

# Impact of Parenting a Child with Cerebral Palsy on the Quality of Life of Parents: A Systematic Review of Literature

Vivek H Ramanandi<sup>1\*</sup>, Trupti Rudra Parmar<sup>1</sup>, Juhi Kalpesh Panchal<sup>1</sup>,  
M M Prabhakar <sup>2</sup>

1.Satish Goswami College of Physiotherapy, Gujarat University, Ahmedabad, Gujarat, India

2.Civil Hospital, Ahmedabad, Gujarat, India

## ABSTRACT

**Purpose:** *The implications of parenting a child with cerebral palsy (CP) are multifaceted, as parents have to cope with their child's functional limitations and specific needs, and prepare for the possibility of long-term dependence. There has been significant research on the consequences of managing these parenting tasks. This article reviews the literature on the effects of parenting children with CP, and summarises the related factors.*

**Methods:** *A systematic search of online databases was conducted and, based on the reference lists of selected articles, further studies were identified. Thirty-six articles that met the inclusion criteria were analysed.*

**Conclusion & Implication:** *Parents of children with CP were found to have lower quality of life, associated with high levels of stress and depression, due to factors such as child behaviour and cognitive problems, low caregiver self-efficacy and low social support. The implications of these findings in relation to the planning and development of interventions addressing the family as a whole are discussed. The aim is to enhance parents' competence and resources so that they are better able to cope with the demands of parenting their children.*

**Key words:** *Cerebral palsy, parenting, care-giving, stress, well-being, quality of life*

## INTRODUCTION

Parenting any child requires considerable resources, but the demand for these resources often increases when some physical or intellectual disabilities are detected during the early stages of the child's life (Cunningham,2000; Risdal & Singer, 2004). Managing and coping with the child's functional limitations and

\* **Corresponding Author:** Dr. Vivek H. Ramanandi, Principal, Satish Goswami College of Physiotherapy, Gujarat University, Ahmedabad, Gujarat, India. Email: vivekramanandi@gmail.com

possible long-term dependence presents a multifaceted challenge to the parents and family. While dealing with everyday living and the needs of the whole family, these demands have implications for the psychological and physical health of the parents (Raina et al, 2005).

With the estimated prevalence of 2 - 2.5 cases per 1,000 births, CP is considered one of the most common developmental disabilities. It 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” (Bax et al, 2005). Although the definition emphasises the motor nature of the disorder, it also recognises that the problems are accompanied by changes in other areas and may be more intense or problematic depending on the person or the developmental stage (Odding et al, 2006; Blair, 2010; Bottcher, 2010).

Although many parents cope quite well with the additional demands of rearing a child with a disability, existing literature shows that they experience great tension and struggle, especially the mothers who have to provide constant and exclusive care, leading to failure to care for themselves, their children and other family members; thus affecting the physical and psychological health and, ultimately, the quality of life of parents (Dellve et al, 2005; Eisenhower et al, 2005; Cheng et al, 2009). Generally, they show higher levels of stress and depression with poor mental health, as compared to parents of children without developmental disabilities and the general population (Rentinck et al, 2007; Byrne et al, 2010; Guyard et al, 2011; Ramanandi & Rao, 2015). Nevertheless, the impact of a child’s disability on the family seems to be related not only to the child’s characteristics, but also to the personal, social and economic variables of the family.

Currently, the focus of the family-centred approach in intervention planning and implementation research has been on different aspects of parents’ health while analysing the potential factors affecting their quality of life, using different samples and methodologies. This heterogeneity in the research has resulted in lack of an overall vision that would enable a more precise understanding of the extent to which parents are affected, and also ascertain the factors that influence better or worse coping with this situation (Guyard et al, 2011).

## **AIM**

This paper aims to provide a comprehensive overview of the studies that have

analysed the impact of parenting on the quality of life of parents of children with CP. To this end, a systematic review of the scientific literature in the field was conducted. The article first describes the outcomes that have been studied in relation to caregivers and parents. Next, the factors related to these outcomes are analysed, while focussing on the points of convergence and divergence among the different studies. Finally, there is a discussion on the possible implications of these findings for designing family-centred intervention strategies to improve the quality of healthcare.

## METHOD

A systematic search of papers in English, published in peer-reviewed journals between January 2003 and December 2016, was carried out using MEDLINE and PubMed electronic databases. Key words and abstracts were searched, using the following descriptors: “cerebral palsy”, “caregivers/parents/mothers/fathers”, and “quality of life/burden/wellbeing/well-being/stress”. The idea was to focus on the most recent and relevant research accessible in digital format.

A total of 118 articles were found, and the titles and abstracts were examined independently by two of the authors. Discrepancies were discussed in order to arrive at a consensus, and irrelevant articles were discarded.

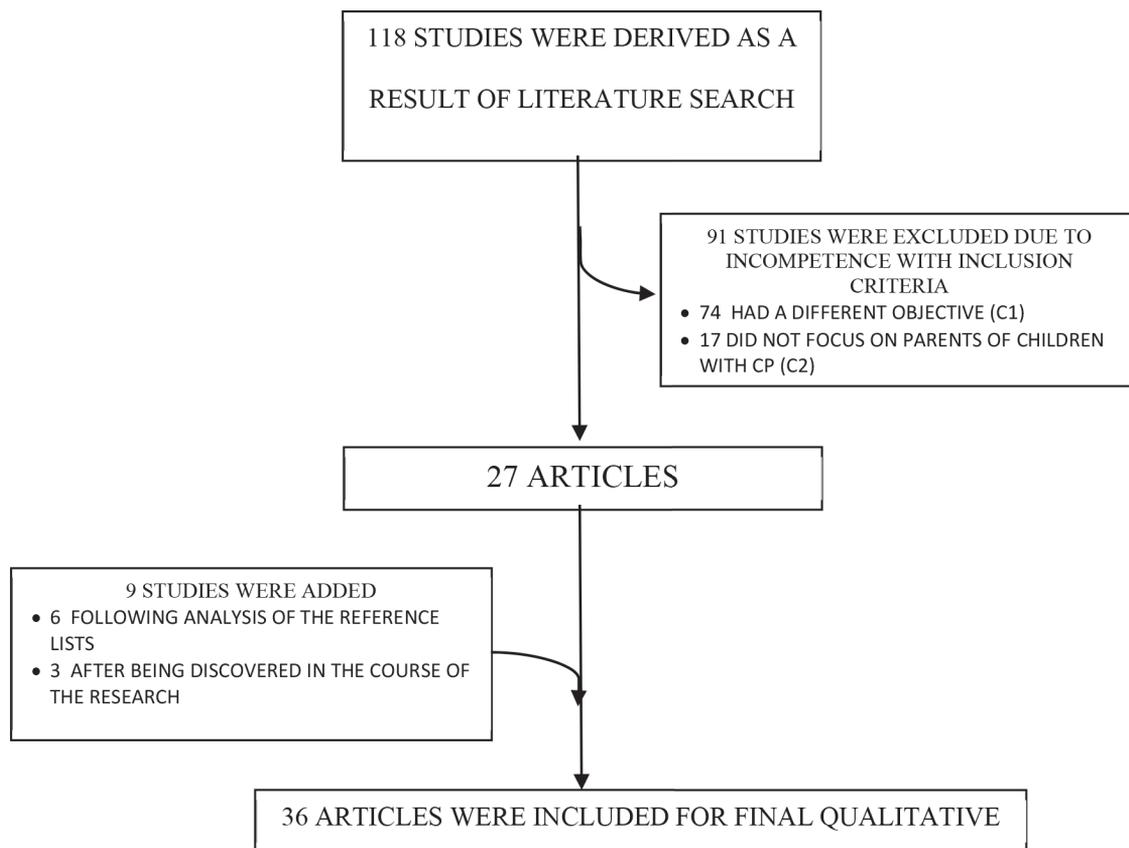
Inclusion of research articles was based on the following criteria:

