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The Physical Health of Caregivers of Children With Life-Limiting Conditions: A Systematic Review

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abstract

CONTEXT: Parental caregiving for a child with a life-limiting condition (LLC) is complex physical and mental work. The impact of this caregiving on parents' physical health is unknown.

OBJECTIVES: (1) To review existing evidence on the physical health of parents caring for a child with a LLC and (2) to determine how physical health of parents is measured.

DATA SOURCES: Medline, Embase, PsycINFO, and Cumulative Index of Nursing and Allied Health Literature were searched.

STUDY SELECTION: Peer-reviewed articles were included if they reported primary data on the physical health of a caregiver of a child with a LLC. Studies were excluded if they described only the caregiver's mental health or if the caregivers were bereaved at the time of data collection.

DATA EXTRACTION: Of 69 335 unique citations, 81 studies were included in the review.

RESULTS: Caregiver health was negatively impacted in 84% of studies. Pain and sleep disturbance were the most common problems. Ways of measuring the physical health of caregiver varied widely. We found an absence of in-depth explorations of the social and economic contexts, which could potentially mitigate the impact of caregiving. Furthermore, we find health interventions tailored to this group remain largely unexplored.

LIMITATIONS: Studies were heterogenous in methodology, making comparisons of results across studies difficult.

CONCLUSIONS: These findings support the need for improving access to interventions aimed at improving physical health in this population. The rate of health-seeking behaviors, preventive health care access and screening for health conditions is understudied and represent important directions for further research.



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Dr Hartley codesigned the data extraction instruments, conducted the search, screened the abstracts for inclusion in the review, extracted the data, conducted the initial analyses, drafted the initial manuscript, reviewed and revised the manuscript, and composed the final manuscript; Prof Bluebond-Langner conceptualized and designed the systematic review, reviewed and revised the manuscript, reviewed the manuscript for important intellectual content, and secured the funding; Dr Candy designed the data collection instruments, screened the abstracts for inclusion in the review, reviewed and revised the manuscript, and reviewed the manuscript for important intellectual content; Dr Downie provided clinical advice and support, reviewed and revised the manuscript, and reviewed the manuscript for important intellectual content; Dr Henderson conceptualized and designed the systematic review, screened the

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Approximately 86 625 children in the United Kingdom live with a life-limiting condition (LLC) or life-threatening illness (LTI), and this number is growing.¹⁻³ LLCs and LTIs are defined by possible and potential outcomes. LLCs are defined as conditions in which “there is no reasonable hope of cure and from which children or young people will die.” LTIs are illnesses “for which curative treatment may be feasible but can fail.”^{3,4} Both LLCs and LTIs can cause “progressive deterioration rendering the child increasingly dependent on parents and carers.”^{3,4} Because of medical advances in care and treatment of children diagnosed with LLCs and LTIs, they now live longer but often with greater medical complexity and increased care needs.^{5,6} At the same time as treatment and management of these children has become more complex and involved, provision has also moved away from hospitals and other institutional locations, into the home.⁷⁻⁹

Although there is evidence that some parental caregivers prefer home care,¹⁰⁻¹² the informal care undertaken by caregivers entails a tremendous amount of time-consuming, complex, physical and mental work.^{9,13,14} Caring for children with LLCs or LTIs in the home involves taking on tasks such as operating supportive and life-saving technologies,^{9,15-17} administering medications,¹⁸ monitoring and recording symptoms,¹⁹ lifting, changing and positioning of the child,^{9,14} delivering care at night,^{6,20} and coordinating care given to their child by professionals.¹³ These tasks are being undertaken by caregivers at a time and in a context in which the child’s death is inevitable and approaching.⁹

Studies of carers of adults with long-term conditions report that they get

little exercise, have poor sleep, and put off health check-ups or medical treatment because of time constraints associated with caregiving.^{21,22} They also have persistent injuries caused by or exacerbated by the physical strain of providing care.²² Furthermore, 46% of those providing care to adults report reduced household expenditure on basics such as food and heating because of financial difficulties associated with caregiving.²¹⁻²⁴ Authors of a recent review of literature on the experiences of caregivers who care for a child with chronic health condition found that they perform similar tasks to caregivers of children with LLCs or LTIs and that they have worse overall mental health as a result.²⁵ However, there have been no systematic reviews of the impact of caregiving demands on the physical health of caregivers of children with LLCs or LTIs. Previous literature indicates that regardless of the condition of the person requiring care, when the health of the caregiver is compromised, the ability to provide care is reduced.^{21,22,26}

Our aims with this systematic review were to (1) describe and synthesize the research conducted to date on the physical health of family caregivers of children with LLCs and LTIs with specific attention to the determinants of health examined in the literature and (2) describe methods commonly used to measure the physical health of caregivers. The protocol for this systematic review was registered with Prospero^{27,28} (registration number: CRD42018099281).

METHODS

Inclusion and Exclusion Criteria

Published empirical studies were included if (1) they reported the physical health of a caregiver and

(2) the caregiver cared for a child with a LLC or LTI listed in the Hain Directory of LLCs and (3) the child was <25 years old.²⁹ Articles were excluded if (1) they did not describe the physical health of a caregiver; (2) caregiver was caring for a child who did not have a LLC or LTI; (3) caregivers were bereaved at the time of data collection; (4) the study was not peer-reviewed; (5) the publication did not describe primary data collection (ie, opinion and systematic and topical reviews were excluded); (5) the study scored below the mean on the Hawker quality checklist.³⁰

Search Terminology

The search strategy was designed to identify research conducted on the health of caregivers caring for a child with a LLC or LTI. However, determining which conditions and diseases from which a child could die before reaching adulthood is not straightforward.³¹ Some conditions are not always life-limiting, or even life-threatening, but rather have a broad spectrum of severity, including the possibility that a child might die of issues related to the illness, as well as the possibility that the child will reach adulthood and their life expectancy will not be compromised. Because of the diversity and spectrum of severity of pediatric LLCs and LTIs, we developed and piloted a search strategy using terms such as “palliative,” “life-threatening,” and “life-limiting” coupled with disease categories from the Hain Directory. However, the results did not identify the preidentified studies that we knew should be identified by the search.³²⁻³⁴ We therefore determined that this review required the development of a list of conditions based on disease categories.

The list of LLCs and LTIs was developed iteratively by using

International Statistical Classification of Diseases and Related Health Problems, 10th Revision categories identified as pediatric LLC or LTIs^{4,29} with the direct input of a pediatric palliative care clinician, as well as data from referrals to the largest UK-based tertiary palliative care team over the preceding 2 years. The search terminology was further confirmed by comparing the search findings to diseases cited in epidemiological research on the leading causes of death among children in the United States and United Kingdom who have LLCs and LTIs.³⁵⁻³⁸ Our search strategy is listed in Supplemental Table 4.

The search terms and linking strategy were checked by a medical librarian and tested iteratively for each database to ensure the terminology used matched that used by each database. Once confirmed, the searches were conducted (October 8 and 9, 2018, and updated on August 18, 2020) in Ovid Medline, Ovid Embase, Ovid PsycINFO, and Cumulative Index of Nursing and Allied Health Literature Plus. All searches were limited to articles in English. The full list of search terms and linking strategy can be found in Supplemental Table 4.

Quality Assessment and Critical Quality Appraisal

As in any systematic review, there is a need to assess the quality and, therefore, the studies' trustworthiness.³⁹ In this review, we excluded studies with serious methodologic flaws or which lacked full presentation of findings. To assess the quality of studies of different methodologies, we used the Hawker checklist, a 9-item checklist that was designed to accommodate studies of different research methodologies while taking into consideration the study

quality.³⁰ This tool has been recommended for use in systematic reviews in which included studies come from various epistemological and methodologic perspectives, as in this review.³⁹ Although there is no accepted cutoff score for inclusion or exclusion of studies using this checklist, in the current review, we calculated the mean of the quality assessment scores for all included studies and used it as a cutoff for inclusion in the review.

Data Extraction and Method of Synthesis

Study characteristics including country of origin, sample size, method of sampling, method of data collection, data analysis, and results of the study as applied to physical health and any covariables were extracted from each included article. We also extracted data on methods for measuring caregivers' physical health; child variables including age, diagnosis, illness characteristics, and stage of the child's illness (when available); and caregiver variables such as ethnicity, marital status, sex, age, employment status, and household income. All extracted data were imported into an Excel file for further analysis.

Given the diverse and heterogeneous mix of study types and methodologies, in this review we use "narrative synthesis" to bring the study findings together.⁴⁰ As in previous reviews of this sort, we adopted a "textual approach to the process of synthesis, to bring out the commonalities and relationships between the studies and the health impacts across them."⁴¹ Narrative synthesis is well suited to this review because it "relies primarily on the use of words and text to summarize and explain the findings of the synthesis."⁴⁰

RESULTS

Search Results

The database searches in 2018 retrieved 102 878 citations, of which 57 272 citations were unique. The database searches in 2020 returned 19 961 citations, of which 12 062 were unique. Titles and abstracts were screened for inclusion by 3 authors (J.H., E.H., and B.C.), resulting in 1249 citations (1054 in 2018 and 195 in 2020) that could not be excluded. Two authors (J.H. and E.H.) critically assessed the full texts of all 1249 studies against the inclusion and exclusion criteria. Any studies for which the condition's life-limiting nature was not clear were assessed for inclusion by a clinician (J.D.). Ninety-seven studies were eligible and underwent quality assessment by using the Hawker checklist. The mean score on the checklist was 25 (SD = 10). As per the systematic review protocol, only the 81 studies scoring 25 or higher on the Hawker checklist were included in the review (see Fig 1).

Description of the Studies

The 81 studies represent the experiences of 9381 parental and familial caregivers, of which 7165 were mothers, 979 were fathers, and 89 were other family members (grandmothers and siblings). There were 1148 caregivers for whom the familial relationship was not described (see Table 1 for a full description of included studies).

Life-Limiting and Life-Threatening Diagnoses of the Children

The children had a range of diagnoses (see Table 1). The most common category was neurologic (cerebral palsy, $n = 20$; epilepsy, $n = 5$; muscular dystrophies, $n = 4$; Rett's syndrome, $n = 4$; neuromuscular disorders, $n = 1$; neurologic disorders of unknown etiology, $n = 1$; encephalopathy, $n = 1$; and Angelman Syndrome, $n = 1$).

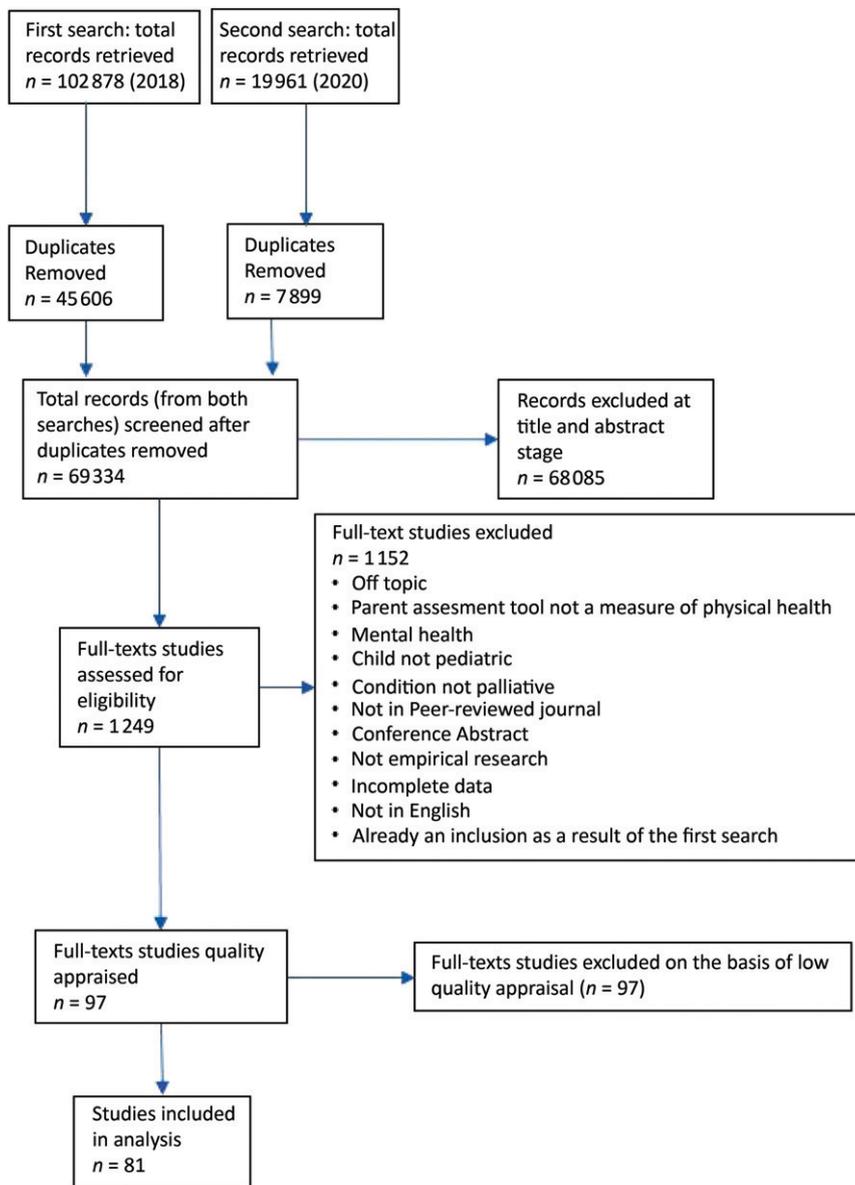


FIGURE 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flowchart.

The second-most common category was oncological and hematologic cancers ($n = 29$). The remaining 12 studies explored the health of caregivers of children with heart disease ($n = 3$); studies in which children had a variety of conditions ($n = 7$); congenital and chromosomal abnormalities such as tuberous sclerosis complex ($n = 1$) and neurofibromatosis ($n = 1$); 1 study of epidermolysis bullosa ($n =$

1) and 2 studies of caregivers of children with cystic fibrosis ($n = 2$). The search did not identify any relevant studies of caregivers of children with gastrointestinal, renal, or metabolic conditions.

Geographic Distribution of Studies

Thirty-one studies (38.2%) were conducted in North and South America. There were 15 studies of European populations (18.51%) and

11 studies originating from Western Asia (13.5%). Eleven studies originated from Eastern Asia (13.5%), 7 studies from Australia (8.6%), and 4 from Africa (4.9%). Two studies explored the experiences of caregivers across multiple countries (2.4%). See Table 1 for further information on the countries included in each study.

Study Design and Measures of Physical Health

We find the methodologies used to measure physical health varied between studies (see Table 2). The majority of the studies ($n = 62$) explored physical health via prevalidated, self-reported questionnaires designed to measure health-related quality of life among the general population.

