

# Quality of life of mothers having cerebral palsied child: A systematic review

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## **Abstract**

### **Aim:**

Caring for a child with cerebral palsy (CP) can influence both the physical and mental health of parents. Mother act as the primary caregiver within the most Indian family. The aim of this systematic review is to describe the quality of life (QOL) of mothers of children with cerebral palsy and identify determinants associated with mother's Quality of life.

### **Method:**

Eligible qualitative studies were systematically searched from three databases and a synthesis was performed. The search was conducted from 2019 until 2021 and there were no date restrictions. The reporting of results is based on ENTREQ guidelines for reporting qualitative systematic reviews.

### **Results:**

The search strategy identified 709 records, 62 of which underwent full-text screening, and 11 met the inclusion criteria. Forward citation tracking identified one additional article, and the automated alerts of studies published after the search date identified two articles. Therefore, 14 articles were included in this systematic review.

## **Conclusion:**

Quality of life (QoL) of mothers with CP children is considered to be affected negatively; hence, in planning a rehabilitation program for CP children, QoL of mothers should also be evaluated in detail and mothers should be encouraged to participate in social activities related to their interests. Further mothers should be involved in the clinical decision making process and Rehabilitation of cerebral palsied child.

**Key words:** Determinants, Quality of life (QoL), Mothers, Caregiver, Cerebral Palsy, Rehabilitation, Review

## **Introduction**

Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, behaviour, by epilepsy and by secondary musculoskeletal problems<sup>1</sup>. The diagnosis and classification of cerebral palsy is mainly based on motor function and posture impairments that occur in early childhood and persist through the course of life; they are non-progressive, but change with age<sup>2</sup>. Caring for a child with cerebral palsy (CP) can influence both the physical and mental health of parents<sup>3</sup>. However, determinants associated with quality of life (QoL) in these parents are yet to be appropriately scrutinised. Disabilities of children may burden their family members, especially their mothers, who are their long-term caregivers<sup>4</sup>. Mother perform and function as the primary caregiver within the most Indian family. Mothers with children having cerebral palsy always traverse a strenuous experience. It influences various facets of their life negatively. This systematic review will assist in recognising the realms of QoL (Quality of Life) which are affected negatively by their children's disability. By considering the findings of this review, suggestions to modify management and exploring the role of mothers in rehabilitation can be recast. It was found from initial review that no systematic reviews were conducted definite to this domain and this review aims to study the aspects of QoL of mothers with cerebral palsied children.

## **Objectives:**

This systematic review is aimed to

- 1) Describe the quality of life (QOL) of mothers of children with cerebral palsy
- 2) Identify determinants associated with mother's Quality of life and intended to bring out pooled evidence on quality of life (QOL) of mothers with children having cerebral palsy, which will affect the rehabilitation of the affected child.

## **Methodology:**

### **Design**

To synthesise the existing evidence, we performed a systematic review of qualitative studies, which was conducted according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement<sup>5</sup> and the Enhancing Transparency in Reporting the Synthesis of Qualitative Research statement.<sup>6</sup>

### **Operational Definition of Cerebral Palsy**

Cerebral palsy (CP) is defined as a “group of permanent disorders of the development of movement and posture” resulting from non-progressive disturbances that occur in the developing fetal or infant brain. The motor disorders of CP are often accompanied by conditions such as disturbance of sensation, perception, cognition, and communication; epilepsy; and secondary musculoskeletal problems (Rosenbaum et al., 2007)<sup>1</sup>

### **Operational Definition of Quality of life (QOL)**

QOL was defined as "individuals' perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the persons' physical health, psychological state, level of independence, social relationships, spiritual, personal beliefs, religion and their relationship to salient features of their environment" (S Saxena , J Orley)<sup>7</sup>

### **Search strategy**

We conducted a comprehensive search of MEDLINE (through PubMed), Scopus and Pedro using a combination of subject headings, MESH words and keywords relating to 1) “cerebral palsy”, 2) Quality of life, and 3) mothers. Specifically, we searched for (exp “Quality of Life”/ or quality of life), and (exp Cerebral palsy / “cerebral palsy”), and (exp Parents/ or parent\* or mother or primary giver) and restricted the search to studies on humans and published in English. Boolean words of AND, OR, NOT and truncations wherever necessary were used during the search process. There were no date restrictions. To ensure no records were omitted from the search strategy, reference lists of all included studies were manually searched (backward citation tracking), and Scopus, and Google Scholar were used to identify articles citing the articles included in this review (forward citation tracking). In addition, alerts were set on Google Scholar to identify studies published after the search date using the terms mentioned above. The search was conducted from 2019 in the mentioned databases.

The review included qualitative peer-appraised studies. Qualitative data from mixed methods-studies, case studies, cross sectional studies, phenomenological studies, grounded theory, and ethnographic methods were screened and included if the qualitative factor is relevant. Also, any study that uses qualitative methods for data collection such as interviews (individual and focus group), and qualitative methods for data analysis such as thematic analysis were included.