1. The objective of the article was to describe or explain the impact of parenting/care-giving on the well-being and quality of life of the parents of children with CP.
2. The sample of parents did not include, in an undifferentiated manner, caregivers of children with developmental disorders other than CP (autism, Down syndrome, etc.).

The full texts of articles considered relevant by both the reviewers were obtained and analysed. In addition, the reference lists of included papers were examined to identify any additional articles that might have been missed by the search strategy.

At the end of this iterative process, a further 9 relevant articles were found and added to the selection (Fig. 1).

As the heterogeneity among the articles was vast, it was difficult to find a critical appraisal tool (CAT) that could prove suitable for them all. Moreover,



the recent literature on CATs highlights their lack of validation and reliability, while highlighting the fact that the tools are usually based on each appraiser's concept of research quality (Crowe & Sheppard, 2011). For both these reasons, it was considered more appropriate to conduct a descriptive analysis rather than a critical appraisal of the work.

The information was tabulated after being properly cross-checked by two authors independently. The authors were in agreement that Table 1 accurately reflected the reviewed studies' components, and concurred that it would give readers a comprehensive overview of the selected studies.

## RESULTS

Table 1 presents an overview of the 36 empirical articles that were analysed. It highlights the type of study, purpose, population, the variables and measures of the studies, and the main findings. Most of them (n=31) were cross-sectional and quantitative studies, one was longitudinal, and four were descriptive or

phenomenological studies made through observations, in-depth interviews or using a combined qualitative and quantitative methodology.

TABLE 1 (Part-1):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
1	Britner, 2003	C Q	To examine the relation between maternal self-report measures of family functioning and the child diagnosis of severe CP, mild CP, or control.	1. Mothers of severe CP: 27 2. Mothers of mild CP: 30 3. Mothers of children without chronic conditions: 30 4. Children's age: 15-44 months (mean age 31.4 months)	Severity of CP	1. Family functioning 2. Social support 3. Family support 4. Parent Stress Using- Dynamic Adjustment Scale (DAS), Support Functions Scale (SFS), Family Support Scale(FSS), Parental Stress Index-Short Form (PSI-SF).	Significant differences were found in parenting stress between the CP groups and the control group. No significant differences were found in social support and family functioning.
2	Manuel et al, 2003	C Q	To assess the importance of disability severity & child functional status as predictors of maternal depressive symptoms, & the moderating effects of maternal appraisal, social support & family income on the relationship between disability factors & maternal depressive symptoms.	1. Mothers of children with CP: 2702. Children's age: 1.1-17.8 years	1. Children's disability severity 2. Children's functional status 3. Maternal social support 4. Appraisal of the illness situation Using- Global Rating Scale, FIM for Children, Scale developed in conjunction with Medical Outcomes Study, Impact on the Family Scale.	1. Depression Using- Centre for Epidemiologic Studies-Depression Scale Short Form (CED-D).	1. The relationship between child functioning and maternal depression was moderated by social support. 2. A high proportion of mothers suffered stress.
CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs- years							
Whenever there were significant differences between the control group and the group of parent caregivers of children with cerebral palsy, the latter presented results that were in line with worse physical and mental health and lower quality of life.							

TABLE 1 (Part-2):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
3	Brehaut et al, 2004	C Q	To compare the physical and psychological health of caregivers of children with CP with that of the general population of caregivers.	1. Primary caregivers of children with CP: 4682. General population of caregivers: 79633. No data on the children's age.		1. Distress 2. Chronicity of distress 3. Emotional problems 4. Cognitive problems 5. Frequency of contact 6. Family functioning 7. Number of chronic diseases 8. Physical problems. Using- Subset of items from Composite International Diagnostic Interview (CIDI), Subset of items from the Health Utility Index (HUI), Items from the Social Network and Frequency of Contact Index, Items from the Family Assessment Device.	Significant differences were found between parent caregivers and the general population of caregivers in: 1. Economic status 2. Frequency of contact 3. Level of distress 4. Chronicity of distress 5. Emotional problems 6. Cognitive problems 7. Chronic diseases 8. Sight problems 9. Hearing problems 10. Physical pain. No significant differences were found in social support and family functioning.
CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs- years							
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TABLE 1 (Part-3):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
4	Eker and Tüzün, 2004	C Q	To evaluate the quality of life of mothers with children suffering from CP compared with those who have children with minor health problems.	1. Mothers of children with CP: 40 2. Mothers of children with minor health problems: 44	Motor ability of children  Using- GMFCS.	Quality of life of mothers  Using- SF-36Health Survey.	1. Significant differences were found between parent caregivers and the control group in all subscales except for physical functioning.
5	Wang and Jong, 2004	C Q	To compare parental stress in parents of children with CP with that in parents of children with typical development, and to analyse correlations between parental stress and parents' characteristics, the child's earliest characteristics, the child's age when rehabilitation was first commenced, and weekly frequency of rehabilitation.	1. Mothers of children with CP: 59 2. Fathers of children with CP: 4 3. Mothers of children with healthy development: 38 4. Fathers of children with healthy development: 2	1. Motor ability of the children  2. Rehabilitation  Using- Age of the children when rehabilitation commenced and frequency of rehabilitation, GMFCS.	Stress  Using- PSI.	1. Scores in child domain of the PSI were correlated with motor ability of the children with CP and with the age when commencing rehabilitation and its frequency.  2. The parent domain score and the total score of PSI were negatively correlated with the age when rehabilitation was commenced.  3. The total score of the PSI was related to the severity of the motor disability.
CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs- years							
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TABLE 1 (Part-4):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
6	Ones et al, 2005	C Q	To evaluate the quality of life and psychological status of mothers of children with CP and to assess the relation with the degree of their child's disability.	1. Mothers of children with CP: 46 2. Mothers with healthy children: 46 3. Children's age: 1.5–12 years	Motor ability of children Using- GMFCS.	1. Quality of life of mothers 2. Depression Using- BDI & Nottingham Health Profile-1 (NHP-1).	1. In mothers of children with CP lower quality of life was related with higher levels of depression. 2. No significant correlation was observed between depression and motor ability of children. 3. Significant differences were found in quality of life and depression between caregivers and the control.
7	Barlow et al, 2006	C Q	To examine the level of maternal anxiety and depressed mood in mothers of children with cerebral palsy (CP) and the associations between maternal psychological well-being and self-efficacy and perception of children's eating, sleeping and mobility.	1. Mothers of CP children: 78 2. Normative sample data comparison 3. Children's age: 0–16 years (mean age 6 years)	1. Self-efficacy 2. Children's functioning Using- Generalised Self-Efficacy Scale and 3 questions regarding difficulties in sleeping, eating and mobility.	1. Psychological wellbeing Using- Hospital Anxiety and Depression Scale (HADS).	1. Significant differences were found in anxiety and depression between parent caregivers and normative data. 2. Low self-efficacy was significantly associated with greater anxiety and depressed mood. 3. Higher levels of anxiety were significantly associated with mothers' perception of difficulties in children's sleeping.
CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs- years							
Whenever there were significant differences between the control group and the group of parent caregivers of children with cerebral palsy, the latter presented results that were in line with worse physical and mental health and lower quality of life.							