Qualitative methods such as interviews, focus groups, and participant observation were the second-most common group of methodologies included in this review ($n = 14$) (see Table 1). Researchers in 5 studies employed objective measures of health; those in 2 used activity trackers^{42,43} and those in 3 studies explored immune function through salivary or blood cortisol measurement.⁴⁴⁻⁴⁶ Of the aforementioned studies, researchers in 2 evaluated interventions^{42,47} and those in 8 used mixed methods.^{15,43,44,47-51} Table 2 outlines the different measures of caregiver health used by the included studies.

The Effects of Caregiving on Caregiver Physical Health

An overwhelming number of studies found caregiver health was directly and negatively impacted by the nature of the care they provided to their child ($n = 68$, 84%). When explored according to the health measure, 28 studies^{26,48,49,51-76} employing the 36-Item Short-Form Health Survey (SF-36) demonstrated that physical

TABLE 1 Table of Inclusions

Author, Year of Publication, and Location of Study	Aims and Objectives	Child's Condition	Study Design	Caregiver Health Measure	No. and Sex of Caregivers	Hawker Quality Assessment Score	Study Results Related to Physical Health ^a	Study Conclusions
1 Albayrak et al ⁷⁵ (2019), Turkey	The aims with this study were to evaluate pain, care burden, depression level, sleep quality, fatigue, and IQOL among a group of mothers of children with CP and to compare their results with a group of healthy controls.	CP	Case-control	SF-36; Pittsburgh sleep quality index	168 caregivers: 101 mothers (case); 67 mothers (control)	33/36	General health score: 55.44 (SD: 7.61) case; 52.23 (SD: 10.88) control. Body pain subscale: 28.01 (SD: 19.39) case; 27.31 (SD: 18.38) control. Role physical functioning subscale: 57.67 (SD: 45.1) case; 71.64 (SD: 35.59) control. Physical functioning subscale: 82.07 (SD: 27.97) case; 76.26 (SD: 21.12) control. Physical component score subscale: 55.8 (SD: 12.8) case; 58.19 (SD: 7.89) control.	In this study, compared with matched controls, mothers of children with CP had higher pain, increased care burden, reduced sleep quality, increased fatigue.
2 Alvaranga et al ²⁵ (2020), Brazil	To evaluate the oral HRQoL of caregivers of individuals with CP.	CP	Case-control	Oral Health Impact Profile	98 caregivers: 95 case mothers; 3 case fathers; 197 control	30/36	Functional limitation: 1.31 (SD: 1.80) case; 1.34 (SD: 1.6) control. Physical pain: 2.96 (SD: 2.1) case; 2.98 (SD: 2.1) control. Physical disability: 2.22 (SD: 2.4) case; 1.84 (SD: 2.0) control.	Oral HRQoL was not different for all caregivers of children with CP. Those parents who had other siblings in the family and who had diabetes had decreased oral health IQOL and were more likely to have had tooth extractions. Parents of the children with heart disease reported severe impairment across multiple domains of IQOL including a lowered sense of well-being with regard to energy and general health, limitations in function due to physical and emotional reasons.
3 Arafa et al ⁵⁵ (2008), Egypt	To describe the HRQoL of parents whose children are suffering from heart diseases and to identify the most important factors that could affect it.	Heart disease	Cross-sectional	SF-36	800 caregivers: 400 case; 400 control (Caregiver sex not given)	33/36	General health score: 46.25 (SD: 23.49) case; 73.15 (SD: 22.03) control. Body pain subscale: 82.60 (SD: 11.8) case; 81.80 (SD: 12.3) control. Role physical functioning subscale: 39.53 (SD: 34.35) case; 61.81 (SD: 39.89) control. Physical functioning subscale: 75.76 case (SD: 17.11); 79.84 (SD: 14.10) control. Physical component score subscale: not given.	
4 Barrera et al ¹¹ (2012), Canada	To examine, longitudinally, maternal and paternal HRQoL before and 1 and 2 y after stem cell transplant and compared these outcomes with normative values.	Cancer	Longitudinal	SF-36	84 caregivers: 49 mothers; 35 fathers (pre-SCT assessment) 26 mothers; 20 fathers (1 y after SCT) 31 mothers; 19 fathers (2 y after SCT)	25/36	General health score: not given. Body pain subscale: not given. Role physical functioning subscale: not given. Physical component score subscale (mothers): 52.73 (SD: 9.89) pre-SCT assessment; 52.98 (SD: 7.44) 1 y after; 55.91 (SD: 4.67) 2 y after. Physical component score subscale (fathers) 52.33 (SD: 8.70) pre SCT assessment; 52.77 (SD: 7.03) 1 y after; 53.32 (SD: 6.57) 2 y after.	HRQoL for both mothers and fathers was in the normal range. However, risk factors for poor physical HRQoL were found among parents 2 y post stem cell transplant, including: being <30 y for mothers; having a child with behavior problems, diagnosis of other leukemias (mainly AML), and being older than 30 y for fathers. The authors postulate that younger mothers may be more prone to neglect their physical health when they are caring for a sick child, but that this picture is more complex for fathers.
5 Bella et al ⁴⁴ (2011), Brazil	To evaluate the level of salivary cortisol and perceived burden, stress, and health of mothers and primary caregivers of children with CP and those for mothers of children of the same age without developmental problems.	CP	Mixed methods	Saliva sample; SF-36	75 caregivers: 37 case; 38 control (caregiver sex not given)	27/36	SF-36: General health score: 54.75 (SD: 23.19) case; 73.18 (SD: 18.16) control. Body pain subscale: 51.29 (SD: 24.99) case; 62.95 (SD: 17.31) control. Role physical functioning subscale: 63.16 (SD: 39.31) case; 78.38 (SD: 35.92) control. Physical functioning subscale: 79.61 (SD: 20.64) case; 89.32 (SD: 13.45) control. Physical component score subscale: not given. Cortisol: Immediately after awakening 0.91 (SD: 0.58) case; 0.70 (SD: 0.32) control. 30 min after awakening 1.02 (SD: 0.63) case; 0.85 (SD: 0.41) control. Before lunch 0.48 (SD: 0.26) case; 0.33 (SD: 0.13) control. Before dinner 0.27 (SD: 0.19) case; 0.18 (SD: 0.13) control. Cortisol, as well as awakening response 0.17 (SD: 0.39) case; 0.11 (SD: 0.49) control. Area under the curve of cortisol 11.47 (SD: 5.24) case; 8.17 (SD: 2.89) control.	Mothers of children with CP experienced stress, which impaired the hypothalamus-pituitary-adrenal cortex axis function. They also reported reflecting negatively on certain aspects of their physical and psychological well-being. However, this finding was primarily the case among those mothers who had lower socioeconomic conditions and alongside caring for their child.
6 Benaroya-Milshtein et al ⁴⁵ (2014), Israel	The main aim with this study is to evaluate the relationship between depression and immunologic function in parents of children with cancer.	Cancer	Mixed methods	Saliva sample	32 caregivers: 29 mothers; 3 fathers	35/36	Immunologic parameters: Cortisol (nmol/L) = 235.71 (SD: 120.6) depressed; 297.71 (SD: 157.8) nondepressed. CD4 % = 37.00 (SD: 8.89) depressed; 50.00 (SD: 5.46) nondepressed. CD8 % = 30.60 (SD: 6.99) depressed; 22.36 (SD: 4.25) nondepressed. CD4/CD8 = 1.26 (SD: 0.40) depressed; 2.28 (SD: 0.63) nondepressed. CD56 % = 12.60 (SD: 4.04) depressed; 12.00 (SD: 4.10) nondepressed.	A high prevalence of depressive symptoms was found in parents of children with cancer. A possible immune imbalance may occur in those parents who are exposed to continuous stress. Further research is required to identify specific mediators of depression and cell-mediated immunity in caregivers of cancer children.
7 Birenbaum et al ¹⁵ (1996), United States	To describe parent's health during the terminal illness of their child and during the first year after their child's death from cancer.	Cancer	Longitudinal	Duke	80 caregivers: 47 mothers; 33 fathers	30/36	0.77 (SD: 0.16) case. Before death; 0.78 (SD: 0.14) case 2 wk after death; 0.81 (SD: 0.15) case 4 mo after death; 0.79 (SD: 0.13) case 12 mo after death. Duke-UNC norms: 0.76 (SD: 0.16) female; 0.71 (SD: 0.17) male; 0.72 (SD: 0.17) total.	There was no difference between the parents' scores and normative scores for the Duke scale at any of the time points included in this study. The authors attributed this finding to the sample being white, well-educated, and in a higher socioeconomic group to begin with and therefore maybe more protected from negative health outcomes.

TABLE 1 Continued

Author, Year of Publication, and Location of Study	Aims and Objectives	Child's Condition	Study Design	Caregiver Health Measure	No. and Sex of Caregivers	Hawker Quality Assessment Score	Study Results Related to Physical Health ^a	Study Conclusions
8 Björk et al ⁸⁷ (2009), Sweden	To elucidate families' lived experiences during cancer treatment.	Cancer	Qualitative	Interviews	18 caregivers: 9 mothers; 9 fathers	29/36	Parents felt that there were constant demands on them, which made them feel tired as well (pg 426). The working parent often felt tired when going to work, whereas the parent at home generally felt exhausted dealing with the ill child, hospital visits, siblings, and the household (pg 426). General health score: 40.90 (group 1: mothers who sleep through almost every night). General health score: 36.54 (group 2: mothers who have interrupted sleep once per night 4 or more nights per wk). General health score: 36.34 (group 3: mothers who have interrupted sleep twice or more per night, 4 or more nights per wk). General health score: 50.5 (SD: 10.4) norm. Body pain subscale: 45.20 (group 1). Body pain subscale: 42.73 (group 2). Body pain subscale: 33.31 (group 3). Body pain subscale: 52.2 (SD: 8.9) (norm). Role physical functioning subscale: 43.77 (group 1). Role physical functioning subscale: 38.79 (group 2). Role physical functioning subscale: 43.77 (group 3). Role physical functioning subscale: 50.8 (norm). Physical functioning subscale: 47.88 (group 1). Physical functioning subscale: 47.88 (group 2). Physical functioning subscale: 47.88 (group 3). Physical component score subscale: 47.74 (group 1). Physical component score subscale: 47.49 (group 2). Physical component score subscale: 43.47 (group 3). Physical component score subscale: 50.3 (norm).	Parents reported feeling drained, frustrated, sad, anxious on them as parents of an ill child. Working parents felt tired going to work. Parents at home described competing needs of their ill child, hospital visits, siblings and the household. Mothers with children with the highest daytime care needs also experienced high nighttime care responsibilities. These mothers reported chronic sleep interruption, poor maternal subjective health, and lower participation in health activities that may service to support maternal health over time.
9 Bourke-Taylor et al ⁸⁸ (2013), Australia	This study aims were to (1) determine the frequency with which mothers awaken to attend to their child with a developmental disability, (2) identify the child-related factors associated with the need to provide nighttime attention for a child with a disability, (3) assess the impact of chronic sleep disturbance on maternal health and maternal capacity for participation in health-promoting activity.	CP, developmental delay, autism spectrum disorder, autism, Asperger's, intellectual disability, language disorders, epilepsy, visual impairment, additional childhood psychiatric diagnosis, ADHD	Mixed methods	SF-36	152 caregivers: 152 mothers	34/36	General health score: 47.66 (SD: 11.62) female; 50.26 (SD: 9.69) male. Body pain subscale: 47.72 (SD: 11.29) female; 52.47 (SD: 9.84) male. Role physical functioning subscale: 46.99 (SD: 8.89) female; 52.12 (SD: 6.74) male. Physical functioning subscale: 48.91 (SD: 8.33) female; 52.79 (SD: 5.19) male. Physical component score subscale: 49.74 (SD: 8.15) female; 52.39 (SD: 6.97) male.	The caregiver sample reported more physical health problems than did the national sample. They reported as a greater overall number of chronic conditions, compared with the national sample. The caregiver sample also reported more vision, hearing, and pain problems. Authors conclude it seems likely that caring for a child with a disability is associated with negative effects on the physical health of the caregiver. The physical component score of the SF-36 was comparable to the general population. The authors conclude the physical health of the caregivers in the study was not a major cause for concern.
10 Brehaut et al ⁸⁵ (2004), Canada	To compare the physical and psychological health of caregivers of children with CP with that of the general population.	CP	Case-control	Health Utility Index	468 caregivers: (caregiver sex not given)	30/36	General health score: 47.66 (SD: 11.62) female; 50.26 (SD: 9.69) (male). Body pain subscale: 47.72 (SD: 11.29) (female); 52.47 (SD: 9.84) (male). Role physical functioning subscale: 46.99 (SD: 8.89) (female); 52.12 (SD: 6.74) (male). Physical functioning subscale: 48.91 (SD: 8.33) (female); 52.79 (SD: 5.19) (male). Physical component score subscale: 49.74 (SD: 8.15) (female); 52.39 (SD: 6.97) (male).	The caregiver sample reported more physical health problems than did the national sample. They reported as a greater overall number of chronic conditions, compared with the national sample. The caregiver sample also reported more vision, hearing, and pain problems. Authors conclude it seems likely that caring for a child with a disability is associated with negative effects on the physical health of the caregiver.
11 Byrne et al ⁸⁴ (2010), Ireland	To assess the health status of caregivers of children with CP in Ireland. Secondary aims were to (1) investigate differences in the health of caregivers, as per the SF-36, to compare with that of the Irish general population, using previously established norm scores and (2) examine the effects of caregiver sex, time spent caring and the dependency level of the child, on the health of caregivers.	CP	Cross-sectional	SF-36	161 caregivers: 100 mothers; 61 fathers	28/36	General health score: 47.66 (SD: 11.62) female; 50.26 (SD: 9.69) male. Body pain subscale: 47.72 (SD: 11.29) female; 52.47 (SD: 9.84) male. Role physical functioning subscale: 46.99 (SD: 8.89) female; 52.12 (SD: 6.74) male. Physical functioning subscale: 48.91 (SD: 8.33) female; 52.79 (SD: 5.19) male. Physical component score subscale: 49.74 (SD: 8.15) female; 52.39 (SD: 6.97) male.	The physical component score of the SF-36 was comparable to the general population. The authors conclude the physical health of the caregivers in the study was not a major cause for concern.