## **Selection of study and process of data management**

The PRISMA and ENTREQ guidelines for reporting qualitative systematic reviews was used to demonstrate the selection processes and results. All retrieved studies were initially imported into Mendeley to assist in removing duplicates. After removing the duplicates, Mendeley results were shared between the two reviewers to independently screen the articles by title and abstract, guided by the eligibility criteria. The studies reviewed by the two reviewers and consensually agreed upon will be subjected to the full-text review. A third reviewer adjudicated any discrepancies between the two reviewers. The two reviewers independently reviewed the full text of all eligible studies. In the case where there are differences between the two reviewers, consensus was sought through discussion on the differences with the third reviewer. Finally, the full texts of all relevant studies found to meet the inclusion criteria was retained for the final systematic review.

## **Study exclusion criteria**

Studies were excluded if not available in English, conference abstracts, books or grey literature and editorial comments were not included in the review. Studies were excluded if the mothers had existing chronic conditions, such as diabetes, heart diseases, or neurologic disorders, pregnant women, and those who had additional caregiving responsibilities apart from their routine maternal care (for instance, taking care of another disabled person).

## **Quality appraisal**

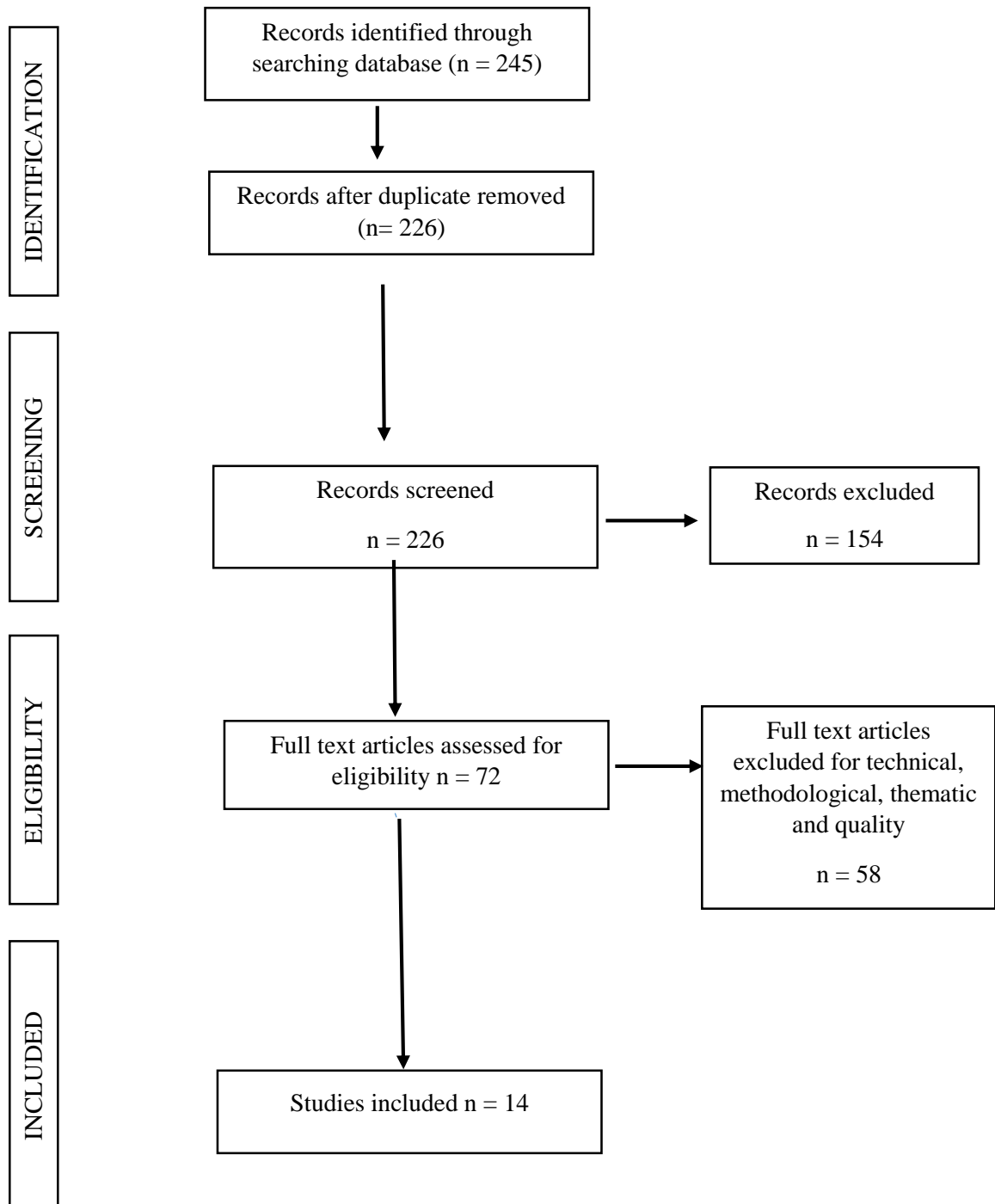
All retrieved articles eligible for inclusion were critically appraised for quality assessment process during the synthesis of results. Two independent reviewers using the Joanna Briggs Institute's Critical Appraisal Checklist for Qualitative Research assessment tool conducted the critical appraisal<sup>8</sup>. The third reviewer moderated disagreements between the two reviewers, and the contentious points was discussed among the three reviewers to arrive at a consensus. This tool was developed primarily for use in systematic reviews. The results were used to determine the quality of the studies included and consistent with the standard quality appraisal for articles reporting on qualitative studies.