TABLE 1 (Part-5):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
8	Raina et al, 2005	C Q	To examine the determinants of physical and psychological health of adult caregivers of children with CP.	1. Primary caregivers of children with CP: 468 2. Mean age of children: 10.6 years	Children: 1. Motor ability 2. Activities of daily living 3. Cognitive function 4. Child behaviour Using- GMFCS, PEDI, Selected questions of the HUI, SDI. Caregivers: 1. Perception of formal care 2. Stress management 3. Mastery 4. Self-esteem 5. Chronic health conditions 6. Job-caregiving conflict 7. Social support Using- CHIPS, MAST-Q1, ESTEEM-Q1, Pearlin's Scale, Social network and Frequency of Contact Index.	1. Health 2. Distress 3. Depression Using- SF-36, Mc Master Health Utility Index, Subset of items from CIDI.	1. The most important predictors of caregiver's wellbeing were child behaviour, care-giving demands and family function. 2. Self-perception and stress management were significant direct predictors of psychological health but not of physical health. 3. Social support was not directly linked with well-being.
CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs- years							
Whenever there were significant differences between the control group and the group of parent caregivers of children with cerebral palsy, the latter presented results that were in line with worse physical and mental health and lower quality of life.							

TABLE 1 (Part-6):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
9	Skok et al, 2006	C Q	To study how severity of disability, perceived stress and perceived social support impact on the well-being of a group of mothers caring for school-aged children with CP.	1. Mothers of children with CP: 43 2. Children's age: 5–12 years	1. Motor ability of the children 2. Stress 3. Social Support Using- GMFCS, Perceived Stress Scale (PSS), Multidimensional Scale of Perceived Social Support (MSPSS).	Wellbeing Using- Psychological Wellbeing subscale of the Profile of Adaptation to Life (PAL), Satisfaction with Life Scale (SWLS).	1. Severity of the physical disability in the children was not significantly correlated with well-being of the mothers. 2. Higher levels of stress were related with lower levels of well-being. 3. Mothers with higher levels of social support experienced also higher levels of well-being. 4. Perceived social support mediated the relationship between stress and well-being.
10	Hamzat and Mordi, 2007	C Q	To compare the health of caregivers of children with CP with that of caregivers of children without CP, and to investigate the relationship between severities of motor disorder in children with CP and health of their caregivers.	1. Caregivers of children with CP: 71 2. Caregivers of children with normal development: 70 3. Children's age: 6 months-12 years	Motor ability of children Using- GMFCS.	Health of caregivers Using- General Health Questionnaire (GHQ).	1. No relationship was found between the functional level of children (meaning the severity of CP) and the general health of caregivers. 2. Significant differences were found in GHQ between caregivers and the control group.
CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs- years							
Whenever there were significant differences between the control group and the group of parent caregivers of children with cerebral palsy, the latter presented results that were in line with worse physical and mental health and lower quality of life.							

TABLE 1 (Part-7):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
11	Ho et al, 2008	C Q	To examine whether overprotection is related to the psychological well-being of CP clients and their caregivers.	1. Caregivers of children with CP: 14 2. Children with CP: 14 3. Children's age: 10–20 years	1. Perceived overprotection 2. Perceived severity of the disability Using- A single-item scale for each variable	1. Level of anxiety 2. Level of depression 3. Satisfaction with life 4. Psychological state Using- Chinese Hospital Anxiety & Depression Scale, Chinese Satisfaction With Life Scale & The Faces Rating Scale.	1. Caregivers with a greater tendency to overprotect tended to exhibit more depression and anxiety responses. 2. Caregivers' satisfaction with life correlated negatively with their perception of their children disability. 3. The psychological state of caregivers was not related with the functional level of children.
12	Ketelaar et al, 2008	C Q	To explore the relation between parental distress in the parenting role and the child's limitations in functional skills and the child's behavioural difficulties, in parents of children with CP.	1. Parents of children with CP, levels I, II and III in GMFCS: 42. 2. Children's age: 3–8 years.	1. Children's functional skills 2. Children's Behaviour Using- Paediatric Evaluation of Disability Inventory (PEDI) & Vineland Adaptative Behaviour Scale (VABS).	Stress Using- Parental Stress Index (PSI).	Maladaptive behaviour of children significantly contributed to parental stress (parent domain scales of PSI).
CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs- years							
Whenever there were significant differences between the control group and the group of parent caregivers of children with cerebral palsy, the latter presented results that were in line with worse physical and mental health and lower quality of life.							