TABLE 1 Continued

Author, Year of Publication, and Location of Study	Aims and Objectives	Child's Condition	Study Design	Caregiver Health Measure	No. and Sex of Caregivers	Hawker Quality Assessment Score	Study Results Related to Physical Health ^a	Study Conclusions
12 Chen and Clark ¹⁰ (2007), Taiwan	To explore the relationship between the level of child disability and age at diagnosis and family-related factors of caregiver health, income, employment, family support, and family hardness with family function ability in families of children with Duchenne muscular dystrophy	Duchenne muscular dystrophy	Cross-sectional	Duke Health Profile	126 caregivers: 72 mothers; 54 fathers	30/36	Physical health: 66.11 (SD: 19.51). Perceived health: 78.17 (SD: 34.83). Pain 43.25 (SD: 26.55). Disability: 7.94 (SD: 19.40). Total: 67.48 (SD: 15.79).	Parents in this study reported poorer health status and more anxiety, depression, pain, and disability than members of the general population. Note: shares a sample with Chen et al. ^{10a,11,14}
13 Chen ^{10b} (2008), Taiwan	To test the possible effects of psychosocial mediators of parent health, family hardness and family support on family function in relation to age at diagnosis of children with Duchenne muscular dystrophy	Duchenne muscular dystrophy	Cross-sectional	Duke Health Profile	126 caregivers: 72 mothers; 54 fathers	31/36	Physical health: 66.11 (SD: 19.51). Perceived health: 78.17 (SD: 34.83). Pain 43.25 (SD: 26.55). Disability: 7.94 (SD: 19.40). Total: 67.48 (SD: 15.79).	Parents continued to report poorer health status and more anxiety, depression, pain, and disability than members of the general population. Parent health was positively correlated with family function such that as family function scores increased so too did parent health scores. Note: shares a sample with Chen et al. (2007, 2010).
14 Chen and Clark ^{11,14} (2010), Taiwan	To provide information on the effects of family resources on parental health using data collected in previous studies.	Duchenne muscular dystrophy	Cross-sectional	Duke Health Profile	126 caregivers: 72 mothers; 54 fathers	34/36	Physical health: 66.11 (SD: 19.51). Perceived health: 78.17 (SD: 34.83). Pain 43.25 (SD: 26.55). Disability: 7.94 (SD: 19.40). Total: 67.48 (SD: 15.79).	The child's dependence did not correlate with parental health status. Parental employment, parental education, perceived child health, family hardness, and family support were found to correlate with parental health. Note: shares a sample with Chen et al. ^{10a,11,14}
15 Collins et al. ^{6b} (2016), Australia	To provide an in-depth exploration of the prevalent lived experiences of parents who are currently providing care for a child with an LLC in Australia.	Mixed LLC	Qualitative	Semistructured interviews	14 caregivers: 12 mothers; 2 fathers	35/36	"There's an ongoing cost, and it's both the physical cost, and the emotional cost" (C14) (pg 954). "Just caring for him and the seizures, I think the stress brought everything of a head and I had a heart attack" (C03). "I don't sleep properly, I don't eat properly. And when I get stressed I lose wt" (C05). "When you've got someone else in the family that's unwell, you do end up putting yourself last. We can't do what we need to look ourselves" (C13). "I probably need continued therapy to help me cope but I just can't make it to the appointments" (C03) (pg 954). "The harsh reality is he's heavy and awkward to lift. It's one thing for me to put my back out, but I can't expect others to do it" (C03) (pg 955).	Consistent with research from the United Kingdom and Canada, caregivers qualitatively reported the many years of providing care (in this sample, median of 7 y) impacted their own emotional and physical health. Although recognizing this impact, caregivers were unable to prioritize their own needs while necessarily continuing to provide care.
16 Courtney et al. ^{6b} (2018), Ireland	To explore mothers' perspectives of the experiences and impact on themselves and their family when their child has a life-limiting neurodevelopmental disability.	CP	Qualitative	Semistructured interviews	12 caregivers: 12 mothers	32/36	"If I've had a really bad night with the boys ... it can be a struggle to be honest ... there's days that like ... I'm physically and emotionally drained" [mother of child aged 3]. Pg 707.	Parents found their child's care took a physical toll, including musculoskeletal problems associated with lifting the child or equipment. Exhaustion was a pervasive problem, which was attributed to a chronic lack of sleep associated with care requirements. Despite their exhaustion, mothers described the need to remain constantly alert and responsive to their child's health.
17 Czupryna et al. ^{6a} (2014), Poland	To evaluate the prevalence of back pain and its underlying causes in mothers of children with CP.	CP	Cross-sectional	Jackson Moscovitz scale	179 caregivers: 179 mothers	28/36	0: no pain (n = 37, 20.67%). 1: occasional pain (n = 19, 10.61%). 2: intermittent pain (n = 89, 32.96%). 3: frequent and intense pain (n = 34, 18.99%). 4: very frequent pain (n = 27, 15.05%). 5: constant pain (n = 3, 1.68%).	Four-fifths of mothers reported pain of various location. Pain intensity was associated with the functional status of the child whereby mothers of children who were totally immobile reported higher pain scores and mothers of children who were ambulatory experienced almost no pain.
18 Dambi et al. ^{6b} (2015), Zimbabwe	To establish what proportion of caregivers of children with CP, living in a high-density area of	CP	Longitudinal	EQ-5D	46 caregivers: 38 mothers; 5	34/36	Mobility: 31 (67.4%) no problems case; 15 (32.6%) some problems case; 33 (66.8%) no problems control; 5 (13.2%) some problems control. Self-care: 38 (82.6%) no problems	Most of the caregivers reported physical strain and pain or discomfort. The physical strain or pain may be accounted for by their child's need for assistance with

TABLE 1 Continued

Author, Year of Publication, and Location of Study	Aims and Objectives	Child's Condition	Study Design	Caregiver Health Measure	No. and Sex of Caregivers	Hawker Quality Assessment Score	Study Results Related to Physical Health ^a	Study Conclusions
	Harare, Zimbabwe, reported as experiencing excessive strain.				grandmothers; 3 siblings		case, 8 (17.3%) some problems case; 37 (87.4%) no problems control; 1 (2.6%) some problems control. Usual activities: 31 (67.4%) no problems case; 15 (32.6%) some problems case; 32 (84.2%) no problems control; 6 (15.8%) some problems control. Pain or discomfort: 14 (30.4%) no problems case; 32 (69.6%) some problems case; 20 (52.6%) no problems control; 18 (47.4%) some problems control.	activities of daily living, particularly lifting or carrying the child.
19 Davis et al ⁸ (2010). Australia	To explore the QoL of mothers and fathers of children with CP aged 3–18 y and examine whether the impact of caring for a child with CP changes from childhood to adolescence.	CP	Qualitative	Semistructured interviews	37 caregivers: 24 mothers; 13 fathers	32/36	"I'm getting older now and she plays havoc on my body, on things that I can do and can't do. I can't run any more." (Mother of Sarah aged 5 y, GMFCS level II). "Physically I'm finding it challenging lately because she's grown so much and she is so dependent mobility-wise, so I'm finding that much more demanding." (Mother of Michelle aged 9 y, GMFCS level V) (pg 67). "Six years of her life waking up most nights. It can be anything from one to 3 times a night. So it's broken sleep and it's not great, so I find I have to pace myself." (Mother of Meredith aged 6 y, GMFCS level V) (pg 67). "Oh look extremely sleep deprived, extremely sleep deprived. Yeah Cooper can wake anywhere between... oh anywhere from say 3 to 8 times a night. And that makes it hard." (Mother of Cooper aged 9 y, GMFCS level V) (pg 67)	Parents indicated that the physical demands associated with caring for a child with a physical disability have a profound impact on their own physical health, particularly as their child grows and becomes heavier. Parents also indicated that caring for their child often involves interrupted sleep because of their child's dependence throughout the night.
20 Dehghan et al ²⁶ (2016). Iran	The researchers hypothesized that the QoL of mothers of children with CP would be impacted by the gross motor function, type of CP, and age of their children.	CP	Cross-sectional	SF-36	424 caregivers: 424 mothers	29/36	General health score: 43.58 (SD: 21.95); 65.0 (SD: 20.8) norm. Body pain subscale: 47.40 (SD: 22.34); 76.4 (SD: 26.2) norm. Role physical functioning subscale: 29.59 (SD: 34.96); 66.5 (SD: 39.1) norm. Physical functioning subscale: 55.35 (SD: 24.76); 82.9 (SD: 22.1) norm. Physical component score subscale: 39.21 (8.40).	Physical component scores of the SF-36 were markedly different among mothers of children with different types of CP. Mothers of children with spastic hemiplegia reported worse scores than mothers of children with spastic quadriplegia and dyskinesia.
21 Eiser et al ⁶⁵ (2005). United Kingdom	To explore relationships between mothers' QoL and more illness-specific worries, predicted that mothers who rated their own QoL to be poor would also rate their children's QoL to be poor.	Cancer	Cross-sectional	SF-36	87 caregivers: 87 mothers	30/36	General health score: 73.0 case; 75.0 norm. Body pain subscale: 84.2 case; 79.9 norm. Role physical functioning subscale: 67.0 case; 84.6 norm. Physical functioning subscale: 91.77 case; 89.5 norm. Physical component score subscale: not given. SDs not given.	Mothers scores on the SF-36 were lower than expected across most subscales, with notable exceptions being the subscales relating to physical function and pain, in which mothers reported functioning within the normal range. The authors attribute this finding to the huge burden experienced by children and their parents during the initial period of treatment of cancer.
22 Elcigli and Conk ¹⁰⁰ (2010). Turkey	To determine the burden on mothers of children who have cancer and the related effects on the family unit.	Cancer	Qualitative	In-depth Interviews	23 caregivers: 23 mothers	30/36	"He was alright when he came here. He had two cycles and the diarrhea started and hasn't stopped since. There's as they were trying to cope with the child's sickness and diarrhea, vomiting, loss of appetite; he didn't eat, he just drank water. I couldn't keep up with it. I couldn't eat, I couldn't even go to the toilet. He's constantly going—every minute." (pg 177). "I've been extremely tired. I've lost my appetite. I've had a lot of headaches. I even went to a neurologist because I was losing sensations in my hands. He said it was because of stress. My forgetfulness is at an extreme. You forget things, sometimes when I'm home, I even forget what I was going to do. Sometimes I forget what the doctors said." (pg 177). "I don't sleep. Even at 2 or 3 o'clock in the morning I don't feel like sleeping. You think you'll forget while you're sleeping but no, even in your dreams you're still there. We don't want to sleep." (pg 177)	Mothers reported problems with their own physical health as they were trying to cope with the child's sickness and the emerging problems during the treatment. Mothers complained most frequently of symptoms such as headache, backache, aching neck, loss of appetite, menstrual irregularity, and insomnia. Mothers reported less time to devote to maintaining their health.
23 Eker and Tüzün ⁸⁹ (2004). Turkey	To evaluate the QoL and consequent burden of care, on	CP	Case-control	SF-36		35/36	General health score: 51.30 (SE: 3.47) case; 69.68 (SE: 3.21) control. Body pain subscale: 61.18 (SE: 3.35) case; 75.41 (SE: 3.35) control.	Mothers of children with CP had significantly lower QoL scores in all subscales of the SF-36, except for the

TABLE 1 Continued

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24 Eyigor et al ⁶⁰ (2011), Turkey	mothers who look after children with CP at home compared with those who have children with minor health problems. The main research question was whether the perceived QoL differs between the 2 groups. The investigation was focused on whether there is an association between the QoL of mothers and the severity of a child's motor disability.	Cancer	Case-control	SF-36	84 caregivers: 40 case mothers; 44 control mothers	33/56	3,85) control. Role physical functioning subscale: 57.63 (SE 6.06) case; 77.27 (SE 4.99) control. Physical functioning subscale: 88.88 (SE 2.14) case; 90.57 (SE 1.90) control. Physical component score subscale: not given.	physical functioning subscale, when compared with mothers of children with minor health complaints. The groups were matched on a variety of sociodemographic variables before data collection.
25 Figueiredo, et al ⁶¹ (2020), Brazil	To compare the QoL and psychological state of mothers whose children are hospitalized for cancer treatment in Turkey with the QoL and psychological state of mothers who have healthy children. The secondary goal of the study is to assess the factors affecting the QoL of mothers who have children with cancer. Finally, the third goal of the study is to investigate the mothers' satisfaction levels with regard to being informed about the disease and treatment program and the treatment team during the period in which their children receive treatment.	CP	Mixed methods	SF-36 and interviews	150 caregivers: 100 case mothers; 50 control mothers	29/36	General health score: 61.44 (SD: 23.47) case; 71.96 (SD: 17.88) control. Body pain subscale 73.60 (SD: 19.81) case; 72.54 (SD: 20.92) control. Role physical functioning subscale: 46.35 (SD: 48.81) case; 79.50 (SD: 35.24) control. Physical functioning subscale: 89.95 (SD: 16.24) case; 90 (SD: 12.90) control. Physical component score subscale: not given.	Mothers of hospitalized children with cancer had lower SF-36 scores than mothers of healthy children and reported more psychological symptoms. Health of mothers of children with cancer was reported to "change" as a result of their child's symptoms.
26 Foster et al ⁶¹ (1998), United Kingdom	To describe the QoL related to the state of health of caregivers of patients with TGP who were fed by gastrostomy, to assess the results linked to the mental health of these caregivers, to compare our data with data from other studies on children with CP without gastrostomy, and to evaluate the possible interference of gastrostomy in the QoL.	Cystic fibrosis	Cross-sectional	SF-36	30 caregivers: 30 mothers (used population norms)	28/36	SF-36: General health score: 63.93 (SD: 16.68). Body pain subscale: 55.1 (SD: 25.98). Role physical functioning subscale: 71.17 (SD: 26.74). Physical functioning subscale: 51.67 (SD: 35.92). Qualitative results not reported.	The HRQoL of caregivers of children with tetraparesis CP who were fed by gastrostomy reported scores below the average of the general population.
27 Fotiadou et al ⁶⁷ (2008), United Kingdom	To examine the correlates of the well-being of mothers of children and adolescents with cystic fibrosis.	Cancer	Case-control	SF-36	50 caregivers: 50 mothers	35/56	General health score: 79.02 (SD: 21.24) case; 74.10 (SD: 20.30) control. Body pain subscale 75.08 (SD: 20.42) case; 79.40 (SD: 22.00) control. Role physical functioning subscale: 82.16 (SD: 28.58) case; 84.00 (SD: 32.00) control. Physical functioning subscale: 89.78 (SD: 18.37) case; 89.40 (SD: 16.10) control. Physical component score subscale: not given.	Mothers had similar scores on the SF-36 as the general population. However, when they did report lower well-being, this was associated with problems surrounding their child's illness and treatment. Maternal well-being in these families is not necessarily associated with the illness per se but indirectly due to treatment demands and support.
27 Fotiadou et al ⁶⁷ (2008), United Kingdom	To identify the characteristics of optimistic parents of children with cancer. To examine the relationship between optimism, anxiety, depression, life	Cancer	Case-control	SF-36	217 caregivers: 70 case mothers; 30 case fathers; 87 control mothers; 30 control fathers	35/56	General health score: 65.9 (SD: 4.4) case; 73.1 (SD: 18.4) control. Body pain subscale: not given. Role physical functioning subscale: not given. Physical functioning subscale: not given. Physical component score subscale: not given.	Caregivers reported increased anxiety and depression levels and decreased subjective health perception and life satisfaction in comparison with the control group.

