ridge *et al.*, 2017), making it difficult for fathers to be actively involved in caregiving activities.

When exploring parental caregiving for children with a disability, it is important to consider the perspectives of both mothers and fathers due to the growing interest in co-parenting (Boyd *et al.*, 2019) and parental role-sharing (Farber, 2000). Given the increasing interest in family-centered care in pediatric health service delivery globally (Cook *et al.*, 2022), we argue that focusing solely on mothers and their experiences of the caregiving role may overlook crucial information and fail to capture the complete picture of care provision for children with CP. While little targeted exploration of the experiences of Arab parents of children with CP has been conducted, studies from other contexts have explored fathers' experiences of caring for a child with CP. For instance, studies conducted in the United States (Bonsall, 2018) and Australia (Davis *et al.*, 2010) found that fathers of children with CP experienced high levels of stress and anxiety and decreased sense of control over their lives due to caregiving responsibilities. These studies provide valuable insights into the experiences of fathers caring for children with CP, but further research is needed in Arab countries to gain a better understanding of the unique experiences and challenges faced by Arab fathers of children with CP. Future research should examine if and how fathers and mothers of children with CP function together as a family caregiving network, including what they are doing in their roles, how they coordinate their efforts to provide fulsome support for their children. Generating this knowledge may help clarify family dynamics, identify individuals who may need more support in their roles and inform the development of appropriate strategies to avoid negative caring outcomes.

In terms of support needs, this scoping review identified that parents of children with CP face significant challenges in accessing appropriate health and social care services. Specifically, the included studies show that healthcare systems in the included countries may not be adequately equipped to meet the needs of these families. The parents' reports of a marked absence of sensitive care and emotional support indicate a critical void in the provision of comprehensive assistance (Al-Gamal, 2013; Mohamed Madi *et al.*, 2019; Nazzal *et al.*, 2018). In light of acknowledged deficiencies in healthcare professionals' collaboration (Alwhaibi *et al.*, 2022; Mohamed Madi *et al.*, 2019; Mohammed *et al.*, 2016; Nazzal *et al.*, 2018), insufficient financial support (Nazzal *et al.*, 2018), inadequate information about their children’s condition (Al-Gamal *et al.*, 2013; Almasri *et al.*, 2014; Alwhaibi *et al.*, 2022; Wyne *et al.*, 2017), and stigma (Mohamed Madi *et al.*, 2019; Nazzal *et al.*, 2018), parents often find it challenging to navigate caring for a child with CP. Addressing these unmet needs will enhance the well-being of parents and holds profound implications for the overall care and outcomes for children with CP. The findings of this scoping review highlight a critical need for extensive, standard access to support networks that can be tailored to the specific needs of each family and cultural sensitivity to the health and social care delivery for families of children with CP in the Arab context (Alheresh *et al.*, 2013). We call for a paradigm shift in health and social care practices, incorporating culturally sensitive family-centered approaches to better meet the diverse needs of families of children with CP in the Arab region (Shevell *et al.*, 2019).

The literature about CP caregiving in the Arab context is further dominated by studies documenting the negative consequences of caregiving, including parental stress, depression, anticipatory grief, and poor quality of life and overall well-being (Al-Gamal, 2013; Al-Gamal *et al.*, 2013; Mohammed *et al.*, 2016). These studies are typically cross-sectional and rarely make explicit links between parents' roles, the frequency of their caregiving tasks, or the severity of the children's condition. These findings have several implications. First, there is a need to carefully document what parents are doing in enough detail to understand the variability in their tasks and the frequency and demands of these tasks as their child grows. CP is well known to be variable and result in long-term impairments(Al-Gamal, 2013). Therefore, it can be expected that demands on caregivers also vary. Understanding how parental caregiving evolves over time and how tasks and the time required vary may provide important insights into why parents experience the negative outcomes that have been documented. Second, documenting the positive consequences of caregiving can help parents stay motivated and resilient as they care for their child with CP. Additionally, this knowledge can inform how health and social care providers support families by acknowledging the challenges they face while also recognizing the strengths and positive aspects of their experiences.