TABLE 1 (Part-8):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
13	Glenn et al, 2009	C Q	To investigate factors predicting parenting stress in mothers of pre-school children with CP.	1. Mothers of children with CP: 80 2. Children's age: 8-46 months	1. Motor ability of children 2. Development of the children 3. Family needs 4. Family support 5. Family functioning 6. Environment 7. Coping 8. Locus of control Using- GMFCS, Griffiths Mental Development Scales, Family Needs Scale, FSS, Family Adaptability and Cohesion Evaluation Scale III, Home Observation, Coping Strategies, Brief locus of Control Scale.	Stress Using- Parental Stress Index (PSI).	1. Three factors were found to be relevant in accounting for the total stress of mothers: family needs, family adaptability and cognitive impairment of children. 2. Cluster analysis showed four different types of families combining different levels of variables.
14	Parkes et al, 2009	C Q	To describe the health of children with CP and investigate predictors of stress in their parents.	1. Parents of children with CP: 102 2. Children's age: 8-12 years.	1. Children's health 2. Motor ability of children 3. Intellectual impairment of children 4. Emotional and behavioural problems of children Using- Child Health Questionnaire (CHQPF50), GMFCS, IQ, Strengths and Difficulties Questionnaire (SDQ).	Stress Using- Parental Stress Index (PSI).	1. The motor function of children with CP was not related to their overall health nor to their behavioural or emotional problems. 2. The emotional and behavioural problems of the children showed a significant relationship with the level of parental stress.
CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs- years							
Whenever there were significant differences between the control group and the group of parent caregivers of children with cerebral palsy, the latter presented results that were in line with worse physical and mental health and lower quality of life.							

TABLE 1 (Part-9):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
15	Unsal-Delia-lioglu et al, 2009	C Q	To determine whether there was any difference, with respect to depression, between mothers of children with CP and mothers of healthy children, and to evaluate whether some additional factors had an impact on the depression of the mothers.	1. Mothers of children with CP: 49 2. Mothers of healthy children: 50 3. Mean age of children: 5.6 years	Motor ability of children Using- GMFCS.	Depression Using- Beck Depression Inventory (BDI).	1. No relationship was found between the CP severity and mothers' depression. 2. Relationship between family income and mothers' depression. 3. Relationship between speech problems of children with CP and mothers' depression. 4. Significant differences were found between caregivers and the control group in depression.
16	Byrne et al, 2010	C Q	To assess health status of caregivers of children with CP.	1. Female caregivers of children with CP: 100 2. Male caregivers of children with CP: 61 3. Children's age: 0-18 years	1. Number of hours per day spent with the child 2. Dependency level of children Using- GMFCS.	General health of mothers and fathers Using- SF-36.	1. Female caregivers spend more time than the male caregivers in caring for the children. 2. Female caregivers have lower scores than male caregivers in all measures of SF-36 except in general health domain. 3. The only significant difference between caregivers of more dependent or independent children was in the bodily pain domain.
CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs -years							
Whenever there were significant differences between the control group and the group of parent caregivers of children with cerebral palsy, the latter presented results that were in line with worse physical and mental health and lower quality of life.							

TABLE 1 (Part-10):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
17	Cheshire et al, 2010	C Q	To compare the psychosocial well-being of parents of children with CP and that of parents of children without a long-term health condition in the UK.	1. Parents of children with CP: 70 2. Parents of children without chronic diseases: 70 3. Mean age of children with CP: 6.4 years 4. Mean age of children in the comparison group: 7.3 years		1. Negative well-being 2. Positive well-being Using- Hospital Anxiety & Depression Scale, (HADS), Satisfaction with Life Scale.	Significant differences were found in anxiety, depression & satisfaction between parent caregivers and the control group.
18	Davis et al, 2010	C QL	To explore the QOL of mothers and fathers of children with CP and to examine whether the impact of caring for a child with CP changes from childhood to adolescence.	1. Mothers of children with CP: 24 2. Fathers of children with CP: 13 3. Children's age: 3–18 years	Motor ability of children Using- GMFCS.	Quality of Life of parents Using- 30–45 min interviews with open questions.	The parents described various aspects of quality of life affected by the child's illness (physical health, social relationships, family relationships, work, independence, etc.).
CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs- years							
Whenever there were significant differences between the control group and the group of parent caregivers of children with cerebral palsy, the latter presented results that were in line with worse physical and mental health and lower quality of life.							

TABLE 1 (Part-11):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
19	Kaya et al, 2010	C Q	To compare musculoskeletal pain, quality of life and depression between mothers of children with CP and mothers of healthy children.	1. Mothers of children with CP: 81 2. Mothers of healthy children: 60 3. Children's mean age: 6 years	Dependency level of children Using-GMFCS.	1. Quality of life of mothers 2. Symptoms of depression in mothers 3. Presence of pain 4. Location of pain Using-100 mm Visual analogue scale, BDI, SF-36, Standardised Nordic Questionnaire.	Significant differences were found between caregivers and the control group in: 1. Musculoskeletal pain and lower back pain. 2. The SF-36 dimensions of physical role and mental health. 3. Symptoms of depression.
20	Romeo et al, 2010	C Q	To examine the QoL of parents of children with different forms of CP and to establish the possible effects of behaviour problems on this quality of life.	1. Mothers of children with CP: 100 2. Fathers of children with CP: 100 3. Mothers of healthy children: 30 4. Fathers of healthy children: 30 5. Children's age: 4-10 years	1. Dependency level of children 2. Cognitive function of children 3. Children's behaviour Using-GMFCS, Wechsler Intelligence Scale for Children (WISC), Child Behaviour Checklist(CBCL).	Quality of life of parents Using-World Health Organisation Quality of Life BREF (WHOQOL-BREF).	1. Parents of children with hemiplegia had poorer psychological health than parents of children with diplegia & quadriplegia. 2. Parents of children with diplegia and quadriplegia had lower physical health than parents of children with hemiplegia. 3. Significant differences between parents of children with CP and the control group in QoL, both for physical & psychological health.

CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs- years

Whenever there were significant differences between the control group and the group of parent caregivers of children with cerebral palsy, the latter presented results that were in line with worse physical and mental health and lower quality of life.

TABLE 1 (Part-12):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
21	Sajedi et al, 2010	C Q	To evaluate depression in mothers of children with CP and to assess its relation to severity and type of CP.	1. Mothers of children with CP: 43 2. Mothers of healthy children: 77 3. Children's age: 6 months -8 years	1. Disability severity 2. Type of CP. Using- GMFCS.	Maternal depression Using- Beck Depression Inventory (BDI).	1. The severity of child motor disability was not significantly correlated with depression of caregivers. 2. No significant differences were found in depression between mothers with children with different types of CP. 3. Significant differences in depression were found between caregivers and the control group.
22	Huang et al, 2011	C QL	To describe the care-giving experiences of Taiwanese mothers of children with CP.	1. Mothers of children with CP: 15 2. Children's age: 8 months- 14 years	In-depth interviews were conducted to obtain information related to the study's objective.	In-depth interviews were conducted to obtain information related to the study's objective.	Four main concerns emerged from the interviews: experiencing burden, managing challenges, being marginalised, and encountering limited support.
23	Diwan et al, 2011	C Q	To evaluate depression & quality of life in mothers of children with cerebral palsy.	1. Mothers of children with CP: 30		1. Maternal depression 2. Quality of life of mothers Using- Beck Depression Inventory (BDI) & SF-36 Survey.	1. Presence of prevalent depression in mothers. 2. Affected QoL especially role limitation due to physical and emotional problems. 3. More affected social functioning.

CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs -years

Whenever there were significant differences between the control group and the group of parent caregivers of children with cerebral palsy, the latter presented results that were in line with worse physical and mental health and lower quality of life.

TABLE 1 (Part-13):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
24	Magill Evans et al, 2011	L Q & QL	To examine the well-being of mothers of children and young adults with CP.	1. Mothers of children with CP: 21 2. Children's age: 13–22 years : 1st measure 20 – 30 years : 2nd measure		1. Life satisfaction of mothers 2. Social support of mothers 3. Family functioning 4. Expectations for the child's future 5. Semi-structured interview of mothers Using- Multidimensional Scale of Perceived Social Support, (MSPSS), Family Assessment Device ver. 3 (FAD), Future Questionnaire (FQ), Life Situation Survey (LSS).	1. Mothers' scores on the standardised measures did not change significantly over time. 2. Many mothers reported physical and emotional challenges due to ongoing care-giving.
25	Okurowska-Zawada et al, 2011	C Q	To analyse the quality of life of parents of children with CP and to compare with that of parents of healthy children.	1. Parents of children with CP: 40 2. Parents of healthy children: 40 3. Children's age: 6–17 years	Dependency level of children Using- GMFCS.	Quality of life of parents Using- WHOQOL- BREF.	Significant differences were found in quality of life between caregivers and the control group.
CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs -years							
Whenever there were significant differences between the control group and the group of parent caregivers of children with cerebral palsy, the latter presented results that were in line with worse physical and mental health and lower quality of life.							

TABLE 1 (Part-14):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
26	Parkes et al, 2011	C Q	To describe stress in parents of children with CP and investigate associations with very high stress.	1. Parents of children with CP : 785 2. Children's age: 8-12 years	1. Motor ability of children 2. Use of arms and hands 3. Intellectual impairment 4. Visual impairment 5. Hearing impairment 6. Communication impairment 7. Parental employment 8. Parental educational qualifications 9. Area of residence. 10. Child's body pain Using- GMFCS, Bimanual Fine Motor Function, Formal IQ assessment ,Visual acuity assessment, Child Health Questionnaire.	Parenting stress Using- PSI-SF.	1. Significant differences were found in stress between caregivers & the general population. 2. The factors significantly associated with an increased risk of very high parental stress were three child variables: communication impairment, pain, and intellectual impairment. 3. The severity of child motor disability was not significantly correlated with stress of parents.
CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs- years							
Whenever there were significant differences between the control group and the group of parent caregivers of children with cerebral palsy, the latter presented results that were in line with worse physical and mental health and lower quality of life.							

TABLE 1 (Part-15):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
27	Sawyer et al, 2011	C Q	To describe the relationship between maternal mental health problems and both care-giving time and time pressure reported by mothers of children with CP.	1. Mothers of children with CP: 158 2. Children's age: 6–17 years	1. Maternal care-giving time 2. Time pressure of mothers 3. Maternal social support 4. Children's emotional & behavioural problems 5. Dependency level of children Using- Time-diary, Time Crunch Scale, Interpersonal Support Evaluation List (ISEL), Strengths & Difficulties Questionnaire (SDQ), GMFCS.	1. Maternal mental health problems 2. Depressive symptoms of mothers Using- General Health Questionnaire (GHQ), Centre for Epidemiological Studies Depression Scale (CES-D).	1. The dependency level of children was not related to time pressure of mothers. 2. The dependency level of children was not related to the mental health of mothers. 3. Mothers with more time pressure showed poorer mental health.
28	Ström et al, 2011	C Q	To investigate the QOL of parents or carers of children with CP in Cambodia.	1. Parents or carers of children with CP: 40 2. Children's age: 1–13 years		Quality of Life of parents or carers. Using- Comprehensive Quality of Life Scale A5 (ComQOLA5).	The three domains where parents showed lower levels were: health, material well-being and emotional well-being.
CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs- years							
Whenever there were significant differences between the control group and the group of parent caregivers of children with cerebral palsy, the latter presented results that were in line with worse physical and mental health and lower quality of life.							

TABLE 1 (Part-16):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
29	Majnemer et al, 2012	C Q	To describe family distress as reported by parents of children with CP. To identify the factors associated with distress.	1. Parents of children with CP: 95 2. Children with CP: 95 3. Mean age of children : 9.2 years	1. Socio-demographic Questionnaire 2. Motor ability of children 3. Cognitive function 4. Functional Limitations Using- GMFCS, Vineland Adaptive Behaviour Scale, Strength & Difficulties Questionnaire.	1. Stress 2. Impact on family 3. Child's health status Using- PSI, The Impact on Family Scale, Family related items on Child Health Questionnaire.	1. The amount of stress was high with high levels of defensive behaviour. 2. Child's health impacted on parents' time, emotional status, and family activities. 3. Family distress measures are more strongly associated with behavioural difficulties as compared to motor and cognitive abilities.
30	Alaee et al, 2014	C QL	To explain the problems that parents of children with CP experience when caring for their children.	1. Parents of children with CP: 172. Children's age: 2.5-16 years		Parenting experiences of parents Using- In-depth semi-structured interview of 30-60 minutes.	The parents described various aspects of parenting experiences leading to identification of two main categories, sub-divided into seven sub-categories: 1. Social Challenges (Inadequate facilities & services, Unsupportive interactions, Limitation of parents' social relations, Social seclusion of child and parents). 2. Psycho-emotional Challenges (Intrapersonal conflicts, Being worried, Sense of loneliness).

CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs- years

Whenever there were significant differences between the control group and the group of parent caregivers of children with cerebral palsy, the latter presented results that were in line with worse physical and mental health and lower quality of life.

TABLE 1 (Part-17):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
31	Nimbalkar et al, 2014	C QL	To explore the psychosocial problems experienced by the parents of children with CP in rural & urban settings.	1. Parents of children with CP: 13 2. Mean age of children: 5.7 years		Psychosocial problems of the parents Using- Focus Group Discussions (FGDs).	Various psychosocial problems were identified as per description by parents in FGDs, including: 1. Disturbed social relationships 2. Health problems 3. Financial problems 4. Moments of happiness 5. Worries about future of the child 6. Need of more support services 7. Lack of adequate no. of physiotherapists.
32	Krstic et al, 2015	C Q	To evaluate the differences in risk factors between mothers who were resolved and unresolved to their child's diagnosis of CP.	1. Mothers of children with CP: 100 2. Children's age: 2-7 years.	Child's Health Status (Functional Status, FS II(R)).	1. Resolution of loss or trauma associated with learning of their child's disability 2. Depressed state & Transitory variations in depressive mood 3. Family stress or vulnerability Using- Depression Scale (DS) & (Family Inventory of Life events & Changes -FILE)	The effects of functional status of a child, cumulative stress and maternal depression on mother's resolution lead to the confirmation of assertion that mothers who were unresolved (i.e. not clear about the condition and its outcomes) were under considerably larger amount of stress than resolved ones.
CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs- years							
Whenever there were significant differences between the control group and the group of parent caregivers of children with cerebral palsy, the later presented results that were in line with worse physical and mental health and lower quality of life.							