TABLE 1 Continued

Author, Year of Publication, and Location of Study	Aims and Objectives	Child's Condition	Study Design	Caregiver Health Measure	No. and Sex of Caregivers	Hawker Quality Assessment Score	Study Results Related to Physical Health ^a	Study Conclusions
28 Garip et al ⁸¹ (2017), Turkey	satisfaction, coping, and subjective health perception in parents of children with cancer and parents of healthy children. To demonstrate the relationship between fatigue, depression, and QoL of mothers and to assess whether any additional factors related to the severity of CP had an influence on the fatigue of the mothers.	CP	Case-control	Nottingham Health Profile	140 caregivers: 90 case mothers; 50 control mothers	29/36	Pain: 19.31 (SD: 23.78) case; 9.71 (SD: 14.55) control. Physical mobility: 11.38 (SD: 17.33) case; 5.50 (SD: 9.16) control. Energy: 67.22 (SD: 39.77) case; 16.99 (SD: 27.55) control. Sleep: 23.11 (SD: 27.63) case; 13.20 (SD: 16.95) control.	Mothers of children with CP reported higher fatigue compared with mothers of healthy children. This finding was consistent regardless of the clinical parameters of the child's CP.
29 Granek et al ¹⁰¹ (2014), Canada	To explore how single parents of children with cancer describe their caregiving experiences and to understand their contextual life stressors.	Cancer	Qualitative	Interviews	29 caregivers: 24 mothers; 5 fathers	33/36	Caring for a child with cancer had a marked health impact on parents, including a range of physiologic and psychological symptoms. Many parents described disturbances related to sleep, diet and exercise habits, and reported instances of anxiety, depression, and generally feeling down while their child was on active treatment and/or in the recovery stage (pg 189). Parents achieved the 70 000 per wk steps goal during wk 3 of the intervention, but it remained below target for the rest of the 12 wk duration of the study. However, there was continued evidence of increased activity compared with baseline in 80% of parents up to week 8 (<i>n</i> = 12), and in 75% of parents for the study duration (<i>n</i> = 11). A beneficial change was seen for median parent test scores on all psychometric instruments indicating that increasing exercise rates may have had other beneficial effects for parent mental health.	Single parents' overall physical health was compromised as a result of their caregiving duties. Physical health problems were dated to before and during their child's diagnosis, perhaps indicating the need for early intervention for these parents.
30 Halliday et al ⁴² (2017), Australia	To explore the feasibility of a 12-wk pedometer monitored walking intervention among parents of children with cancer.	Cancer	Longitudinal evaluation of an intervention	Fitbit	15 caregivers: 9 mothers; 6 fathers	33/36	The findings of this study suggested that encouraging the parents to increase their exercise in the form of a greater daily step count has a positive impact on stress, HRQoL and overall health.	
31 Hatzmann et al ¹²⁴ (2008), Netherlands	To determine the HRQoL of parents of chronically ill children compared with parents of healthy schoolchildren.	Mixed diagnoses, some of which are considered chronic, potentially LLCs	Cross-sectional	TAAQoL	958 caregivers: 533 case; 425 control (caregiver sex not given)	35/36	Parents study group report a seriously lower HRQoL than the comparison group, and on average, 45% of parents were at risk for HRQoL impairment, which can influence the well-being of their children and their ability to provide care as their child's disease progressed and became more complex. Subsets of parents of children with metabolic disease and sickle cell disease reported lower well-being than others.	
32 Jensen et al ⁵⁰ (2017), United States	To fill a knowledge gap by identifying the most important domains that should be assessed in an efficient (ie, both adequately thorough and	Epilepsy	Mixed methods	PROMIS and focus group discussions	19 caregivers: 16 mothers; 3 fathers	35/36	PROMIS: Global physical health: 44.5 (6.6) case; 50.0 (10.0) norm. Physical function: 47.8 (6.6) case; 50.0 (10.0) norm. Sleep disturbance: 54.7 (8.8) case; 50.0 (10.0) norm. Pain interference: 50.6 (9.5) case; 50.0 (10.0) norm. Qualitative: Caregivers reported that knowing their child could	The most discussed burden by all caregivers was sleep deprivation and fatigue as a result of the need to tend to their child at night. Caregivers felt they needed to be vigilant to their child's needs throughout the day and night.

TABLE 1 Continued

Author, Year of Publication, and Location of Study	Aims and Objectives	Child's Condition	Study Design	Caregiver Health Measure	No. and Sex of Caregivers	Hawker Quality Assessment Score	Study Results Related to Physical Health ^a	Study Conclusions
	adequately brief) measure of caregiver impact for caregivers of children and young adults with severe epilepsy.						experience a life-threatening seizure in their sleep or even have sudden unexpected death in epilepsy during sleep contributed to a lack of restful sleep for these caregivers. Caregivers felt they needed to be aware of and alert to their child's needs throughout the day and night, not only because of seizures, but also to provide help with toileting or other needs. "It's hard to turn off... I didn't even think about that until he got diagnosed with epilepsy that he could pass away in his sleep. That rocks my world." Another mother shared that her sleep routine consisted of setting an alarm every 4 h during the night to wake up and check on her daughter. The inability to "turn off" then often led to feelings of exhaustion and lack of energy to keep up with the caregiver's own self-care needs such as the need to stay physically fit and eat healthy foods. "I mean, there's a reason that sleep deprivation is a torture device... I mean, everything about your physicality just lowers. You tend to be drawn to worse foods and more caffeine, and you just don't have the energy to maybe do what you would have set out to do, like go for a run." "I actually think one of the biggest differences in caring for a child with epilepsy versus maybe other chronic illnesses is your uncertainty at night, and the profound lack of sleep... I think you're already dealing with something so emotionally heavy and physically exhausting during the waking hours that the sleep component is just a crazy facet of caregiving for someone with epilepsy."	
33 Kaya et al ⁵⁸ (2010), Turkey	To evaluate MSP in mothers of children with CP and to determine the effects of the zone of pain on health-related QoL and symptoms of depression.	CP	Cross-sectional	SF-36	141 caregivers: 81 case mothers; 60 control mothers	27/36	General health score: 58.00 (SD: 16.81) case; 64.45 (SD: 16.56) control. Body pain subscale 64.53 (SD: 23.71) case; 80.86 (SD: 18.81) control. Role physical functioning subscale: 63.02 (SD: 40.87) case; 89.67 (SD: 25.59) control. Physical functioning subscale: 82.34 (SD: 18.06) case; 90.10 (SD: 11.85) control. Physical component score subscale: not given.	Mothers of children with CP reported significantly more muscular skeletal pain and LBP compared with mothers in the control group.
34 Killian et al ⁶² (2016), United States	The authors hypothesized that more severe clinical features of the child would negatively impact caretaker physical QoL but would positively impact caretaker mental QoL.	Rett Syndrome	Longitudinal	SF-36	727 caregivers: 727 mothers	32/36	General health score: not given. Body pain subscale: not given. Role physical functioning subscale: not given. Physical functioning subscale: not given. Physical component score subscale: 52.8 (SD: 9.7) Baseline. Physical component score subscale: 51.0 (10.2) 5-y follow-up.	Caregiver QoL was similar to caregivers of those with other chronic conditions. Increased clinical severity was associated with lower physical health among caregivers.
35 Klassen et al ⁶² (2008), Canada	The objectives of this report were to measure QoL in parents of children with cancer, and to assess relationships between parental QoL and parent and child characteristics.	Cancer	Cross-Sectional	SF-36	411 caregivers: 358 mothers; 53 fathers	35/36	General health score: 65.2 (SD: 19.0) female; 69.8 (SD: 20.7) male. Body pain subscale: 68.2 (SD: 24.7) female; 68.5 (SD: 25.3) male. Role physical functioning subscale: 66.1 (SD: 29.7) female; 74.9 (SD: 27.6) male. Physical functioning subscale: 85.1 (SD: 19.2) female; 85.7 (SD: 18.9) male. Physical component score subscale: 52.7 (SD: female case; 49.7 (SD) female control; 52.5 (SD) male case; 51.4 (SD) male control.	Parents of children with cancer reported lower QoL compared with population norms. Differences in QoL were significant across all domains, except for physical function, for both mothers and fathers.
36 Klassen et al ⁶⁶ (2011), Canada	The authors' hypotheses were as follows: (1) child health and caregiving strain would be associated directly with parental HRQoL and (2) relationships	Cancer	Cross-sectional	SF-36	411 caregivers: 358 mothers; 53 fathers	32/36	General health score: <12 mo 65.7 (SD: 18.5); >12 mo 66.1 (SD: 20.9). Body pain subscale: <12 mo 67.3 (SD: 25.0); >12 mo 70.3 (SD: 24.0). Role physical functioning subscale: <12 mo 66.5 (SD: 30.6); >12 mo 74.7 (SD: 26.0). Physical functioning subscale: <12 mo 84.6 (SD: 19.6); >12	Child health and caregiver strain had a direct impact on parental HRQoL. However, it was not clear what variables could mediate this relationship.

TABLE 1 Continued

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37 Klassen et al ⁷ (2012), Canada	between child health and caregiving strain, and parental HRQoL would be mediated by self-perception and coping and supportive factors. To determine if single parents differ from parents from 2-parent families in terms of caregiver demand (the time and effort involved in caregiving), and HRQL. To explore the health impact of caregiving for 2 marginalized groups of parents caring for a child with cancer: immigrants and single families.	Cancer	Cross-Sectional	SF-36	315 caregivers: 274 mothers; 41 fathers	34/36	mo 86.6 (SD: 17.8). Physical component score subscale: not given. General health score: not given. Body pain subscale: not given. Role physical functioning subscale: not given. Physical component score subscale: 50.1 (SD: 9.6) single parent; 53.4 (SD: 8.1) 2 parents. Sleep disturbance: "I slept very little; couldn't sleep properly. I used to always think about her. Even if I did ever fall asleep, I used to wake up suddenly out of fear. I would go and check up on her to see if she is alright and breathing normally." (South Asian parent, female). "Our sleeping patterns changed.... We were up all night and then sleep all day because.... he would get his chemo and stuff throughout the day so he just wanted to sleep. He didn't feel well, and then he'd start feeling better at night, so then when he was up at night then, well, we'd play some video games.... Basically our clock switched around." (Single parent, female). Daytime fatigue: "Due to the sleep deprivation, it made me get into, twice, car accidents where I hit the car in front of me.... While waiting for a red light, I was thinking.... my eyes... I just wanted to rest a bit, and unexpectedly, I didn't step on the brakes enough." (Chinese parent, female). "And that's exactly what it feels like, it feels like a big heavy blanket is kind of over. I'm tired physically, fatigued all the time" (Single parent, female). "Change in appetite wasn't feeling hungry sometimes. Sometimes I would get hungry, but sometimes I wouldn't." (South Asian parent, male). "I was just so stressed out that I just wasn't eating very well at all probably, and if I did eat something it was like gross like comfort food that I wouldn't even normally eat." (Single parent, female). "Wt gain or loss: Health was affected. I stayed indoors a lot, which was fine in the beginning—but then from staying indoors in that small space, then you get fat... heavy." (South Asian parent, female). "I think I lost like fifty pounds in three months. To tell you the truth all I did was cry.... I had no strength at all, I had lost all that wt, I had no strength, I had no ambition to go out, I just, I just wanted to be on my own and then that wasn't healthy either." (Single parent, female). "Other health conditions I think before I was maybe in a very difficult situation and very high stress. My period is all over the place, and now it's even more ridiculous; it stopped." (Chinese parent, female). "I've had health issues of my own, I was very sick and I was just recovering when she was diagnosed...." (Single parent, female).	Both single parents and those from 2-parent households had low scores on the SF-36. There was no difference between groups on the SF-36 scores. Household finances did appear to lead to improved outcomes. Parents reported sleep disturbance, changes in appetite or wt, anxiety, depression, social isolation, and social role limitations.
38 Klassen et al ²⁴ (2012), Canada		Cancer	Qualitative	Interview	79 caregivers: 61 mothers; 18 fathers	35/36		
39 Launwick et al ⁷⁷ (2006), Australia	To examine the maternal, family, child, and disability characteristics that are positively associated with the mothers'	Rett Syndrome	Cross-sectional	SF-12	135 caregivers: 135 mothers	34/36	General health score: not given. Body pain subscale: not given. Role physical functioning subscale: not given. Physical component score subscale: 48.6 (SD: 10.1) case; 50 (SD: 10) pop. norm.	Mothers in this study had lower scores on physical health and well-being compared with the general population norms from the United States and Australia. The authors suggest the practical day-to-day needs of families for feeding, sleep, behavior challenges, and community