## **Data extraction and synthesis**

Data relevant to describing patient and parent characteristics, parental QOL, and factors associated with parental QOL were extracted and by reviewed by the independent reviewers. Quality appraisal approach was used in the synthesis of data. Thematic synthesis was addressed by addressing aims, context, rationale, methods and findings, reliability, validity, appropriateness of methods for ensuring findings are grounded in participant perspectives. Meta – ethnography by addressing the relevance of study. Critical interpretive synthesis assesses the degree to which the research findings inform theory development. Meta-study assess the epistemological soundness (the theory of the nature and grounds of knowledge) and rigour of the research methods. Study characteristics were extracted include detailed information of the selected studies which included author names, nation of participants, age of the participants, exclusion criteria, care giver characteristics along with method for QoL assessment, aim and main results.

## Results

The Preferred Reporting Items for Systematic Reviews and Meta- Analyses (PRISMA) guidelines were followed. The search strategy identified 709 records, 62 of which underwent full-text screening, and 11 met the inclusion criteria. Forward citation tracking identified one additional article, and the automated alerts of studies published after the search date identified two articles. Therefore, 14 articles were included in this systematic review.



**Table 1: Flow chart (modified Preferred Reporting Items for Systematic Reviews and Meta-Analyses PRISMA 2009 flow diagram)**

## Study and participant characteristics

The included studies were studies published till April 2021. The characteristics of these studies are presented in table 1. Studies were conducted wide range of population from Asia, Africa and South America and Australia. Studies were excluded if the primary care giver was not the mother. The main outcomes along with the study aims and conclusion are presented in table 2.

Author and year	Nation(s) Participants	Total Participants (N)	Age range (mean $\pm$ SD)	Exclusion criteria	Caregiver's characteristics
Ata Farajzadeh, Saman Maroufizadeh, (2019) <sup>9</sup>	Tehran, Iran	203	20-52 years (34.48 $\pm$ 6.74)	The caregivers with chronic conditions, such as diabetes, heart diseases, or neurologic disorders, pregnant women, and those who had additional caregiving responsibilities apart from their routine maternal care	<b>Marital Status</b> – Single 40 (19.7) Married 163 (80.3) <b>Education level</b> - Primary/Secondary 142 (70.0) University 61 (30.0) <b>Employment</b> - Unemployed 134 (66.0) Employed 69 (34.0) <b>Type of CP</b> - Hemiplegic 64 (31.5) Diplegic 76 (37.4) Quadriplegic 63 (31.0)
Yasemin Ozkan 2018	Kutahya, Turkey	120	8.64 $\pm$ 3.45 years	No exclusion criteria mentioned in the article	Homemakers or those who gave up a job for illness of their children. Aged 18 years or older. Primary caregivers.
Bina Pandit, Jitendra Kumar Singh 2020	Sarlahi and Rautahat district of Nepal	96	20 to 70 years (median of age is 34)	No exclusion criteria mentioned in the article	<b>Age (in years)</b> 20-30 - 40 (41.7) 31-40 - 33 (34.4) 41-50 - 14 (14.6) 51+ - 9 (9.4) <b>Gender</b> Male - 13 (13.5) Female - 83 (86.5) <b>Type Of Family</b> Small - 51 (53.1) Joint - 45 (46.9)

					<b>Marital status</b> Married - 89 (92.7) Widow - 7 (7.3) <b>Education</b> Illiterate - 71 (74.0) Primary - 11 (11.5) Secondary - 11 (11.4) High school and above - 3(3.1)
K. Vadivelan, P. Sekar 2020	Rural and peri-urban areas in Tamil Nadu, India.	10 (Until data saturation)	30 to 40 years	No exclusion criteria mentioned in the article	Women in the age range of 30 to 40 years Children were 5 boys and 5 girls between the ages of 2–10 years
ADEGOKE Babatunde O. A., ADENUGA Olubunmi O. 2014	Ibadan, Nigeria.	80	30.53± 3.65 29.33± 3.55	Mothers with no prior history of psychological disorder or any chronic medical condition that could negatively affect quality of life.	<b>Education</b> Pre-secondary Post-secondary <b>Occupation</b> Skilled Unskilled <b>Religion</b> Christian Islam <b>Mean Age (years)</b>
E. Davis, A.Shelly 2009	Melbourne Australia	Twenty-four mothers and 13 fathers. N = 37	Not mentioned in the article.	No exclusion criteria mentioned in the article.	<b>Gender</b> Male 13 (35.14) Female 24 (64.86) <b>Relation</b> Biological parent 34 (91.9) Adoptive 3 (8.1) <b>Child, n (%)</b> Age (years) 3–7 11 (44) 8–12 6 (24) 13–18 8 (32) <b>Gender</b> Male 10 (40) Female 15 (60) <b>GMFCS levels</b>