TABLE 1 (Part-18):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
33	Ramanandi and Rao, 2015	C Q	To assess the parenting stress levels in parents of children with cerebral palsy as compared to parents of normal children. To ascertain variables predictive of parenting stress levels.	1. Parents of children with CP: 43 2. Parents of normal children: 45 3. Mean age of children with CP: 8.5 years 4. Mean age of normal children: 8.9 years		1. Parenting stress 2. Demographic details including number of siblings, socio-economic status, educational level of parents, degree of support. Using- PSI- SF (Gujarati Translated Version).	1. The parenting stress levels amongst parents with CP children were generally higher. 2. The levels of stress experienced by parents of CP children was found to be associated with levels of education, job status of the parents and the type of family.
34	Barbosa et al, 2016	C Q	To describe socio-demographic, parental stress and perceived social support indicators for primary caregivers of children with CP and to investigate whether these variables are associated.	1. Primary caregivers of children with CP: 100. 2. Age of children: 1- 12 years.	Motor ability of children Using- GMFCS.	1. Sociodemographic information 2. Parenting stress 3. Structural & functional social support Using- Sociodemographic Inventory (SDI), PSI, (Medical Outcome Social Support Survey -MOS-SS).	1. Financial difficulties, low education levels and restricted access to the healthcare services increase hindrances for effective social integration. 2. Perceived social support acts as a protecting factor against the negative impact of parental stress. 3. Child's problems along with the pain and sensory impairments lead to increase in burden of caregivers.
CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs- years							
Whenever there were significant differences between the control group and the group of parent caregivers of children with cerebral palsy, the latter presented results that were in line with worse physical and mental health and lower quality of life.							

TABLE 1 (Part-19):		REVIEW STUDIES					
No.	Study	Type	Purpose	Population	Factors Related with Impact of Parenting Measured through-	The Impact of Parenting on QoL of Parents Measured through-	Relevant Results
35	Pushpalatha and Shivakumara, 2016	C Q	To find the difference in stress, burden and coping between caregivers of children with cerebral palsy and children with autism.	1. Caregivers of children with CP: 30 2. Caregivers of children with autism: 30 3. Age group of children: 7-12 years		1. Parenting stress 2. Parental burden 3. Coping Using- PSI, Schedule to Assess Burden by Pai and Kapur, Coping Checklist by Rao, Subbakrishna & Prabhu.	1. The stress on the caregivers of autistic children is more as compared to the caregivers of CP children due to availability of better rehabilitation services for CP children. 2. The caregivers of CP children experience more burden as compared to caregivers of autistic children due to its significant correlation with degree of disability/dependence. 3. Coping strategies used by the caregivers in both groups are varied, based on the circumstances, and caregivers of children with CP are found to use less coping strategies.
36	Wang et al, 2016	C Q	To verify the correlations among parenting stress, social support and life satisfaction in mothers of children with CP.	1. Parents of children with CP: 369		1. Parenting stress 2. Perceived social support 3. Satisfaction with life Using- PSI-SF, MSPSS, Satisfaction with Life Scale (SWLS).	1. Parenting stress was negatively correlated with total social support and life satisfaction. 2. Family and friends' support play a major role in the mediating effects on the link between parenting stress and life satisfaction.
CP- cerebral palsy; C- cross-sectional; L- longitudinal; Q- quantitative; QL- qualitative; Yrs- years							
Whenever there were significant differences between the control group and the group of parent caregivers of children with cerebral palsy, the latter presented results that were in line with worse physical and mental health and lower quality of life.							

In keeping with the main objectives of this review, the results are arranged in two categories: first, the impact of parenting, where the outcomes that have been analysed and how those outcomes are affected by the task of parenting, have been described; and second, factors related to the impact of parenting have been divided in three parts: child-related factors, family-related factors, and contextual factors.

## **The Impact of Parenting**

Of the 36 empirical studies, 32 studies (88.8 %) included quantitative data on some variables related to the impact of being responsible for the job of parenting. These variables were generally related to the status of the primary caregiver, usually the mother. Data was found on very specific aspects such as stress, depression, or anxiety experienced by the parent or caregiver. More global variables, such as parents' general well-being or quality of life were also found in some of the studies.

A variety of groups was used to compare data from the parents of children with CP. In 11 of the articles analysed (30.55 %), a control group of parents of children without health problems was used to compare data from the parents of children with CP. In one study, a comparison was made with a general population of caregivers, obtained through a national population health survey, and in some other studies the results were compared with a normative sample. One study compared the data from the group of parents of children with CP with data from a group of parents of children with autism.

Most of the studies focussed on the impact of the care-giving process on parents' mental health (25 articles or 69.44 %) and found that these parents experienced high levels of stress, anxiety and depression. Studies using normative sample data, or ones that made comparisons with general population samples, showed differences in levels of anxiety and depression (Barlow et al, 2006; Diwan et al, 2011; Sawyer et al, 2011), distress (Brehaut et al, 2004), and stress (Manuel et al, 2003; Skok et al, 2006; Ho et al, 2008; Glenn et al, 2009; Parkes et al, 2009; Parkes et al, 2011; Majnemer et al, 2012; Nimbalker et al, 2014; Alaei et al, 2015; Krstić et al, 2015; Lima et al, 2016; Wang et al, 2016). Similar patterns were found in research done with a control group of parents of children without CP (Britner, 2003; Wang & Jong, 2004; Unsal-Delialioglu et al, 2009; Cheshire et al, 2010; Kaya et al, 2010; Sajedi et al, 2010; Ramanandi & Rao, 2015). One of the studies compared the variables with those of parents of children with autism and found more stress in

parents of autistic children although lower burden of parenting (Pushpalatha & Shivakumara, 2016).

Interestingly, Ones et al (2005) observed that 46 mothers of children with CP, when compared to 46 mothers of healthy children, showed higher levels of depression and lower quality of life but similar levels of anxiety. The authors concluded that mothers' anxiety might be more related to acute life events, like the moment when they received the diagnosis; however, anxiety can lead to depression over time, which is more observable when the situation becomes chronic. The specific characteristic of cerebral palsy being a non-progressive disease, together with the family's changing process of adaptation to the situation, could also be a possible explanation for the findings. In a similar study by Ramanandi and Rao (2015), 43 parents of children with CP were compared with 45 parents of normal children, and the conclusion was that the parenting stress levels were generally higher amongst the parents of children with CP. The level of parenting stress experienced by parents of children with CP was found to be associated with levels of education and job status of the parents, as well as on the type of family.