TABLE 1 Continued

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40 Lee et al ⁷⁸ (2019), Korea	good physical health and mental well-being. The aims of this study were to identify the determinants affecting HRQoL among mothers of children with CP	CP	Cross-sectional study	SF-12	180 caregivers: 180 mothers	36/36	General health score: not given. Body pain subscale: not given. Role physical functioning subscale: not given. Physical functioning subscale: not given. Physical component score subscale: 44.5 (SD: 8.0).	participation are factors affecting maternal health and well-being. Mothers reported a high prevalence of chronic conditions (80.6% reporting 1 or more). Among the chronic conditions listed, back pain was the most prevalent (47.2%), followed by migraine or headache (40%). Diagnosis of a chronic condition was a significant determinant of physical HRQoL.
41 Litelman et al ⁷⁹ (2011), United States	To examine the relationship between child clinical characteristics and HRQoL among parents of children with cancer or brain tumors, and (2) determine how parental psychosocial factors impact this relationship.	Cancer	Cross-sectional	SF-12	75 caregivers: 67 mothers; 8 fathers	33/36	General health score: not given. Body pain subscale: not given. Role physical functioning subscale: not given. Physical functioning subscale: not given. Physical component score subscale: 54.4 (SD: 6.4); 50 (SD: 10) pop. norm.	Parents reported better physical health compared with population norms for the United States.
42 Lv et al ⁸⁰ (2009), China	To assess the impact of childhood epilepsy on parental QoL and psychological health, and to investigate possible correlations between parental QoL and background variables as well as parental anxiety and depression.	Epilepsy	Case-control	SF-36	553 caregivers: 200 case mothers; 63 case fathers; 200 control mothers; 70 control fathers	35/36	General health score: 60.93 (SD: 22.53) case; 78.36 (SD: 14.39) control. Body pain subscale: 90.21 (SD: 12.09) case; 91.29 (SD: 11.53) control. Role physical functioning subscale: 64.01 (SD: 39.41) case; 96.58 (SD: 10.47) control. Physical functioning subscale: 90.21 (SD: 12.09) case; 93.01 (SD: 6.81) control. Physical component score subscale: Not given.	The parents of children with epilepsy had significantly lower QoL scores in SF-36 for all subscales.
43 Mandrell et al ²⁵ (2016), United States	To assess HRQoL from the time of diagnosis until disease progression in a cohort of children with DIPG.	Brain tumor	Longitudinal	SF-36	25 caregivers: 24 mothers; 1 father	29/36	General health score: 55.30 (SD: 7.76) Baseline; 55.59 (SD: 7.48) Week 2; 57.55 (SD: 6.34) Week 4; 57.02 (SD: 7.09) Week 6; 54.72 (SD: 8.01) Week 16; 56.34 (SD: 7.35) Week 24; 49.39 (SD: 10.22) norm. Body pain subscale: 57.69 (SD: 6.10) Baseline; 59.31 (SD: 6.58) Week 2; 58.65 (SD: 6.24) Week 4; 58.24 (SD: 6.34) Week 6; 58.17 (SD: 8.05) Week 16; 58.29 (SD: 8.18) Week 24; 49.11 (SD: 10.29) norm. Role physical functioning subscale: 54.73 (SD: 3.87) Baseline; 54.44 (SD: 4.77) Week 2; 53.00 (SD: 7.77) Week 4; 52.84 (SD: 6.55) Week 6; 52.28 (SD: 9.13) Week 16; 51.97 (SD: 8.34) Week 24; 49.09 (SD: 10.33) norm. Physical functioning subscale: 54.40 (SD: 5.20) Baseline; 53.62 (SD: 8.98) Week 2; 55.68 (SD: 9.72) Week 4; 55.31 (SD: 3.24) Week 6; 56.40 (SD: 1.25) Week 16; 56.40 (SD: 1.30) Week 24; 48.70 (SD: 10.59) norm. Physical component score subscale: 57.66 (SD: 6.49) Baseline; 58.28 (SD: 5.34) Week 2; 57.63 (SD: 4.50) Week 4; 57.38 (SD: 2.63) Week 6; 57.39 (SD: 4.27) Week 16; 57.34 (SD: 4.27) Week 24; 49.12 (SD: 10.45) norm.	When compared over time, mothers reported higher HRQoL on 5 of the 8 domains: physical functioning, physical role, bodily pain, general health perceptions, and energy and/or vitality, when compared with a US population norm.
44 Martinson et al ⁰² (1997), China	To describe the Chinese parental psychosocial reactions to their child's cancer treatment and death. Two related-questions were the following: "Is there a difference between the psychosocial reaction of Chinese fathers and mothers?" and "Is there a difference in these psychosociological reactions depending on the stage of illness of the child?"	Cancer	Qualitative	Semistructured interviews	178 caregivers: 89 mothers; 89 fathers	26/36	The stress on parents of having a child with cancer is generally accepted. Evidence of this stress includes increase in headaches, difficulty in sleeping, loss of appetite, and wt loss. These symptoms must be viewed in light of the somatization prevalent in the Chinese culture, which has been documented by several other studies (eg 2). Distress symptoms experienced by the parents, including colds, sleeping difficulties, loss of appetite, changes in wt, dizziness, and headaches, are reported in Table 2. With regard to colds, only among parents in the group with a new diagnosis did the fathers report having had more colds than the mothers (1 of 5 fathers suffered from colds). For fathers whose child had died, 23%	Distress symptoms experienced by the parents, included colds, sleeping difficulties, loss of appetite, changes in wt, dizziness, and headaches.

TABLE 1 Continued

Author, Year of Publication, and Location of Study	Aims and Objectives	Child's Condition	Study Design	Caregiver Health Measure	No. and Sex of Caregivers	Hawker Quality Assessment Score	Study Results Related to Physical Health ^a	Study Conclusions
45 Matthews et al ⁴⁵ (2014). United States	To compare the sleep of children with ALL during maintenance treatment with controls and to measure the effect on maternal sleep.	Cancer	Mixed methods	Actigraphy	52 caregivers: 26 case mothers; 26 control mothers	33/36	reported having had colds. Both the mothers and fathers of the children under treatment reported low rates of colds—4% and 8%, respectively (pg 4). Compared with colds, experiences of difficulty sleeping were more than double, for both the mothers and fathers, across the 4 groups (pg 5). Loss of appetite was reported by 48% of the fathers and 64% of the mothers in group A. For group B, the symptom was reported by fewer parents (44% of mothers and 16% of fathers), but for group C, the incidence of loss of appetite was highest of all (76% for both mothers and fathers). For parents whose child had died, loss of appetite was reported by 58% of mothers and 52% of fathers. Not surprisingly, wt loss corresponded with loss of appetite, with 85% of the fathers losing wt and 85% of mothers losing wt during the child's terminal phase of illness. Dizziness was reported by >20% of both fathers and mothers for all groups except group B (child under treatment). Mothers throughout the 4 groups reported more dizziness than fathers, with >60% from group C reporting the symptom.	The findings suggested that perceived severity and impact of insomnia is greater in mothers of children with ALL during maintenance treatment compared with matched controls. This is consistent with findings from qualitative studies of mothers of children with ALL.
46 Morhun, et al ⁴⁶ (2020). Canada	The aims of the study were to examine HRQL, stress, and psychological distress in parents of young children (0–4 y) diagnosed with cancer, and the associations between parent psychosocial functioning and child treatment characteristics.	Cancer	Cross-sectional	SF-36	35 caregivers: 33 mothers; 2 fathers	33/36	General health score: 69.52 (SD: 23.73). Body pain subscale: 81.29 (SD: 24.09). Role physical functioning subscale: 75.00 (SD: 36.44). Physical functioning subscale: 87.35 (SD: 24.22). Physical component score subscale: not given. All scores were compared with population norms.	No differences were observed between population norms and the study parents in 3 of the 4 health categories (physical functioning, role limitation—physical and bodily pain).
47 Merri et al ⁸⁰ (2018). Australia	To examine longitudinally the well-being of parents of individuals included in the Australian Rett Syndrome Database.	Rett Syndrome	Longitudinal	SF-12	198 caregivers: (caregiver sex not reported)	32/36	Physical component score subscale 2002: 46.6 (SD: 10.5). Physical component score subscale 2008: 47.1 (SD: 10.2). Physical component score subscale 2009: 46.1 (SD: 10.3). Physical component score subscale 2011: 47.3 (SD: 10.3).	Physical well-being of caregivers deteriorated over the longitudinal study. The physical component scores of the SF-36 decreased with parental age, particularly, for single parents and parents with poor family function; when parental income was low, there were 2 or more siblings and for parents who lived in more rural locations.
48 Nakamanya et al ¹⁰³ (2015). Uganda	To investigate maternal experiences of caring for a child affected by neurologic impairment after NE ("birth asphyxia") in Uganda.	Encephalopathy	Qualitative	In-depth Interviews	16 caregivers: 15 mothers; 1 "caretaker"	29/36	"When you come, you have to climb steps yet the child is heavy and you really get exhausted. I had personally gotten tired of those exercises." (25-y-old mother of 3, G1 2 participant) (pg 1474). "The failure to see the child grow and perform tasks like other children worried the mothers. Two mothers claimed hypertension from worrying too much about the child." (pg 1472). "They variously stated that often without anyone else to assist, minding and carrying the child on their backs and/or hands as they moved from one unit to another in the hospital, often for long hours, or as they helped the child through the prescribed physiotherapy exercises, was too physically exhausting for them." (pg 1474).	The failure to see the child grow and perform tasks like other children worried the mothers. Two mothers claimed hypertension from worrying too much about the child.

TABLE 1 Continued

Author, Year of Publication, and Location of Study	Aims and Objectives	Child's Condition	Study Design	Caregiver Health Measure	No. and Sex of Caregivers	Hawker Quality Assessment Score	Study Results Related to Physical Health ^a	Study Conclusions
49 Neu et al ⁴⁶ (2014), United States	To compare physiologic and emotional stress of mothers of children during maintenance treatment of ALL with matched control mothers.	Cancer	Case-control	Salivary Cortisol	52 caregivers: 26 case mothers; 26 control mothers	34/36	Cortisol: AUC (nmol/L): 15.5 (SD: 7.9) case; 18.1 (SD: 6.7) control. CAR (nmol/L) (diff wake to 30 min): 1.3 (SD: 5.0) case; 2.7 (SD: 3.7) control. Slope: -0.3 (SD: 0.4) case; -0.5 (SD: 0.5) control. Mothers of children with ALL continued to experience emotional distress months after the initial diagnosis.	Mothers of children with ALL showed a trend for greater perceived stress over the past month but did not have significant cortisol differences compared with the matched sample. Mothers of children with ALL continued to experience emotional distress months after the initial diagnosis.
50 Neu et al ⁴⁷ (2014), United States	To explore maternal perceptions of their sleep quality during maintenance treatment of their child's ALL and to discover what sleep strategies mothers used to attain sleep and/or cope with lack of sleep.	Leukemia	Qualitative	Semistructured interviews	20 caregivers: 20 mothers	35/36	"I have not had a good night's sleep since the diagnosis," or "I get so tired that I collapse sometimes," or "I don't remember what it's like to have sleep." (415). "I had a hard time falling asleep before. I would wake up once. Now, I am always checking on him." One mother described her typical night: "The kids are out of control—really rambunctious and my husband has left for his night shift. The kids are up 3–4 times before settling. I go to bed at midnight; the baby's up at 1:30, then my daughter (with ALL) wakes up. The baby wakes up again at 3 AM but everyone is asleep by 4 AM. The baby is up again at 6 AM, then it's time to get up."	Mothers of children with ALL reported continued sleep disruption during maintenance treatment of their child's ALL for a variety of reasons.
51 Ones et al ⁴⁸ (2005), Turkey	To evaluate the QoL and psychological status in mothers of children with CP and to assess their relationship with regard to the degree of their child's disability.	CP	Case-control	Nottingham Health Profile	92 caregivers (sex not given); 46 case; 46 control	30/36	Pain: 18.91 (SD: 21.57) case; 7.88 (SD: 6.76) control. Sleep: 31.35 (SD: 25.62) case; 11.42 (SD: 8.68) control.	Mothers of children with CP scored significantly worse on all domains of the Nottingham Health Profile compared with controls.
52 Orsey et al ⁴⁷ (2017), United States	The study aimed to assess the feasibility and preliminary efficacy of a yoga intervention for pediatric patients with cancer in active treatment and for their families.	Cancer	Mixed methods evaluation of an intervention	SF-12	20 caregivers (sex not given)	30/36	General health score: not given. Body pain subscale: not given. Role physical functioning subscale: not given. Physical component score subscale time point 1: 54.871 (8.0SD). Physical component score subscale time point 2: 51.490 (4.4SD).	No statistically significant differences were noted for the Physical Health Composite or caregiver burden.
53 Pierre-Louis et al ¹⁰⁴ (2018), United States	To understand parents' perceptions of stressors associated with parenting a child with NF, coping needs, and interest in a mind-body intervention focused on adapting coping, self-care, and increased QoL.	Neurofibromatosis	Qualitative	Focus groups (video)	30 caregivers: 27 mothers; 3 fathers	27/36	"I have constant stressors, always! This is not going away and it's actually starting to affect my own health in the last year" (pg 965). "Important, I say I impacted my health, I was down for a while. [Medical condition] which I think is exacerbated by stress" (pg 965). Parents of youth with chronic illness are at an increased risk for emotional and physical health problems due to the demands associated with caretaking (pg 966). Although several parents noted making managing stress a priority and engaging in healthy coping, many more noted knowledge of strategies they should employ (eg, exercise, mindfulness), but difficulties implementing such strategies (Pierre-Louis et al ¹⁰⁴) (pg 966).	Parents reported heightened stress affecting their physical health. Parents of youth with chronic illness are increased risk for physical health problems due to the demands associated with caregiving.
54 Prudente et al ⁶³ (2010), Brazil	To analyze the QoL of mothers of children with CP correlated with the evolution of their children's gross motor function after 10 mo of rehabilitation.	CP	Longitudinal	SF-36	100 caregivers: 100 mothers	27/36	General health score: 74.45 (SD: 21.14) first assessment; 76.15 (SD: 19.84) last assessment. Body pain subscale: 54.66 (SD: 27.55) first assessment; 69.23 (SD: 23.69) last assessment. Role physical functioning subscale: 65.75 (SD: 34.83) first assessment; 68.25 (SD: 40.02) last assessment. Physical functioning subscale: 82.65 (SD: 15.87) first assessment; 79.60 (SD: 21.45) last assessment. Physical component score subscale: not given.	Mothers of children with CP reported an improvement in pain after their child attended 10 mo of rehabilitation. No statistically significant differences were found for the other domains of the SF-36.
55 Pukka et al ⁸¹ (2018), Canada	To assess HRQoL in mothers 10 y after their child's diagnosis of epilepsy.	Epilepsy	Longitudinal	SF-12	159 caregivers: 159 mothers	34/36	General health score: not given. Body pain subscale: not given. Role physical functioning subscale: not given. Physical component score subscale: 53.0 (SD: 7.6) case; 50 (SD: 10) pop. norm.	Ten years after their child's diagnosis of epilepsy, the physical health component of mothers' HRQoL was significantly, though marginally, better compared with population norms of women of a similar age.