					Level I 1 (4) Level II 4 (16) Level III 3 (12) Level IV 5 (20) Level V 12 (48)
Leila Dehghan and Hamid Dalvand Awat Feizi 2014	Tehran, Iran.	424	35.27 ± 6.34	No exclusion criteria mentioned in the article.	<b>Age</b> (years; mean + SD) -35.27 + 6.34 <b>Marital status</b> Married -420 (99.05%) Divorced- 4 (.94%) <b>Level of education</b> Illiterate -8 (1.9%) High school- 135 (31.8%) Diploma and associate degree- 214 (50.5%) Bachelor's degree or higher -67 (15.8%) <b>Job</b> Householder -390 (92%) Full time 34 (8%) <b>Number of children at home</b> 1- 243 (57.3%) 2 -124 (29.2%) 3- 57 (13.4%)
Cejane Oliveira Martins Prudente, Maria Alves Barbosa. 2010	Goiânia , Goiás, Brazil	146 (46 lost to follow up)	Not mentioned in the article.	No exclusion criteria mentioned in the article.	Not available
Meen Hye Lee, Alicia K.Matthews. 2019	Seoul, Gyeonggi, and Incheon Provinces in Korea.	180	39.7 ± (4.70)	Mothers who did not identify themselves as primary caregivers were excluded from the study.	<b>Age</b> (years) - 39.7 (4.70) <b>Marital status</b> Married - 170 (94.4%) Other (partnered/divorced/widowed) - 10 (5.6%) <b>Religion</b>



					<p>Yes - 123 (57.2%)                  No - 77 (42.8%)</p> <p><b>Education</b>                  Less than high school - 5 (2.8%)                  Graduate of high school - 52 (28.9%)                  Graduate of college - 112 (62.2%)                  Graduate of graduate school - 11 (6.1%)</p> <p><b>Occupation</b>                  Yes - 31 (17.2%)                  No, or on leave from occupation - 149 (82.8%)</p> <p><b>Income</b>                  &lt;1000 dollars - 11 (6.1%)                  1000 to &lt; 3000 dollars - 59 (32.8%)                  3000 to 5000 dollars - 72 (40.0%)                  &gt;5000 dollars - 38 (21.1%)</p> <p><b>Number of chronic conditions –</b>                  mean - 2.13 (1.91)                  0 - 35 (19.4%)                  1 - 48 (26.7%)                  2 - 38 (21.1%)                  &lt;3 - 59 (32.8%)</p> <p><b>3 frequently reported chronic conditions</b>                  Back pain - 85 (47.2%)                  Migraine/headache - 72 (40.0%)                  Sleep disorders - 47 (26.1%)</p> <p><b>Parenting stress –</b>                  mean - 3.44 (0.62)</p> <p><b>Health-promoting behaviors –</b></p>
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					mean - 1.96 (0.45)
Yesim Garip, Sumru Ozel 2016	Turkey	90 (Experimental group ) Control group (50)	Mother s 34.266 8.47 ± (20–58) years Childre n9.746 5.5± 3 (2–18) years	<b>Inclusion criteria</b> for the mothers of children with CP were as follows: having a child with CP and living with him/her; absence of a severe or chronic disease such as diabetes mellitus, stroke, etc., and the absence of a severe chronic psychological disease.	<p><b>Age</b> [years; mean ± SD(min-max)] mothers of CP - 34.2668.47 (20–58) Control group - 31.9066.66 (20–49)</p> <p><b>Marital status</b>  <b>Married</b>                      MCP - 84 (93.3)                      CG - 47 (94)  <b>Divorced</b>                      MCP - 6 (6.7)                      CG - 3 (6)</p> <p><b>Education level</b>                      Illiterate                      MCP - 2 (2.2)                      CG - 1 (2)                      Primary school                      MCP - 47 (52.2)                      CG - 22 (44)                      Secondary school                      MCP - 14 (15.6)                      CG - 8 (16)                      High school                      MCP - 20 (22.2)                      CG - 15 (30)                      University                      MCP - 7 (7.8)                      CG - 4 (8)</p> <p><b>Number of children</b> [mean±SD (min–max)]                      MCP - 2.1760.84 (1–5)                      CG - 2.1660.71 (1–4)</p> <p><b>Type of family</b>                      Core family                      MCP - 82 (91.1)                      CG - 44 (88)                      Combined family                      MCP - 8 (8.9)                      CG - 6 (12)</p>