This review identified limited existing research about parents of children with a CP in an Arab context, particularly related to their experiences. To draw lessons from the experiences of parents and other caregivers in the Arab region, further research needs to be conducted to explore their needs and positive aspects of their caregiving role. It is evident that socioeconomic factors, healthcare infrastructure, and cultural attitudes towards disability profoundly influence the caregiving experience. For example, high-income countries generally offer more robust support systems and resources (Elangkovan *et al.*, 2020),whereas parents in low- and middle-income countries often encounter substantial barriers to accessing necessary care and support (Vadivelan *et al.*, 2020). Additionally, cultural attitudes towards disability and the availability of specialized care services can vary significantly between different context, impacting the experiences of parents and caregivers. Accordingly, there is a need to emphasize the importance of considering the specific context and challenges faced by parents of children with CP in the Arab context and adjusting support systems to meet parent's needs.

The scoping review revealed a lack of studies focusing on interventions and strategies explicitly targeting parents of children with CP in the Arab context. Empowering parents through targeted support interventions can improve their self-efficacy and coping strategies and may contribute to a reduced likelihood of maltreatment, neglect, or abuse toward children with CP. For instance, globally it was evident that psychoeducational programs and workshops enhance parental well-being, knowledge, coping skills, and decrease caring burden (Dambi *et al.*, 2017). Parents can also be engaged as active participants in decision-making processes and involved in designing and evaluating targeted interventions for optimal well-being (Al-Gamal, 2013; Al-Gamal *et al.*, 2013; Mohamed Madi *et al.*, 2019; Nazzal *et al.*, 2018). However, further research is needed to evaluate the effectiveness and long-term outcomes of such interventions and strategies within the specific cultural and social Arab contexts.

Limitations

This review has several limitations that warrant consideration. First, this review was limited to only peer-reviewed articles. The restriction to only peer-reviewed literature meant that grey literature, such as dissertation theses, government reports, or studies commissioned by CP societies or other similar organizations, were not included. It is possible that this approach excluded culturally relevant contextual information. Second, we restricted the search to one Arabic database, which may have excluded studies addressing more diverse topics in another database. Third, the search in the Arabic database was conducted in English due to limitations in the database's acceptance of Arabic words, which may have resulted in missing relevant studies.

CONCLUSIONS

The current scoping review has shown the paucity of information regarding parental caregivers of children with CP in the Arab context. Future research should focus on understanding the caregiving networks of these children, examining how these networks develop and operate as care needs evolve over time. Additionally, it is critical to investigate the activities of caregivers, the ways they acquire necessary skills, and the positive and negative consequences of their caregiving roles. Additionally, researchers have yet to comprehensively explore the experiences of the parents of children with CP in the Arab context. Addressing these gaps will contribute to the development of evidence-based practices and policies that positively impact the lives of families affected by CP.

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Author contributions

Conceptualization, AA, AF, HA, DM; search strategy and literature searches, AR; study selection, AA, SM, SP; data extraction, AA, SM, SP; data synthesis and interpretation, AA, SM, SP, AF; writing—original draft preparation, AA, SM, SP, AF; writing—review and editing, AA, SM, SP, AF, HA, DM, AR. All authors have read and agreed to the published version of the manuscript.

Conflicts of interest

The authors declare that they have no conflict of interest.

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Appendix I: Search terms used in database searches.

MEDLINE (Ovid)

Search	**Query**	**Records retrieved**
#1	cerebral palsy/ or "cerebral palsy".mp.	32571
#2	Iraq* or Egypt* or Syria* or Jordan* or Lebanon* or Palestine* or Qatar* or Bahrain* or "Saudi Arabia*" or SA or "United Arab Emirates" or UAE or Oman* or Somali* or Sudan* or Mauritania* or "Comoros Islands" or Djibouti or Algeria* or Morocco* or Libya* or Tunisia* or Kuwait* or Yemen.mp.	234715
#3	#1 AND #2	25

Embase (Ovid)

Search	**Query**	**Records retrieved**
#1	cerebral palsy/ or "cerebral palsy".mp.	49513
#2	Iraq* or Egypt* or Syria* or Jordan* or Lebanon* or Palestine* or Qatar* or Bahrain* or "Saudi Arabia*" or SA or "United Arab Emirates" or UAE or Oman* or Somali* or Sudan* or Mauritania* or "Comoros Islands" or Djibouti or Algeria* or Morocco* or Libya* or Tunisia* or Kuwait* or Yemen.mp.	332483
#3	#1 AND #2	25

CINAHL (EBSCO)