TABLE 1 Continued

Author, Year of Publication, and Location of Study	Aims and Objectives	Child's Condition	Study Design	Caregiver Health Measure	No. and Sex of Caregivers	Hawker Quality Assessment Score	Study Results Related to Physical Health ^a	Study Conclusions
56 Raina et al. ⁷² (2009), Canada	To examine, within a single multidimensional model, a comprehensive set of factors that are relevant to the caregiving situation.	CP	Cross-sectional	SF-36	468 caregivers: 442 mothers; 26 fathers	30/36	General health score: 67.90 (SD: 23.04). Body pain subscale: 67.97 (SD: 25.48). Role physical functioning subscale: 68.75 (SD: 39.02). Physical Component score subscale: 83.75 (SD: 21.77). Physical Component score subscale: not given (scores compared with national population sample).	Caregivers reported average scores of well-being on the SF-36. A higher level of behavior problems was associated with lower levels of physical health of the caregivers. Less caregiving demands were associated with better physical well-being of caregivers. The authors conclude predictors of caregivers' well-being were child behavior, caregiving demands, and family function.
57 Read et al. ⁴⁹ (2010), United Kingdom	To examine sleep and well-being in young men with neuromuscular conditions on assisted ventilation and their main carers. The hypothesis was that ventilation would be associated with sleep problems and that the latter would be linked to patient and carer well-being.	Neuromuscular Disorders	Mixed methods	SF-36 and Interviews	10 caregivers: 8 mothers; 2 fathers	36/36	General health score: 56.6 (SD: 19.6) case; 71.4 (SD: 23.4) norm. Body pain subscale: 59.7 (24.9) case; 80.7 (SD: 25.5) norm. Role physical functioning subscale: 65.6 (SD: 44.1) case; 83.6 (SD: 33.8) norm. Physical functioning subscale: 80.9 (SD: 16.4) case; 87.2 (SD: 20.1) norm. Physical component score subscale: not given.	Most caregivers reported poor sleep quality in the qualitative interviews. On the SF-36 they reported mildly/moderately reduced physical well-being. A third or more noted a moderate impact from the illness on different aspects of family life (ie, physical health, finances, and leisure).
58 Reilly et al. ⁷³ (2015), Sweden	To compare parental HRQoL, anxiety, and depression at baseline and 2 y after epilepsy surgery in a population-based series of children and young people who underwent surgery between 1995 and 1999 and to compare with population norms.	Epilepsy	Longitudinal	SF-36	94 caregivers: 50 mothers; 44 fathers	30/36	General health score: 73.33 female case; 78.08 male case; 77.78 female control; male control 78.27. Body pain subscale: 73.02 female case; 81.88 male case; 74.09 female control; male control 78.57. Role physical functioning subscale: 78.13 female case; 82.84 male case; 86.10 female control; 88.96 male control. Physical functioning subscale: 91.54 female case; 94.65 male case; 90.33 female control; male control 93.13. Physical component score subscale: not given. SD not given.	Mothers' baseline scores on 7 of 8 SF-36 domains were significantly lower than reference values. Scores at follow-up improved on these 7 domains. Fathers' scores on the physical component score was significantly lower than reference values.
59 Reilly et al. ⁷⁴ (2017), Sweden	To assess and compare HRQoL and emotional well-being in mothers and fathers of children with drug-resistant epilepsy referred for presurgical evaluation in Sweden.	Epilepsy	Cross-sectional	SF-36	219 caregivers: 117 mothers; 102 fathers	33/36	General health score: 68.3 baseline female; 73.9 follow-up female; 77.8 control female; 76.6 baseline male; 82.1 follow-up male; 78.3 control male. Body pain subscale: 67.4 baseline female; 77.1 follow-up female; 74.1 control female; 83.5 baseline male; 90.1 follow-up male; 78.6 control male. Role physical functioning subscale: 66.5 baseline female; 78.1 follow-up female; 86.1 control female; 83.5 baseline male; 90.1 follow-up male; 78.6 control male. Physical functioning subscale: 87.2 baseline female; 94.6 follow-up female; 90.3 control female; 97.7 baseline male; 99.2 follow-up male; 93.1 control male. Physical component score subscale: not given.	Both fathers and mothers had significant impairments in HRQoL compared with Swedish population norms. Physical health status was worse only in mothers and only in relation to 2 of the 4 SF-36 physical domains. The authors suggest that parenting a child with drug-resistant epilepsy is more emotionally than physically demanding for both parents, particularly mothers.
60 Remedios et al. ⁸² (2015), Australia	To evaluate the impact of out-of-home respite care on levels of fatigue, psychological adjustment, QoL and relationship satisfaction among caregivers of children with life-threatening conditions and, second, to determine caregivers' perceptions and experiences of out-of-home respite from qualitative responses to open-ended questions in the survey.	Mixed medical conditions	Longitudinal	SF-12	58 caregivers: 33 mothers; 25 fathers	32/36	Physical component score subscale: 45.9 (SD: 10.3) before; 46.6 (SD: 11.0) after; Physical component score subscale: 50 (SD: 10) pop. norm.	Caregivers reported clinical levels of distress and substandard levels of physical health compared with normative data in American and Australian populations.
61 Rensen et al. ⁸⁵ (2020), Netherlands	In this study, parental sleep, distress, and QoL are compared with that of the general population, between medium risk and standard risk groups and those on and off dexamethasone.	Leukemia	Longitudinal	SF-12	121 caregivers: 111 mothers; 20 fathers	33/36	Physical component score subscale: 53.7 (SD: 7.2) case; 52.5 (SD: 7.3)-54.8 (SD: 5.9) range of pop. norms.	Results of this study were reported by the prognosis of the child's cancer. This study found that parents across both the standard risk and medium risk groups reported more sleep problems and distress when compared with reference values.

TABLE 1 Continued

Author, Year of Publication, and Location of Study	Aims and Objectives	Child's Condition	Study Design	Caregiver Health Measure	No. and Sex of Caregivers	Hawker Quality Assessment Score	Study Results Related to Physical Health ^a	Study Conclusions
62 Rentsz et al ¹⁴ (2015). United States	The objective of this study is to investigate the well-being burden of caregivers of tuberculous sclerosis complex patients in the United States.	Tuberculous sclerosis complex	Cross-sectional	SF-12	275 caregivers: sex not given; 176 case, 99 control	35/36	General health score: 48.6 (SD: 5.9). Body pain subscale: 48.2 (SD: 9.0). Role physical functioning subscale: 48.1 (SD: 8.2). Physical functioning subscale: 51.9 (SD: 7.1). Physical component score subscale: 51.0 (SD: 7.5) pediatric; 46.5 (SD: 8.4) adult.	Compared with healthy adults in the US population, tuberculous sclerosis complex caregivers had significantly worse physical health and more depressive symptomatology. However, when caregivers of pediatric patient's physical is compared with the health of caregivers of adult patients, caregivers of adult patients reported significantly lower mean physical HRQoL scores. Mothers of children with cancer who had high family/friend support demonstrated trajectories of physical health-related functioning that were more stable than the trajectories of mothers with low family/friend support.
63 Rini et al ¹² (2008). United States	To investigate whether social support from family and friends (family/friend support) attenuated ("buffered") adverse effects of having low spouse support (spousal support) among mothers of children undergoing HSCT.	Cancer	Longitudinal	SF-36	163 caregivers: 163 mothers	32/36	General health score: not given. Body pain subscale: not given. Role physical functioning subscale: not given. Physical functioning subscale: not given. Physical component score subscale: 57.54 (SD: 6.20) at time of HSCT; 56.34 (SD: 6.82) 3 mo; 56.41 (SD: 6.94) 6 mo; 56.66 (SD: 5.86) 12 mo.	Mothers of children with cancer who had high family/friend support demonstrated trajectories of physical health-related functioning that were more stable than the trajectories of mothers with low family/friend support.
64 Rubira et al ⁶⁵ (2012). Brazil	To evaluate the burden of care and QoL of caregivers of children and adolescents with cancer during chemotherapy treatment, and to relate them to each other and sociodemographic data.	Cancer	Cross-sectional	SF-36	160 caregivers: 142 mothers; 18 fathers	31/36	General health score: 70.82 (SD: 1.50). Body pain subscale: 70.84 (SD: 2.17). Role physical functioning subscale: 66.09 (SD: 3.61). Physical functioning subscale: 79.53 (SD: 1.51). Physical component score subscale: not given.	When compared with the population of caregivers of healthy children and in the adult Brazilian population, scores of all dimensions of the SF-36 in the study were lower than in other studies, including normal adult populations of other countries.
65 do Espírito Santo et al ⁶⁶ (2011). Brazil	To evaluate the burden of care and QoL of caregivers of children/adolescents with cancer during chemotherapy treatment and relate them to each other and the sociodemographic data and the presence and degree of signs of depression.	Cancer	Cross-sectional	SF-36	32 caregivers: 28 mothers; 4 fathers	28/36	General health score: 68.3 case; 75.0 norm. Body pain subscale: 60.9 case; 73.0 norm. Role physical functioning subscale: 71.1 case; 87.10 norm. Physical functioning subscale: 83.0 case; 83.0 norm. Physical component score subscale: not given. SD: not given.	The caregivers' QoL was significantly lower on SF-36 domains of emotional role functioning, vitality and pain.
66 Sarajlija et al ¹³ (2013). Serbia	To investigate factors influencing HRQoL and depression in mothers who care for children with Rett Syndrome in Serbia.	Rett Syndrome	Cross-sectional	SF-36	49 caregivers: 49 mothers	27/36	General health score: 49.7 (SD: 27.7) case. Body pain subscale: 51.5 (SD: 32.9) case. Role physical functioning subscale: 52.0 (SD: 37.4) case. Physical functioning subscale: 73.1 (SD: 27.4) case. Physical component score subscale: 54.2 (SD: 28.4). Population norms: not given. 47.4 female; 52 male.	Mothers of children with Rett syndrome reported lower HRQoL. All scores were significantly influenced by maternal age and clinical severity of their child's disease.
67 Seear et al ¹⁵ (2016). Canada	To examine the adverse effects of home-ventilated children and home ventilation on the affected child and the primary caregiver.	Home-ventilated children whose condition is not specified	Mixed methods	Caregiver impact scale	90 caregivers: 78 mothers; 10 fathers; 1 grandmother; 1 foster mother	35/36	General health score: 66.4 (SD: 25.5) mild CHD; 64.7 (SD: 29.0) severe CHD. Body pain subscale: 63.5 (SD: 26.5) mild CHD; 63.9 (SD: 25.9) severe CHD. Role physical functioning subscale: 74.3 (SD: 53.7) mild CHD; 70.8 (SD: 33.5) severe CHD. Physical functioning subscale: 83.9 (SD: 22.8) mild CHD; 83.8 (SD: 23.4) severe CHD. Physical component score subscale: not given.	The burden of home care was reflected in lower levels of physical health among the primary caregivers. Nearly 1 in every 4 caregivers reported the adverse effects of home ventilation as severe.
68 Sileshi et al ⁶⁴ (2017). Ethiopia	To determine the HRQoL of mothers of children with congenital heart disease in a sub-Saharan setting where the access to definitive treatment is rarely available.	Congenital heart disease	Cross-sectional	SF-36	135 caregivers: 135 mothers	26/36	General health score: 66.4 (SD: 25.5) mild CHD; 64.7 (SD: 29.0) severe CHD. Body pain subscale: 63.5 (SD: 26.5) mild CHD; 63.9 (SD: 25.9) severe CHD. Role physical functioning subscale: 74.3 (SD: 53.7) mild CHD; 70.8 (SD: 33.5) severe CHD. Physical functioning subscale: 83.9 (SD: 22.8) mild CHD; 83.8 (SD: 23.4) severe CHD. Physical component score subscale: not given.	Mothers of children with congenital heart disease in this study had significantly lower QoL in all domains of the SF-36 compared with the control group.
69 Steele and Davies ¹⁰⁵ (2006). Canada	To enhance understanding of the experiences of families with a child who has a neurologic I/I.	Progressive I/I	Qualitative	Interviews and participant observation	29 caregivers (sex not specified)	29/36	The constant, unrelenting nature of the 24 h/d, 7 d/wk care required by the child took a physical toll on parents. Many suffered from exhaustion, injuries, migraine headaches, anemia, or livers. Parents reported that the months and years of not sleeping felt like the "worst times of our lives." They were on call 24 h/d. They were often up at night for hours and became exhausted. Yet, they needed to function at work the next day or continue caring for the child while carrying on with daily living. One father stated that he took naps during the day so he	Fatigue as a result of caregiving was a particularly prevalent symptom that held the potential to impact on parents in multiple ways. Parents often needed help to alleviate the impact of their experience, but it was not always available in a useful manner. Despite the negative aspects, caring for the child was never viewed by parents as a burden.

TABLE 1 Continued

Author, Year of Publication, and Location of Study	Aims and Objectives	Child's Condition	Study Design	Caregiver Health Measure	No. and Sex of Caregivers	Hawker Quality Assessment Score	Study Results Related to Physical Health ^a	Study Conclusions
70 Suthoff et al ⁸⁴ (2019). Multinational	The objective of this study was to quantify the mental/physical health, social/emotional, and productivity burden experienced by primary caregivers of children with CF during a pulmonary exacerbation event necessitating hospitalization and treatment with IV antibiotics, compared with a period of "wellness."	Cystic fibrosis	Prospective, observational cohort study	SF-12	88 caregivers: 74 mothers 14 fathers	32/36	could keep going. He felt lucky that his employer supported him by allowing flexibility in his schedule. Without such support, he could not continue working. Other parents felt that they had no choice but to quit work. They could not do "two jobs." (Pg 580). As children deteriorated and lost the ability to move or walk, parents had to lift and carry them everywhere. Moreover, as time passed, the children grew and became heavier. Parents were often lifting a child of 30–40 pounds plus a wheelchair that weighed another 30 pounds. These children lost muscle control and could not hang on to their parents when, for example, they were being lifted in and out of the bath; they were a dead wt. Many parents complained of sore backs. (pg 580). Most parents in this study were also exhausted. They were on call 24 h-a-day, 7 d-a-week. Many parents reported that they suffered through months and years of not sleeping. Fatigue has only relatively recently been identified as a major issue in society, so although it is prevalent, researchers and practitioners are only now showing increased interest in understanding this phenomenon. (pg 583). Exhaustion that manifested itself in a number of ways. The effects were often subtle and not explicitly recognized as being attributable to fatigue. Potential effects of fatigue included physical weariness, impaired cognitive functioning, slowed speed of information processing, and depression. In families of children with NLTIs, these effects could result in actions such as parents administering incorrect medications or failing to follow correct procedures when using medical equipment. Fatigue has also been associated with affective, cognitive, and behavioral responses that include irritability, impaired cognitive functioning, and inability to concentrate on daily tasks (Ream and Richardson, 1996). These responses were evident in families in the current study. One particular aspect of cognitive functioning, attentional impairment, was especially striking. This aspect was exemplified in the strategy of going into slow motion. Some families reported that they eased their pace and went into slow motion so as going at 10 km/hour instead of the usual 100 km/hour and said this was essential for survival. However, going into slow motion also diminished their ability to learn new things or to process information, a fact that was often not recognized by professionals. (pg 582).	This study found no relationship between the health of a caregiver during episodes of pulmonary exacerbation—related hospitalization of a child with CF.