Less attention has been paid to the effects of the parenting situation on the quality of life of parents (8 articles or 22.22 %). According to the studies reviewed, the quality of life of parent caregivers of children with CP is worse than that of the general population and that of parents of children without health problems. Davis et al (2010) conducted a qualitative study through semi-structured interviews to explore the quality of life of fathers and mothers of children with CP. The authors concluded that parenting a child with CP can positively impact on a parent's ability to build new social support networks; however, the parenting situation can negatively impact on parents' physical health, social relationships, freedom and independence, family relationships, and financial stability. Interestingly, Ström et al (2011) observed that the parents or carers of children with CP showed lower levels in the domains of health, material well-being and emotional well-being when assessed for comprehensive quality of life.

Significant differences in quality of life measures, such as the Short Form 36 Health Survey (SF-36, the most used measure in the analysed studies), the World Health Organisation Quality of Life Bref (WHOQOL-BREF), or other measures (Eker & Tüzün, 2004; Ones et al, 2005; Kaya et al, 2010; Romeo et al, 2010; Okurowska-Zawada et al, 2011) were found in the quantitative studies. In all these studies, parents of children with CP had worse levels of quality of life than parents of healthy children.

Some studies analysed the number of physical problems that parents of children with CP had as a result of the parenting situation. Brehaut et al (2004) compared 468 primary caregivers of children with CP with general population data, and found significant differences between the two groups in frequency of chronic diseases, sight and hearing problems, and physical pain. Similar results were found in a study by Kaya et al (2010), where musculoskeletal pain, quality of life and depression in mothers of children with CP were compared with data from mothers of healthy children. Mothers of children with CP had more musculoskeletal and lower back pain than mothers of healthy children, and the pain was more severe and chronic among mothers who had higher levels of depressive moods.

There was only one longitudinal study (Magill-Evans et al, 2011). The work used a very small sample, so it was difficult to analyse the evolution of the effects of parenting over time. However, results of this study were in accordance with the findings of quantitative studies, reporting that parenting a child with CP affects mothers' physical and emotional well-being.

### **Factors Related to the Impact of Parenting**

Most often, studies on the impact of parenting children with CP were conducted in relation to the following: child-related factors (especially, the severity of the child's disability and the cognitive or behavioural problems); family-related factors (such as parents' personal resources and family and marital functioning); and contextual factors (social support).

#### **Child-related Factors**

The severity of the disability was one of the most commonly analysed variables relating to the child. The tool most widely used to measure this was the Gross Motor Function Classification System - GMFCS (Palisandro et al, 1997). Most of the studies showed that the quality of life and mental health of caregivers were not related to this variable (Manuel et al, 2003; Ones et al, 2005; Skok et al, 2006; Hamzat & Mordi, 2007; Ho et al, 2008; Parkes et al, 2009; Unsal-Delialioglu et al, 2009; Kaya et al, 2010; Majnemer et al, 2010; Sajedi et al, 2010; Parkes et al, 2011; Sawyer et al, 2011; Lima et al, 2016).

In contrast, a few studies found a relationship between the well-being of the caregiver and the severity of motor disability in the child with CP. Eker and

Tüzün (2004) observed significant correlations between GMFCS and some subscales of the SF-36, indicating that the quality of life of mothers was significantly correlated with the severity of the child's motor disability.

A study by Byrne et al (2010) compared children with CP, manifesting different degrees of motor problems, and found that parents of more dependent children had more severe body pain compared to parents of children who were more independent, and parents of non-walking children had poorer health than parents of walking children. Similarly, Barbosa et al (2016) showed that the child's motor, intellectual, emotional and behavioural problems, along with the presence of pain and sensory impairments, led to an increase in the burden of caregivers.

Behavioural and emotional problems in the child with CP were other significant variables that were taken into account by some of the studies. All the studies that examined this aspect found that the child's behavioural problems were related to higher levels of stress and worse general well-being of caregivers (Raina et al, 2005; Ketelaar et al, 2008; Parkes et al, 2009; Romeo et al, 2010; Majnemer et al, 2012; Lima et al, 2016).

One study examined the effect of children's cognitive functioning on parents' psychological health and found that the presence of cognitive impairment was an important predictor of stress experienced by the caregiver (Glenn et al, 2009). In this sense, Unsal-Delialioglu et al (2009) found a relationship between speech problems of children with CP and mothers' depression, and Parkes et al (2011) observed that the child's communication difficulties, pain and intellectual impairment, were the factors most related to parental stress.

## **Family-related Factors**

**Parent Factors** -The main interest in some of the selected studies was the influence of parents' personal resources on their adjustment to the child's illness and the parenting situation, while managing their own physical, emotional and social well-being. These studies found low self-efficacy to be strongly associated with poor mental health (Raina et al, 2005; Barlow et al, 2006; Ketelaar et al, 2008). For example, Ketelaar et al (2008) observed that child behaviour was an important predictor of parents' functioning, both directly and indirectly, through its effect on self-efficacy.

In another research, Raina et al (2005) found self-perception and stress management to be significant predictors of parents' psychological health. In

this sense, Sawyer et al (2011) found that time pressure for mothers of children with CP was positively correlated with maternal psychological problems and depressive symptoms, and concluded that it was important to train mothers in stress and time management to prevent psychological problems.

Ho et al (2008) focussed on how parenting influenced the well-being of both the caregiver and the child, and observed that over-protectiveness by caregivers was related to anxiety and depression and a lower perception of happiness, both in children as well as caregivers.

**Family and Marital Adaptation** – The main objective of some of the reviewed studies was to analyse the effects of the parenting duty on family functioning, or else to obtain information on families' adaptation to having a child with CP.

Where families had a child with CP, some studies found that family functioning was similar to families with healthy children or with children who had other health issues (Britner, 2003; Magill-Evans et al, 2011; Majnemer et al, 2012; Krstić et al, 2015). However, other studies that analysed more specific dimensions argued that family and marital adaptation to the parenting situation was somewhat different from that of families where children were without CP. It was found that the mothers of children with CP exhibited less marital satisfaction with respect to role distribution between the parents and leisure time spent with their partner.

**Impact of Family Factors on the Well-being of Caregivers** - Glenn et al (2009) found that the family's needs, adaptability and the cognitive impairment of children were the most relevant factors in accounting for the total stress of mothers. Also, in the study by Raina et al (2005), higher reported family functioning was associated with better psychological and physical health among caregivers.