<p>Kelvin Ying , Hans Van Rostenberghe . 2021</p>	<p>Malaysia</p>	<p>172 Analysed (159)</p>	<p>42.8 ± 8.4 years</p>	<p><b>Biological sex</b> Male - 30 (18.9) Female - 127 (79.9) Missing data - 2 (1.3) <b>Relationship to the children</b> Father - 29 (18.2) Mother - 120 (75.5) Guardian - 10 (6.3) <b>Residing state</b> Kelantan - 35 (22.0) Johor - 81 (50.9) Sarawak - 43 (27.0) <b>Level of education (Child's father)</b> No education or primary school -18 (11.3) Secondary school -89 (56.0) Beyond secondary school -45 (28.3) Missing data -7 (4.4) <b>Level of education (Child's mother)</b> No education or primary school - 22 (13.8) Secondary school - 84 (52.8) Beyond secondary school - 51 (32.1) Missing data - 2 (1.3) <b>Family monthly income</b> Less than RM2000 (~USD494) - 69 (43.4) RM2000-RM3999 (~USD494-988) - 46 (28.9) RM4000 (~USD988) and more - 44 (27.7)</p>
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					<p><b>Children with other disability</b>                  Yes - 15 (9.4)                  No - 141 (88.7)                  Missing data - 3 (1.9)  <b>Age</b> - 42.8 (8.4)</p>
Kurtulus Kaya, Sibel Unsal-Delialioglu	Turkey	81 (Experimental group)	31.07± (5.80)	<p><b>Inclusion criteria:</b>                  (a) Having a child with CP;                  (b) Absence of caring for another child needing assistance with transferring,                  (c) Absence of a severe or chronic medical condition such as stroke, diabetes mellitus etc,                  (d) Absence of previous back surgery,                  (e) Absence of a history of severe or chronic psychological disorder with an onset before the diagnosis of CP in the child.</p>	<p><b>Mother's age (years)</b> - 31.07 (5.80)  <b>Mother's weight (kg)</b> - 65.3 (11.58)  <b>Mother's height (meter)</b> - 1.59 (0.178)  <b>Mother's BMI (kg/m2)</b> -25.72 (4.33)  <b>Number of other children</b> 1.17 (0.96)  <b>Profession</b>  <b>Homemaker</b> 79 (97.5%)  <b>Other</b> - 2 (2.5%)  <b>Education</b>                  *None n (%) - 15 (18.8%) *Primary n (%) - 59 (73.8%)                  *Secondary n (%) - 6 (7.5%)</p>
Mohammad Mahani Khayatza deh, Hamid Reza Rostami	Tehran, Iran	120 (MCCP)	30.3 ± 5.5 years	<p><b>Exclusion criteria:</b>                  (i) Unwilling to continue the study;                  (ii) Any acute changes in health condition</p>	<p><b>Child's gender (boy/girl)</b> - 60/60  <b>Marital dissatisfaction</b> - 36 (35.3)  <b>High fatigue</b> - 27 (22.5)  <b>Marital status</b>                  Married - 102 (85.0)                  Divorced - 16 (13.3)</p>

				<p>or experience of traumatic events, for example dying a close relative, in last two weeks ending to study; and</p> <p>(iii) Questionnaires missing more than 20% of data, missing Q1 or Q2 items or missing more than two items from the domains of World Health Organization Quality Of Life-BREF (WHOQOL-BREF).</p>	<p>Widow -2 (1.7)</p> <p><b>Educational level</b></p> <p>Primary - 31 (25.8)</p> <p>Secondary - 66 (55.0)</p> <p>University - 23 (19.2)</p>
Rabia Terzi, Gülten Tan	Turkey	85	34.77 ± 6.61	<p><b>Exclusion criteria:</b></p> <p>Mothers who had a history of musculoskeletal disease before having a child; those who had undergone locomotor system surgery; those who had a history of rheumatic or psychological diseases; those had active infection</p>	<p><b>Age (year)</b> - 34.75±6.70</p> <p><b>Height (cm)</b> - 160.89±4.81</p> <p><b>Weight (kg)</b> - 68.26±10.02</p> <p><b>Number of children (median)</b> - 1.93±1.01</p> <p><b>Beck score (median)</b> 18.41±11.19</p> <p><b>Educational status</b></p> <p>Primary school -72.9 31</p> <p>High school, university - 23 27.1</p> <p><b>Income status</b></p> <p>Low - 29 34.1</p> <p>Medium, good - 56 65.9</p>

				or severe systemic disease; mothers who were not responsible for the primary care of the child or who had an assistant caregiver; mothers who had an active occupational life; and mothers who had more than one disabled child.	
Serhat TÜRKÖĞLU , Ayhan BİLGİÇ 2016	Turkey	97	Child mean age 9.97±2.59 years 49 (50.5%) boys and 48 (49.5%) girls	Exclusion criteria were as follows: (i) a history of major surgery or having received injections of botulinum toxin- A 6 months prior to the evaluation (ii) or the use of systemic treatments such as steroids and psychotropic drugs 3 months prior to the evaluation.	Mother with at least 5 years of education and the cognitive ability to answer the questionnaire The mean score of the mother's BAI and BDI were 31.46±12.58 and 29.25±12.50