TABLE 1 Continued

Author, Year of Publication, and Location of Study	Aims and Objectives	Child's Condition	Study Design	Caregiver Health Measure	No. and Sex of Caregivers	Hawker Quality Assessment Score	Study Results Related to Physical Health ^a	Study Conclusions
71 Tonga and Düğecik ⁸⁹ (2008), Turkey	To determine factors that affect LBP in caregiver mothers with disabled children who need assistance in daily living activities.	CP and muscular dystrophy	Case-control	Oswestry	88 caregivers: 58 case mothers; 30 control mothers	27/36	6.40 (SD: 5.91) mothers of children with CP; 5.42 (SD: 5.67) mothers of children with MD; 5.80 (SD: 6.79) mothers of healthy children.	At the first interview, 91% of the disabled children's mothers had LBP; 46% of the disabled children's mothers had neck pain, 27% of the disabled children's mothers had back pain, and 20% had leg pain. When asked about the activities of daily life that caused LBP, this study found that lifting (86%), carrying (56%), bending (27%), standing a long time (67%), walking (31%), and housework (56%) were the activities that caused LBP most frequently in mothers with disabled children.
72 Trickett et al ⁹⁶ (2017), Multinational	The study had the following aims: (1) To describe the nature of sleep problems considered most problematic for parents. (2) To explore the impact of children's sleep quality on both children and the rest of the family and to identify a hierarchy of the most stressful impact of children's sleep. (3) To describe management strategies used by parents and parent-reported efficacy. (4) To explore the priorities parents have for future support.	Angelman	Qualitative	Semistructured interviews	50 caregivers: 30 mothers; 20 fathers	30/36	94% (n = 47) of primary caregivers indicated that their child's sleep problems had at some point impacted themselves. As can be seen, these impacts included daytime fatigue and sleep deprivation, the most commonly reported impacts by 70% (n = 35) and 64% (n = 32) of primary caregivers respectively, followed by stress (58%, n = 29), and difficulties coping at work (42%, n = 21). (pg 110). Forty-two percent of parents monitored their child at night, the most frequently cited reason was to monitor their child's medical condition (seizures, oxygen and glucose levels, 24% of total number of families, n = 12), followed by checking whether their child was asleep (24%, n = 12) and whether child needs toileting or was uncomfortable (14%, n = 7). The act of monitoring their child at night impacted on the sleep of 22% (n = 11) of parents and 8% (n = 4) of the children's sleep (pg 110). General health score: 58.5 (SD: 21.7) group A; 60.2 (SD: 23.7) group B; 67.6 (SD: 24.2) group C. Body pain subscale: 46.0 (SD: 7.9) group A; 47.0 (SD: 8.5) group B; 47.0 (SD: 7.4) group C. Role physical functioning subscale: 54.6 (SD: 45.9) group A; 60.4 (SD: 41.8) group B; 76.9 (SD: 40.0) group C. Physical functioning subscale: 78.5 (SD: 25.8) group A; 81.5 (SD: 23.0) group B; 87.1 (SD: 18.6) group C. Physical component score subscale: not given.	This study has revealed that parents of children with Angelman syndrome are concerned about the impact on their child's poor sleep quality on their own well-being, their child's poor sleep quality possibly as a result of a cycle of positive reinforcement of attention during nighttime wakings being maintained.
73 Tsai et al ¹²⁶ (2013), China	To evaluate caregiver-reported psychosocial adjustment and HRQoL of Taiwanese children with newly diagnosed cancer and their caregivers during the first 6 mo of treatment.	Cancer	Case-control	SF-36	179 caregivers: 86 case mothers; 3 case fathers; 90 control mothers	32/36	Both children with cancer and their parents are able to adjust gradually ~3–6 mo after treatment, despite both experiencing considerable distress and poor HRQoL initially.	
74 van Nimwegen et al ⁸⁵ (2016), Netherlands	(1) To assess parental HRQoL in complex pediatric neurology and (2) to gain insight into the relationship between parental HRQoL and several patient and parental variables.	Neurologic problems e causa ignota	Cross-sectional	SF-12	120 caregivers: 63 mothers; 57 fathers	35/36	Physical component score subscale: 51.50 mother; 52.76 pop. norm; Physical component score subscale: 51.76 father; 54.55 pop. norm.	This study found diminished parental physical health. Contrary to previous studies, fathers' physical component scores are more affected than mothers'.
75 Wallander et al ⁸⁵ (1989), United States	To document the adaptation of physically disabled children and their mothers, and to investigate in the children whether they presented with any particular patterns of maladaptation, and to evaluate the combined and unique contributions of disability parameters and chronic disability-related strain to the adaptation of both mother and child.	CP and spina bifida	Cross-sectional	Malaise inventory	50 caregivers: 50 mothers	29/36	2.66 (SD: 2.08)	Mothers of children with CP and spina bifida reported significantly more physical health complaints when compared with norms from mothers of healthy children the Isle of Wight epidemiological study.
76 Wang et al ⁷⁰ (2017), China	To explore the care burden among parents of children with ALL and its related factors.	Cancer	Cross-sectional	SF-36	130 caregivers: 95 mothers; 35 fathers	33/36	General health score: 66.35 (SD: 19.24) 69.55 (SD: 21.32). Body pain subscale: 79.04 (SD: 17.96) 85.61 (SD: 18.37). Role physical functioning subscale: 44.62 (SD: 45.43); 79.51 (SD: 34.70). Physical functioning subscale: 87.12 (SD: 16.87); 90.62 (SD: 15.40). Physical component score subscale: not given.	Parents of children with cancer had lower scores on physical functioning, pain, general health, and role limitation due to physical problems than population norms.

TABLE 1 Continued

Author, Year of Publication, and Location of Study	Aims and Objectives	Child's Condition	Study Design	Caregiver Health Measure	No. and Sex of Caregivers	Hawker Quality Assessment Score	Study Results Related to Physical Health ^a	Study Conclusions
77 Werner et al ⁶⁶ (2019), Switzerland	To assess the prevalence of PTSD in the parents of children with PM or ICD. Furthermore, the study aims (2) to describe HRQoL in the patients' parents as compared with parents of sex- and age-matched healthy controls and to analyze maternal and paternal differences.	Cardiac anomalies	Cross-sectional	SF-36	127 caregivers: 69 case mothers; 57 case fathers; 67 control mothers; 51 control fathers	33/36	General health score: 78.9 (SD: 15.5) case female; 85.7 (SD: 12.4) control female; 77.5 (SD: 17.7) case male; 78.9 (SD: 16.4) control male. Body pain subscale: 83.8 (SD: 21.0) case female; 90.2 (SD: 14.8) control female; 83.3 (SD: 22.6) case male; 89.6 (SD: 16.3) control male. Role physical functioning subscale: 92.8 (SD: 22.3) case female; 98.9 (SD: 5.2) control female; 88.6 (SD: 20.2) case male; 94.6 (SD: 18.2) control male. Physical functioning subscale: 93.6 (SD: 14.0) case female; 98.2 (SD: 4.0) control female; 92.1 (SD: 18.3) case male; 96.7 (SD: 5.5) control male. Physical component score subscale: 54.7 (SD: 7.2) case female; 56.8 (SD: 3.7) control female; 53.9 (SD: 8.4) case male; 51.5 (SD: 3.9) control male.	Parental HRQoL is reduced compared with controls.
78 Wu et al ⁶⁷ (2020), Taiwan	To explore the lived experiences of family caregivers of patients with EB.	EB	Phenomenological	Qualitative	10 caregivers	30/36	In addition to daily life care that causes physical exhaustion, worries over long-term care also hamper sleep quality and foment anxiety and depression. (pg 1557). "I often experience LBP and previously suffered bouts of depression. For some time I was irritable and my emotions were unstable. I remember once when I slapped my child many times and thought of jumping off a building with my child to commit suicide. When my husband returned home from work that day, I told him bluntly that I had slapped his son and wanted to commit suicide with him" (pg 1557).	The authors find that family caregivers of EB patients must provide long-term and complex care, which causes them to shoulder relatively severe physical stress. In addition to daily life care that causes physical exhaustion, worries over long-term care also hamper sleep quality and foment anxiety and depression.
79 Wu et al ⁷¹ (2017), China	To evaluate the QoL of mother and grandmother primary caregivers of children with CP and to compare the difference between these 2 groups of caregivers.	CP	Cross-sectional	SF-36	177 caregivers: 125 mothers; 52 grandmothers	35/36	General health score: 46.99 (SD: 13.15) mothers; 40.82 (SD: 13.24) grandmothers. Body pain subscale: 47.05 (SD: 10.36) mothers; 38.27 (SD: 10.58) grandmothers. Role physical functioning subscale: 46.42 (SD: 13.65) mothers; 36.94 (SD: 11.76) grandmothers. Physical functioning subscale: 49.86 (SD: 8.63) mothers; 41.43 (SD: 11.16) grandmothers. Physical component score subscale: 49.39 (SD: 9.18) mothers; 40.34 (SD: 9.08) grandmothers.	The physical health of grandmother caregivers scored significantly lower than the mother caregivers. Tasks such as heavy lifting and turning, bathing, helping the child use a toilet, getting the child to sleep, dressing and assisting the child to move can put physical strain on caregivers. The primary caregivers of children with CP reported an increased likelihood for numerous physical health problems, especially the low back pain. Experience of increased low back pain caused deterioration of HRQoL. Manual handling may be a contributing factor to a lower physical health.
80 Yamazaki et al ⁶⁷ (2005), Japan	To compare the HRQoL of mothers of children with leukemia to that of mothers of children without leukemia in Japan.	Leukemia	Cross-sectional case control study	SF-36	337 caregivers: 97 case mothers; 240 control mothers	33/36	General health score: 65.5 (SD: 19.0) case; 69.8 (SD: 16.9) control. Body pain subscale: 71.7 (SD: 22.6) case; 75.0 (SD: 22.7) control. Role physical functioning subscale: 83.7 (SD: 23.2) case; 88.6 (SD: 17.5) control. Physical functioning subscale: 91.7 (SD: 9.6) case; 92.5 (SD: 8.9) control. Physical component score subscale: not given.	Mothers of children with leukemia scored lower on the SF-36 compared with controls. When the comparison was adjusted for mother's age, educational status, working status, number of comorbid conditions, annual family income, the presence of other family members requiring mother's care, and residential area, mothers of children with leukemia still had lower scores than mothers of children without leukemia.
81 Yilmaz et al ⁶⁸ (2004), Turkey	To investigate the effect of physical impairment and body composition of mothers with neuromuscular disorders and the resulting low back pain on the mothers.	Muscular dystrophy	Cross-sectional	Oswestry Low Back Disability Questionnaire Scale	30 caregivers: 30 mothers	26/36	16.03 (SD: 11.89) case; norms not given	As children got heavier there was a statistically significant correlation between the BM of children and the BMI of mothers, the wt of the mothers and the back pain of the mothers. The authors recommended wt loss strategies for the children and training in manual handling for the mothers.

ADHD, attention-deficit/hyperactivity disorder; ALL, acute lymphoblastic leukemia; AML, acute myeloid leukemia; AUC, area under the curve; CAR, cortisol awakening response; CF, cystic fibrosis; CHD, coronary heart disease; CP, cerebral palsy; DIPG, diffuse intrinsic pontine glioma; Duke-UNC, Duke-University of North Carolina; EB, epidermolysis bullosa; EQ-5D, EuroQol 5 dimensions questionnaire; GMFCS, Gross Motor Function Classification System; HRQoL, health-related quality of life; HCT, hematopoietic stem cell transplant; ICD, implantable cardioverter defibrillator; IV, intravenous; LBP, lower back pain; MSP, musculoskeletal pain; NE, neonatal encephalopathy; NF, neurofibromatosis; NLI, non-life threatening illnesses; PM, pacemaker; PROMIS, Patient-Reported Outcomes Measurement Information System; PTSD, posttraumatic stress disorder; QoL, quality of life; SCT, stem cell transplantation; TCP, tetraparesis cerebral palsy; TAAQoL, TNO-AZL questionnaire for adult's health-related Quality of life.

^a Some studies had findings which were not related to physical health. For the purpose of this review we report only on findings related to caregiver physical health.

TABLE 2 Quantitative Measures of Caregiver Health

Quantitative Measures of Caregiver Health Summary	
SF 36: The SF-36 is an instrument for evaluating HRQoL. It is composed of 8 scales: PF, RP, bodily pain BP, GH, vitality, SF, RE, and MH. The responses to the questionnaire can be summarized into 2 different scores: the PCS and the MCS, with scores ranging from 0 to 100, with higher scores indicating better functioning. ¹²⁷	
SF 12: The SF-12 is much like the SF-36 questionnaire widely used to measure general health status. The 12-item questionnaire assesses 8 health domains: PF, RP, BP, GH, vitality, SF, RE, and MH. ¹²⁸	
DUKE: DUKE is a self-reported measure of HRQoL in adults. The DUKE contains 6 measures of function: physical health, mental health, social health, general health, self-esteem, and perceived health, and 5 measures related to negative functional health: anxiety, depression, anxiety-depression, pain, and disability. The scoring scale ranges from 0 to 100, with high scores indicating better HRQoL. The 17 questions on the DUKE health profile were derived from the larger Duke-UNC Health Profile. ^{129,130}	
Duke-UNC: The Duke-UNC profile was developed in 1981 and contains 63 questions assessing the health status of adults across 4 health domains: symptom status, physical function, emotional function and social function. Scores are expressed as a proportion ranging from 0.00 for the worst possible to 1.00 for the best possible health status. ¹³¹	
Nottingham Health Profile: The Nottingham Health Profile is a health assessment instrument composed of 38 questions intended to assess subjective health status across 6 domains: physical mobility, energy, sleep, pain, social isolation, and emotional reactions. Respondents are asked “yes” or “no” according to whether they feel the statements in each domain apply to them “in general.” Each question is assigned a weighted value, and the sum of all values in each domain equals 100. The higher the score, the greater the number and severity of health problems. ¹³²	
Oswestry Low back Pain Questionnaire: This is a tool that measures a person’s level of permanent disability. The tool has 10 sections that require the patient to indicate the extent of their low back pain and how much it disrupts their ability to undertake personal care, lifting, walking, sitting, standing, sleeping, sex life (if applicable), social life, and traveling. ¹³³	
EQ-5D: The EQ-5D is a self-completion questionnaire that is a measure of health status. In the first section of the tool, health status is measured across 5 dimensions on a 3-point Likert scale; mobility, self-care, usual activities, pain and discomfort, and anxiety and depression. In the second part of the measure, utility scores are used to transform the 5-digit number obtained from scoring the 5 dimensions into a discrete figure. ¹³⁴	
TNO-AZL Questionnaire for Adult HRQoL: The TNO-AZL is a survey instrument designed to measure adult health-related quality of life (TAAQOL). The dimensions investigated by the scale are gross motor functioning, fine motor functioning, cognition problems, sleep problems, pain problems, social contacts, daily activities, sex, vitality, happiness, depressive mood, and anger. The scale ranges from 1 to 100, with higher scores indicate a better HRQoL. ¹³⁵	
Jackson and Moskowitz scale (also called Katz Index of Independence in Activities of Daily Living, commonly referred to as the Katz ADL): This instrument assesses a person’s functional ability to perform the necessary activities of daily living across 6 domains; bathing, dressing, toileting, transferring, continence and feeding. Scores of 0 mean no pain, with 5 being the maximum level of pain intensity that completely limits performance. ¹³⁶	
HUI: The HUI is a measure of HRQoL and health utilities. The HUI consists of 2 questionnaires: the HUI15, which is a self-administered questionnaire, and the HUI40, which is designed for interviewer administration HUI. ¹³⁷	
Caregiver Impact Scale: The caregiver impact scale is a health measure explicitly designed to assess the impact of caregiving and the extent to which caregiving interfered with the caregivers’ daily activities. ¹³⁸	
The Malaise Inventory: The Malaise Inventory consists of 24-item self-completion questions about both physical and emotional states. The physical health subscale consists of 8 questions. All questions are scored “1” for yes and “0” for no, with a higher score indicating more difficulties. ^{139,140}	
OHIP-14: The OHIP-14 is a 14-item questionnaire derived as a subset of items from the longer Oral Health Impact Profile, a 49-item questionnaire that measures people’s perceptions of the impact of oral conditions on their well-being. ¹⁴¹	
PROMIS: PROMIS is a patient-reported assessment tool that explores physical and mental health status and social well-being. ^{142,143}	

BP, bodily pain; DUKE, Duke Health Profile; Duke-UNC, Duke-University of North Carolina; EQ-5D, EuroQol-5 Dimension; GH, general health; HRQoL, health-related quality of life; HUI, Health Utility Index; MCS, mental component summary; MH, mental health; OHIP-14, Oral Health Impact Profile; PCS, physical component summary; PF, physical functioning; PROMIS, Patient-Reported Outcomes Measurement Information System; RE, role emotional; RP, role physical; SF, social functioning; TNO-AZL, Nederlandse Organisatie voor Toegepast Natuurwetenschappelijk Onderzoek.

health scores were below average population norms, control scores or, in the case of longitudinal studies, showed a reduction in health over time.