**Process of Adaptation**—A few studies examined the evolution of family adaptation to the parenting situation over time. The results of these studies indicated that the coping strategies used by families were different at different moments in the family cycle, and that the degree of family adaptation also varied according to the developmental stage of the child. The authors suggested that families with infants and preschoolers seemed to use more coping behaviour related to increasing knowledge of CP and seeking external resources, and families with school-aged children appeared to use more coping behaviour related to positive family appraisal and had better positive social interactions (Krstić et al, 2015; Pushpalatha & Shivakumara, 2016).

**Differences between Fathers and Mothers** - Only two studies were found that focussed on the differences between fathers and mothers with respect to the parenting situation and the process of adaptation to the child's disability. Byrne et al (2010) conducted a quantitative study with 100 mothers and 61 fathers of children with CP, and observed that mothers spent more time parenting the child than the fathers did, and that mothers had worse mental and physical health. Romeo et al (2010) found that mothers of children with hemiplegia exhibited lower scores than fathers in the area of psychological health, while mothers of children with diplegia and quadriplegia exhibited lower scores than fathers in the area of physical health.

### **Contextual Factors**

**Social Support** -In many studies, social support was found to be an important factor which could contribute either directly or indirectly to the well-being of caregivers (Manuel et al, 2003; Raina et al, 2005; Skok et al, 2006; Magill-Evans et al, 2011; Sawyer et al, 2011; Lima et al, 2016; Wang et al, 2016).

In Manuel et al (2003), the relationship between child functioning and maternal depression was moderated by social support. Along the same lines, Raina et al (2005) concluded that social support had indirect effects on psychological and physical health through family functioning. Skok et al (2006) concluded that perceived social support mediated the relationship between stress and the well-being of mothers of children with CP.

## **DISCUSSION**

This review focuses on the effect that parenting children with cerebral palsy has on the quality of life of parents and on their well-being.

Based on the results of the literature review, the researchers concluded that parent caregivers, especially mothers, experience higher levels of stress and depression and, on the whole, lower quality of life as compared to parents of healthy children. The factors consistently related to this are: child behaviour and cognitive problems, low caregiver self-efficacy, and low social support.

### **Research Implications**

Further research is necessary to better understand how parenting a child with CP impacts on parents' functioning and welfare. First, because many of the studies

in this field use heterogeneous samples – the studies in this review involved children with different age ranges; also, some studies used control groups as a reference while others used normative data. Secondly, although the studies used similar assessment tools for some of the variables (e.g., measures of parental stress or functional aspects in children), most of the measures used were quite different, thus making it very difficult to compare results across studies and to examine the effect size of the factors involved.

The authors of this paper also consider it necessary to further explore the role that caregivers' personal resources (e.g., self-efficacy, self-esteem or coping strategies) play in shaping their well-being. This would help in designing better interventions and therefore promote a process of empowerment that could influence the quality of life of caregivers and their families (Turnbull, 2005).

Another problem that needs to be addressed is the shortage of longitudinal studies in the field. It seems reasonable to assume that the stage at which families are in the child's diagnosis (which can sometimes take a considerable amount of time), and the stage of development of the child, can both affect the family's mood, health and, ultimately, wellbeing, particularly in relation to the primary caregiver. So, as Rentinck et al (2007) pointed out, longitudinal studies are necessary to provide data on the evolution of the effects of parenting over time.

Most of the papers reviewed have studied the impact of the parenting situation on the mother. Research should take into account the possible differences between fathers' and mothers' adaptation to their child's difficulties because, when those differences are taken into consideration, diverse adaptation mechanisms appear. Also, it would be interesting to explore whether the existing differences depend on the gender of the child, and the possible impact on other family members such as siblings or grandparents. These factors have hardly been studied.

### **Clinical Implications**

Overall, the results of this review are not wholly unexpected, but require specific attention in the context of designing interventions. Consistent with a family-centred model, high levels of parental stress sustained over time can affect family dynamics, as well as the health and development of the child with CP. Based on the conclusions of many of the reviewed articles, the authors of this study have formulated a number of guidelines for the design of more effective interventions.

First of all, interventions by health professionals should be aimed at the family as

a whole and not just at the children affected. Therefore, in the future, interventions for children with CP should aim to address the psychosocial needs of families and, fundamentally, to develop parenting skills to meet these needs (Dunst et al, 1988; Trivette et al, 1990; Allen & Petr, 1996). It is important to assess how parents evaluate their own skills and their confidence to cope with the situation. An important goal of the interventions would be to improve on strategies to deal with highly demanding situations. Indeed, the family-centred model seeks to enhance the perception of self-efficacy and encourage a sense of control over daily life.

Secondly, it has been seen that high levels of parental stress are linked with the presence of behavioural problems in the child. While it is true that parents under stress can negatively affect children's behaviour, it is also true that behavioural problems can be related to the disease itself and, in turn, influence parents' moods. Most likely these elements feed on each other (Wanamaker & Glenwick, 1998; Hastings et al, 2006; Sipal et al, 2010) and, therefore, it is important that interventions take this cycle into account and establish mechanisms to break it and increase support for parents.

Thirdly, social support is one of the factors that seem to be associated with parents' emotional health. The practices that have been demonstrated to be most effective when working with parent caregivers of children with disabilities are linked to the nature and quality of social support (formal or informal) available to the family in ordinary everyday situations (Dunst et al, 2007). Consequently, it is important that interventions designed for families provide for social support and place an emphasis on support services and the immediate environment as a basis for training and empowering families (Turnbull et al, 2000). For instance, parent support groups can provide families with a context where they can share emotional issues, relevant information or practical resources (Wanamaker & Glenwick, 1998).

Additionally, due to the widespread diffusion of information technologies and communication, the internet has become one of the main sources of health information, and clients and relatives use the Web to make contact with peers in similar situations. They often tend to organise themselves into virtual communities (Guillamón et al, 2010; Fox, 2011). The authors of the current review are convinced that the interventions aimed at families of children with long-term disabilities need to incorporate the Internet as a means of fostering communication and support among group members (Colineau & Paris, 2010).

## Limitations

This literature review has a few constraints. First, only articles printed after the year 2003 and in the English language were searched for or analysed; so there is the possibility that some potentially relevant articles were overlooked, either because they were published prior to this date or because they were written in a language other than English. Even though it is not easy to be comprehensive, there has been clarity regarding the selection criteria for the studies and this process can be replicated by other researchers.

Secondly, one of the criteria was to analyse only studies that looked at parents of children with CP. Hence it was not possible to arrive at general conclusions about the quality of life of parents with children who had other disorders.

## CONCLUSION

Recent literature confirms that the psychological and physical health of children with CP can negatively affect their parents' quality of life. These effects are related to the behavioural and cognitive characteristics of the child, the functional consequences of the disability, parents' perceived self-efficacy and social support.

These findings should be taken into account when designing and planning family interventions. In order to improve parents' resources to cope with demanding situations, interventions should also be aimed at developing their abilities, coping strategies and strengthening their social networks.

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