**Table 2: Selected articles main characteristics (M: males; F: females; n.a.: not available)**

Author and year	Method(s) for QoL assessment	Aim(s)	Main results
Ata Farajzadeh, Saman Maroufizadeh, 2019	(WHOQOL-BREF), the Beck Depression Inventory, the Caregiver Difficulties Scale, Fatigue Severity Scale, and a demographic information questionnaire.	To identify the factors pertaining to the quality of life (QOL) among the mothers of patients with cerebral palsy.	<b>Conclusion:</b> QOL of mothers of children with cerebral palsy is negatively impacted by various factors such as burden of care, fatigue, and psychological symptoms. Thus, a holistic approach, including training (carrying, positioning, feeding, and how to manage the self-care of children) and psychological interventions, is required to improve QOL among this population.
Yasemin Ozkan 2018	Pediatric Quality of Life (PedsQL) 4.0 Generic Core Scales and by the Zarit Burden Interview.	1. To identify the Qol profiles of children with CP considering topographical classification. 2.To determine the burden of mothers who are primary caregivers of children with CP. 3.To assess the correlation between the child's QoL and the mother's burden.	Considering the mother's burden, the quadriplegia group had a significantly higher score than did the hemiplegia ( $p < 0.001$ ) and diplegia ( $p < 0.001$ ) groups. There were significant negative correlations between the mother's burden and the child's QoL profiles, including physical functioning ( $r = -0.546$ , $p < 0.001$ ).
Bina Pandit, Jitendra Kumar Singh 2020	WHO-QOL BREF	To determine the QOL and factors associated with QOL among primary caregivers	The result of chi-square tests for association between GMFCS and QOL of caregivers was $\chi^2 (3, N=40) = 16.77$ , $p < 0.001$ and the tests for association between perceived stress

		of children with CP.	and QOL of caregivers was $\chi^2 (1, N=40) = 4.409, p=0.03$ . This shows there was association between GMFCS level and QOL, similarly perceived stress and QOL of primary caregivers found to be associated.
K. Vadivelan, P. Sekar 2020	Socio-ecological framework	To identify the intersection between gender, poverty, social stigma and caring for a child with a disability in causing burden to the caregivers.	Caregivers of children with cerebral palsy have unique stressors and burdens in the south Indian context, which are dominated by the intersection of patriarchal gender norms, poverty, stigmatization, and poor public policy. A deeper exploration among a community-based sample of caregivers will help understand these stressors better for guiding public health policies to support the caregivers and improve their quality of life.
ADEGOKE Babatunde O. A., ADENUGA Olubunmi O. 2014	WHOQoL-BREF WHOQoL-100	To compare the QoL of mothers of children with cerebral palsy (MCCP) and that of age-matched mothers of typically developing children (MTDC) and investigate the influence of religious affiliation, occupational status and educational status	Several factors other than the presence of a disability can affect caregiving for any child. Associating the severity of disability and burden of care with quality of life in mothers of children with cerebral palsy do not make for comparison in mothers of children with typically developing children who do not have such factors to contend with.



		on the QoL of the MCCP.	
E. Davis, A.Shelly 2009	Grounded theory framework	To explore the QOL of mothers and fathers of children with CP aged from 3 to 18 years and to examine whether the issues impacting on QOL of parents of children with CP change from childhood to adolescence.	Caring for a child with CP can negatively impact on parents in terms of demands on physical health, disrupted sleep, difficulty in maintaining social relationships, pressure on marital relationships, difficulty in taking family holidays, limited freedom, limited time, a child's long-term dependence, difficulty in maintaining maternal employment, financial burden, difficulty in accessing funding and insufficient support from services.
Leila Dehghan and Hamid Dalvand Awat Feizi 2014	Persian version of the SF-36.	To examine QOL in a large sample of Iranian mothers of children with CP, with reference to the gross motor function and type of CP of their children using 36-item Short Form Health Survey (SF-36) questionnaire.	Results showed that the mean scores of physical functioning, body pain, and social functioning were significantly different among mothers having children with different levels of gross motor function ( $p < .01$ ).
Cejane Oliveira Martins Prudente, Maria Alves Barbosa. 2010	Gross Motor Function Measurement (GMFM-88) 36-item Short-Form Health Survey (SF-36)	To analyze the quality of life of mothers of children with cerebral palsy, correlating it with the evolution of the children's gross motor	The mothers of children with cerebral palsy presented a statistically significant difference for the pain domain only, improving by 14.57 ( $p < 0.001$ ). No statistically significant differences were found for functional