Of the 11 studies employing the 12-Item Short-Form Health Survey (SF-12),^{14,47,77–85} all but 3 studies showed a reduction in at least 1 domain of physical health,^{47,79,84} 2 studies showed a longitudinal reduction in physical health,^{80,82} and 5 showed a lower health score compared with population norms.^{14,47,77,78,85}

The remaining quantitative studies measured caregiver’s health using other questionnaires, activity trackers, or cortisol. Of them, 19 studies^{15,42–46,50,83,86–96} demonstrated that the physical health of caregivers who care for a child with a LLC or LTI was negatively affected.

All qualitative studies ($n = 14$) demonstrated that caregivers felt their health was impacted negatively by a caregiver.^{8,24,87,97–107}

Pain

One of the most common effects of caregiving was pain. Researchers in 32 studies found caregivers reported pain arising from caregiving.* With the exception of 7 studies which specifically explored back pain, the location of pain was nonspecific. The studies that specifically explored back pain and its severity found caregivers experienced pain

*Refs 8, 14, 24, 26, 45, 48, 52, 54, 58, 59, 63, 65, 66, 71, 73–75, 78, 87, 89–92, 94–96, 98, 100, 101, and 108–110.

daily.^{58,71,89,90,94,96,98} In 5 of these studies, researchers suggested pain was a result of the weight of the child,^{58,89,90,94,96} their high levels of dependency,⁸⁹ and/or the physical nature of the care caregivers were required to provide.^{8,48,95,96} Despite the possible connection between caregiver pain and lifting and moving their child, no researchers explored the role of training in lifting and handling. Scant attention was paid to supportive equipment for lifting or moving the child for alleviating pain.

Sleep

Sleep disturbance was reported as an effect of caregiving in 25 studies.[†] Caregiver sleep disturbance was caused by a range of issues, including the child's nighttime seizures,⁵⁰ abnormal sleep patterns characteristic of the child's condition,^{80,104,106} and/or the need for nighttime care.^{8,91,99}

Given the nature of the ways these studies were conducted, it was not possible to determine how much of the sleep disturbance reported by these caregivers was associated with caregiving's psychological burden. However, a significant minority of researchers found correlations between anxiety, depression, or stress and caregiving, which was sometimes related to sleep disturbance.^{49,68,102}

Health-Seeking Behaviors That May Mitigate the Impact of Caregiving

Health-seeking behaviors including attention to a healthy diet, taking exercise, and attendance at the GP are known to lessen ill-health in the general population.⁴⁸ However, these behaviors are underexplored in the literature in this systematic review.

[†]Refs 8, 48–50, 52, 57, 59, 75, 78–80, 83, 88, 91, 92, 96, 98–102, and 104–107.

Seven studies explored exercise,^{24,42,52,98,101,104,105} and 1 study examined the caregiver's diet.²⁴ One study attributed less exercise and poorer diet to caregivers having less time or fewer cognitive resources to devote to their health or feeling that their child's needs were more important than their own health needs.⁹⁸

Caregiver attendance at primary care for regular check-ups, screening, or immunization was explored in 3 studies.^{65,66,98} One study reported that caregivers were aware that they should attend regular health checks but reported caregiving was a barrier to attending these appointments.⁹⁸ There were only 2 studies of interventions (daily walking and yoga)^{42,47} to improve physical health in this population, despite recognition that public health initiatives may need to be modified for caregivers.²²

Smoking, Drinking, and Drug Use

Authors of 12 studies explored coping behaviors detrimental to health, including self-harm,⁸⁷ the use of alcohol,^{45,92,101,104,105} illicit drugs,^{92,101,105} and tobacco.^{92,100,105} Use of alcohol, illicit drugs, and tobacco were explored as coping mechanisms, but the studies did not elaborate on the frequency of use, and no studies reported on interventions to reduce these behaviors. Six studies acknowledged the use of antidepressants.^{14,15,24,44,101,105}

The Context of Caregiving

In 39 studies, researchers examined the larger context (familial, social, health) in which caregiving occurs.[‡] The majority of these studies explored the assistance that caregivers had received either

[‡]Refs 15, 44, 49, 52, 56–58, 61, 63, 67, 69–72, 77–79, 81–84, 86–96, and 109–115.

informally from a spouse or other family member or formally through support services for their child. Some studies suggest a positive impact of respite care for caregivers.[§]

Researchers in 9 studies reported whether the caregiver had a previously diagnosed chronic medical condition,^{||} whereas those in 8 studies explored whether caregivers had preexisting health issues requiring regular prescription medication.[¶] Some studies postulate that caregivers who care for their child for a longer time are at increased risk of developing chronic conditions such as diabetes, arthritis, and hypertension.^{15,72,95} These findings are in keeping with research with caregivers of children with chronic conditions.²⁵

DISCUSSION

In this systematic review, we synthesized the literature around the physical health of parental caregivers of children with LLCs. Eighty-one studies were included. Eighty-four percent of studies reported caregiving negatively impacted caregivers' physical health, with sleep deprivation and pain (especially lower back pain) the most commonly reported issues. These physical effects appeared to be mediated by support for the caregiver's role, including support from a spouse, access to good quality respite care, and professional support for their child's medical needs.

[§]Refs 48–50, 77, 80, 82, 92, 98, 101, and 106.

[¶]Refs 48–50, 77, 80, 82, 92, 98, 101, and 106.

^{||}Refs 15, 24, 44, 57, 67, 70, 72, 82, and 101.

[¶]Refs 15, 44, 46, 49, 65, 66, 94, and 101. A systematic review of research on the physical health of parental caregivers of children with LLCs. Pain and sleep disturbance are recurrent issues for this population.

We note the absence of a straightforward association between the condition with which the child is diagnosed and caregiver health status. Instead, the physical health impact on caregivers was related foremost to the physical characteristics and acuity of the child, including their physical limitations and the child's age and weight. However, our analysis was complicated by the lack of information presented in some articles as to the severity of the child's condition. For instance, that some diseases (eg, cerebral palsy) present with a spectrum of severity, and that children's needs may differ on the basis of this spectrum.

An aim with this review was to identify the methodologies used to assess the physical health of caregivers. We found the tools used to be disparate and varied, using quantitative, qualitative, and mixed methods. Quantitative measures generally explored caregiver health as an aspect of "quality of life" or "well-being." As such, caregivers' physical health as a discrete and independent focus of research remains largely under-explored. Uniformly, the qualitative studies revealed that caregivers discussed the negative physical toll that caring for their child took on them, either in the form of sleep problems or physical pain.

The studies included in this review demonstrate that many factors affect the health of caregivers. Despite differences between and across the included studies, when taken as a whole, they highlight the act of caregiving as intense mental and physical work involving complex medical technologies, taking place in the home and often throughout the night. However, no study in this review looked at the multiplicity of factors impacting caregiver physical health completely and comprehensively. Table 3 describes what is known about the contextual factors leading to reduced

TABLE 3 Finding from the Review and Directions for Further Research Into Parent Physical Health

Findings From This Systematic Review
Parent physical health is characterized by
Increased
↑ Sleep disturbance
↑ Pain
And Moderated by
→ Formal and informal support for caregiving
→ Acuity of the child
We find some evidence that physical health is moderated by
The age of the parent during caregiving
Previous health of the parent
Parent coping behaviors
Role of caregiving tasks
We recommend further research into the role of
Societal perceptions of care
The economic context of care
Public policy to support parental caregiving
Access to interventions to support parent physical health
Health-seeking behaviors
Preventive health behaviors

caregiver physical health, as described in this systematic review. This article confirms that caregivers of children with LLCs and LTIs report higher than average levels of physical pain and disrupted sleep.

The economic, familial, and social contexts in which caregiving takes place have been shown to shape the caregiving experience for caregivers of adults.²² Our findings resonate with a recent study of parents caring for children with life-limiting neurologic conditions. The provision of formal respite care mitigates the negative impacts of caregiving, particularly as the intensity of their child's care needs make maintaining casual social support networks difficult.¹¹⁶

However, this review finds a paucity of literature around societal, economic, and policy factors influencing the physical health of caregivers (including family size, religion, ethnicity, language, socioeconomic status and social class,

and availability of targeted services to improve caregiver health, including public health interventions) despite the clear need for attention to these factors in the development of health improvement initiatives.^{117,118} Also, in this review, we found few studies that considered the caregivers' preexisting, diagnosed physical health. We have set out these factors to demonstrate the interconnected relationship between various aspects of the caregiving experience in Table 3. These contexts include the presence or absence of family or spousal support, access to health insurance, respite care for the child, caregiver age, acuity, and child behavior.

Studies report caregivers approach their own health in a variety of ways, including health-seeking and preventive health behaviors (eg, exercising, healthy eating, attendance for routine screening, etc) and behaviors that, if performed to excess, could lead to poorer health outcomes (smoking, drinking, alcohol use, the use of illicit drugs, etc).¹¹⁹ A small number of studies indicate that lack of time may be a barrier to engaging with health-seeking and preventive health behaviors.^{99,100} Further research is needed for the specific circumstances of caregiving that create these barriers.

Limitations

This study has several limitations. First, we designed a search strategy to capture the many illnesses and conditions from which children could die before reaching adulthood. This required a search sensitive enough to capture the studies on LLCs and LTIs that might not have been tagged as palliative in the research databases while ensuring the number of results returned was manageable. We used broad disease categories in our search, but in doing so, we may have missed studies of rarer conditions or single case reports.

Second, it was not possible within the time frame of this review, or indeed possible given the sheer volume of studies we screened, to perform forward and backward searching for further inclusions. It was also not possible to systematically explore the gray literature for other possible inclusions.

Third, because of the homogeneous nature of the studies' designs included in this review, identifying a suitable quality appraisal tool was challenging, and indeed it is debated within the literature.³⁹ We used the Hawker checklist to score the studies' quality to decide if they were methodologically sound enough for inclusion in this review.³⁰ We excluded only those studies that did not meet the quality threshold and thus attempted to limit bias from poorly conducted studies.^{39,120} However, excluding articles by quality because of the under-reporting of study finding means that our review may have missed studies with relevant findings. Table 1 presents the Hawker scores to be as transparent as possible to our reader. Of note, only 16 studies were excluded on the basis of poor quality, which is a strength of this body of literature on caregiver health.

Directions for Further Research

We recognize that caregivers of children with chronic illnesses share many of the same challenges faced by caregivers of a child with an LLC or LTI. This review has uncovered that the level and intensity of care directly impacts a caregiver's health. We also know from previous research that children who are at the end of life require more intense, physically demanding, around-the-clock care, which places intense physical demands on the caregiver. Understanding the nature of the work required to care for children at home as they approach the end of life is a direction for future research.

Few studies discussed in this review provide data on the intensity and nature of caregiving, the child's place in their illness trajectory, or whether the illness leads to their death. Thus, it is not possible to pinpoint the exact difference that the life-limiting nature of the child's condition has on the health of the caregiver. In studies in which these issues are discussed, the literature is too heterogeneous methodologically, and in clinical category, to ascertain the impact of the life-limited nature of the conditions on caregiver health. More research is needed to look at this issue specifically.

A further limitation of the included studies was a lack of information to include in our review on the specific care activities these caregivers were undertaking. We would recommend an explicit statement about the type of work being conducted in any future studies of caregiver physical health and the caregiver's level of involvement in caring for their child.

We suggest further examination of preventive health care initiatives in this population of caregivers. The majority of the studies in this review were conducted by teams engaged in caring for a child with an LLC rather than the teams involved in the care of the caregivers (eg, primary care settings). A lack of discussion of preventive health care initiatives may be the result of who is conducting this research. Furthermore, we do not know how the various sources of help for caregiver physical health may work together to monitor the health of caregivers providing long-term, around-the-clock care to their child with a LLC.¹²¹

For the most part, many of the studies included in this review were conducted in resource-rich countries. Although it was not within the scope of this review to explore the larger socioeconomic context of the families in each study, the socioeconomic

context may have a bearing on the ability of a family, or parent, to access and use services, particularly formal support for caregiving, which can potentially mitigate the burdens and adverse effects of caring for a child with a LLC or LTI.

CONCLUSIONS

The majority of studies included in this review reported that caregiving had a negative impact on caregiver physical health, specifically related to sleep and physical pain. Support for caregiving (both emotional and practical) seems to mitigate caregiving's negative impact on caregiver physical health. The rate of caregiver health-seeking behaviors, preventive health care, and screening for health conditions is understudied despite recommendations that caregivers engage in these behaviors.²² Most crucially, we find interventions such as the national provisioning of assistance for caregivers such as respite care, mechanical and technological aids, and public health and policy initiatives aimed at aiding caregivers with the increased demands of care within the home remain largely unexplored.

As informal caregiving is expected to continue to grow,¹²² the number of caregivers caring for children with LLCs or LTIs will consequently increase and supporting those caregivers to continue to care for their children in a way that maintains their health will become all the more critical.

ABBREVIATIONS

LLC: life-limiting condition
LTI: life-threatening illness
SF-12: 12-Item Short-Form Health Survey
SF-36: 36-Item Short-Form Health Survey

abstracts for inclusion in the review, codesigned the data extraction instruments, conducted the initial analyses, reviewed and revised the manuscript, and reviewed the manuscript for important intellectual content; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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