Search	**Query**	**Records retrieved**
#1	(MH "Cerebral Palsy")	13,491
#2	(MH "Family+")	263,757
#3	(MH "Caregivers")	41,769
#4	(MH "Bahrain") OR (MH "Egypt") OR (MH "Iraq") OR (MH "Jordan") OR (MH "Kuwait") OR (MH "Lebanon") OR (MH "Libya") OR (MH "Oman") OR (MH "Qatar") OR (MH "Saudi Arabia") OR (MH "Syria") OR (MH "United Arab Emirates") OR (MH "Yemen")	26,110
#5	(MH "Djibouti") OR (MH "Somalia") OR (MH "Sudan")	2,430
#6	(MH "Mauritania") OR (MH "Algeria") OR (MH "Egypt") OR (MH "Libya") OR (MH "Morocco") OR (MH "Tunisia") OR (MH "Africa, Northern")	7,766
#7	(TI (Iraq* or Egypt* or Syria* or Jordan* or Lebanon* or Palestine* or Qatar* or Bahrain* or "Saudi Arabia*" or "United Arab Emirates" or UAE or Oman* or Somali* or Sudan* or Mauritania or "Comoros Islands" or Djibouti* or Algeria* or Morocco* or Libya* or Tunisia* or Kuwait* or Yemen*)) OR (AB (Iraq* or Egypt* or Syria* or Jordan* or Lebanon* or Palestine* or Qatar* or Bahrain* or "Saudi Arabia*" or "United Arab Emirates" or UAE or Oman* or Somali* or Sudan* or Mauritania or "Comoros Islands" or Djibouti* or Algeria* or Morocco* or Libya* or Tunisia* or Kuwait* or Yemen*))	34,835
#8	#4 OR #5 OR #6 OR #7	44,201
#9	#2 OR #3	290,733
#10	#1 AND #8 AND #9	9

APA PsycInfo (Ovid)

Search	**Query**	**Records retrieved**
#1	cerebral palsy/ or "cerebral palsy".mp.	6397
#2	exp family members/	199137
#3	Caregivers/	37682
#4	2 or 3	227946
#5	1 and 4	673

#6	Iraq* or Egypt* or Syria* or Jordan* or Lebanon* or Palestine* or Qatar* or Bahrain* or "Saudi Arabia*" or SA or "United Arab Emirates" or UAE or Oman* or Somali* or Sudan* or Mauritania* or "Comoros Islands" or Djibouti or Algeria* or Morocco* or Libya* or Tunisia* or Kuwait* or Yemen.mp.	38209
#7	#5 AND #6	7

Global Health (Ovid)

Search	**Query**	**Records retrieved**
#1	cerebral palsy/ or "cerebral palsy".mp.	1484
#2	Iraq* or Egypt* or Syria* or Jordan* or Lebanon* or Palestine* or Qatar* or Bahrain* or "Saudi Arabia*" or SA or "United Arab Emirates" or UAE or Oman* or Somali* or Sudan* or Mauritania* or "Comoros Islands" or Djibouti or Algeria* or Morocco* or Libya* or Tunisia* or Kuwait* or Yemen.mp.	110806
#3	#1 AND #2	8

Google Scholar

Search	**Query**	**Records retrieved**
#1	Family AND Caregivers AND Children AND Cerebral palsy AND Iraq OR Egypt OR Syria OR Jordan OR Lebanon OR Palestine OR Qatar OR Bahrain OR "Saudi Arabia" OR "United Arab Emirates" OR UAE OR Oman OR Somali OR Sudan OR Mauritania OR "Comoros Islands" OR Djibouti OR Algeria OR Morocco OR Libya OR Tunisia OR Kuwait OR Yemen.	13

Ulrich's Periodicals Directory (Ulrichsweb.com) databases.

Search	**Query**	**Records retrieved**
#1	Children AND Cerebral palsy AND Family caregivers AND Arabic	0

Appendix II: Data extraction instrument

Citation
Title
Year of publication
Journal name
Country in which the study conducted
Study purpose/objective/aim
Study design
Data collection methods
Theoretical framework
Caregiving characteristics
Sample size
Mean (SD) Age
Relationship with care-recipient
Caregiving tasks
Income
Needs
Experiences
Consequences of caregiving
Details about caregiver assessment and interventions
Care-recipient characteristics
Mean (SD) Age
Gender
GMFCS