		function after ten months of rehabilitation.	capacity, physical conditions, emotional conditions, social conditions, general health status, vitality and mental health, on the other hand.
Meen Hye Lee, Alicia K. Matthews. 2019	SMCP, HPLP-II, SF-12 v2	To investigate the HRQOL of mothers of children with CP in Korea and to comprehensively identify factors associated with HRQOL among those mothers.	The HRQOL results revealed that the physical HRQOL was higher than mental HRQOL in the sample. Longer length of disability of children and lower number of chronic conditions of mothers were significant factors of higher physical HRQOL. Lower parenting stress, more leisure time, engagement in HPB, and greater social support were significantly associated with higher mental HRQOL.
Yesim Garip, Sumru Ozel 2016	Turkish version of FSI, Nottingham health profile (NHP), BDS: Beck Depression Scale.	To evaluate fatigue in the mothers of children with cerebral palsy (CP), and to determine its associations with clinical parameters of CP, depression and quality of life (QoL).	The findings indicate that fatigue levels of mothers with CP children are higher than those with healthy children and associated with depression and deterioration in QoL in terms of physical, social and emotional functioning. This should be considered while designing a family centred rehabilitation programme for children with CP.
Kelvin Ying , Hans Van Rostenberghe. 2021	Pediatric Quality of Life Inventory <sup>TM</sup> Family Impact Module (PedsQL FIM)	To determine the overall impact of having a child with CP on the health-related quality of life (HRQOL) of the	Through multiple linear regression analyses, the mother's level of education, family monthly income, sleeping problems in children with CP, and the existence of children with

		<p>primary caregivers, and family functioning; To identify potential factors which may affect the primary caregivers' HRQOL and family functioning.</p>	<p>other types of disability have been identified as factors contributing to HRQOL and family functioning.</p>
<p>Kurtulus Kaya, Sibel Unsal-Delialioglu 2010</p>	<p>Beck Depression Inventory scores and SF-36</p>	<p>To evaluate musculoskeletal pain (MSP) in mothers of children with cerebral palsy (CP), and to determine the effects of zone of pain on health-related quality of life (QoL) and symptoms of depression.</p>	<p>Deterioration of MH in mothers with cerebral palsied child may be causing them to experience more LBP. Experience of increased LBP causes deterioration of health-related QoL.</p>
<p>Mohammad Mahani, Khayatzaheh, Hamid Reza Rostami 2013</p>	<p>WHOQOL-BREF, SES questionnaire, IMS questionnaire, FSS-P questionnaire</p>	<p>To compare the quality of life (QOL) of Mothers of Children with Cerebral Palsy (MCCPs) with mothers of Typically Developing (TD) children as a Control Group (CG). The association of the mediating variables including socio-economic status (SES), marital</p>	<p>MCCPs have too much problems in carrying their children, because there is not proper transportation system, suitable wheelchair and special assistive technologies in Iran.</p>

		satisfaction and fatigue with maternal QOL.	
Rabia Terzi, Gülten Tan 2016	The Nordic Musculoskeletal Questionnaire-NMQ, Beck's Depression Scale.	To determine musculoskeletal system pain and the related factors observed in the mothers of children diagnosed with cerebral palsy.	A positive correlation was found between the Beck scores of the mothers who had children with cerebral palsy and the level of coarse motor function of the children with cerebral palsy ( $r=0.484$ ; $p=0.3$ ).
Serhat TÜRKOĞLU, Ayhan BİLGİÇ 2016	Beck Depression Inventory (BDI), Beck Anxiety Scale (BAS), HRQOL	To evaluate the impact of maternal anxiety and depression symptoms on parent proxy-reported HRQOL for children with CP.	According to regression analyses, male gender, severity of ID, and higher mothers' BAI scores had negative effects on the PedsQL-P physical scores, and severity of ID and higher mothers' BDI scores had negative effects on the PedsQL-P psychosocial scores. Regarding the determinants of total HRQOL, severity of ID, GMFCS score, and higher mothers' BDI scores negatively impacted the PedsQL-P total scores.

**Table 3: Detailed information of the selected studies, with method for QoL assessment, aim and main results**

### Mother's QOL

Our first objective was to describe QOL in mothers with cerebral palsied child. QoL was predominantly measured using using the World Health Organization Quality of Life Instrument- Abbreviated Version (WHOQOL-BREF), Short Form health survey (SF-36) and the Parental QOL Difficulties Questionnaire, HRQOL. The results of the studies are summarised in the table. The studies show that the mothers with cerebral palsied child had poor QOL. Disability in a child, the basic component of a family, and accompanying challenges affect profoundly other members of the family and may be an intensive source of anxiety. In members of family having to take care of the disabled child all day and for ages, physical and psychosocial health is influenced in a negative way. The studies included the systematic review indicate that QoL of mothers of CP children is affected negatively.

## **Factors associated with mothers QOL**

Our second objective was to identify the factors associated with parental QOL. Few studies reported on the factors associated with parental QOL, often with different variables of interest. Studies consistently found that child's motor status, intellectual ability, functional ability, participation, community support and public policies are factors associated with mothers QoL. Inconsistent results have been reported in terms of family size, patients' sex, and parents' age and employment, education, socio economic status.

## **Discussion**

This systematic review is a small step to add to the existing literature by providing a comprehensive evaluation of the QOL of mothers of Child with cerebral palsy and identifying key factors associated with mothers QOL. We found that mothers of Child with cerebral palsy had poorer QOL clinical factors are a major determinants for poor QOL. The results of this review also highlight the need for social participation and mother centric rehabilitation in planning rehabilitation of cerebral palsied child.

Our first objective was to describe the QOL of mothers with cerebral palsied child. Greater childcare needs have been associated with greater parental burden and poorer parental QOL, associated with symptoms of burnout and restricted social contacts and family interactions. Children with the greatest needs may be cared for by parents more which is related with poor mental and physical health-related QOL.

Our secondary objective was to identify the factors associated with parental QOL. Clinical presentations, family environment, and mother's psychosocial factors were predominantly observed. We found that child's motor status, intellectual ability, functional ability, participation, community support and public policies are factors associated with mothers QoL. Inconsistent results have been reported in terms of family size, patients' sex, and parents' age and employment, education, socio economic status. Mothers QOL was consistently associated with, and often most impacted by, anxiety and depressive symptoms related to child's health status.

Three studies concluded that the most important predictors of the burden were degree of disability, depression and self-efficacy. An important aspect of caregivers burden is the demands of caring ( Elena M. Marrón et al). One study showed that the burden of mothers ranked the highest in the quadriplegia group, followed by the diplegia group, and then the hemiplegia group. Taken together, previous research and the present study indicate that severe disability in children with CP is associated with a lower QoL and higher burden in mothers (Yasemin Ozkan). Two studies concluded that when the level of functional dependence increases in disabled children, there occurs an excessive physical burden on mothers; this physical burden further increases in lifting, carrying and transfer activities in particular. In this regard, it was concluded that mothers' experience of upper extremity, lower back and neck problems stems from disabilities of children with CP in gross motor function and functional independence (E. Kavlak et al.).

Results of one study highlighted the issues that are important to parents as primary caregivers of children and adolescents with CP and has significant implications for programme planning and service delivery. A major concern for parents included difficulty in accessing funding and insufficient support from services. Parents indicated that more financial stability and better access to services would improve their QOL. Therefore, professionals who plan and deliver services must endeavour to improve current programmes while also finding new and innovative ways to meet the needs of parents (E. Davis)

A limitation of the literature evaluating QOL mothers with cerebral palsied child is the qualitative nature of the studies. Furthermore, the natural course of parental QOL throughout their child's management is unknown and presents an area for future research. The studies considered for the review included the quality of life of mothers alone and other environmental factors, which might be detrimental, were not considered.

## **Conclusion:**

Disability in a child, the basic component of a family, and accompanying challenges affect mothers quality of life. In light of the literature and our findings, QoL of mothers with CP children is considered to be affected negatively. Therefore, in planning a rehabilitation program for CP children, QoL of mothers should also be evaluated in detail. Additionally, mothers should be encouraged to take part in social activities related to their interests, and those with depressive symptoms should be supported psychologically. Therefore, it is considered that mothers undertaking the most significant role in the rehabilitation and caring for the child, should be involved in the management of cerebral palsied child.

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## **Contributors**

All the authors conceived the study and contributed to the conceptualisation of the study. Rathish and Sandhya developed and executed the search strategy. All authors were involved in the screening process of the selected articles. Rathish was involved in the writing of the article. Dr. Meena and Dr. Kavitha helped draft the protocol and edited the draft protocol. All authors read and approved the final manuscript.

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**Ethics approval:**

This protocol did not require ethical approval, since it is a protocol for a systematic review.

**Abbreviations**

CP	Cerebral Palsy
QOL / QoL	Quality of Life
ENTREQ	Enhancing Transparency in Reporting the Synthesis of Qualitative Research statement
MCP	Mothers of Cerebral Palsy child
CG	Control Group
BMI	Body Mass Index
MCCP	Mothers of Children With Cerebral Palsy
BAS	Beck Anxiety Scale
BDI	Beck Depression Inventory
WHOQoL-100	World Health Organisation Quality of Life questionnaire
WHOQOL-BREF	World Health Organisation Quality of Life questionnaire – Abbreviated (short)
MTDC	Mothers of Typically Developing Children
HRQOL	Health-related quality of life
MH	Maternal Health
ID	Intellectual Disability

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