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REVIEW ARTICLE

Stress reduction interventions for parents/family of children with chronic diseases: a scoping review

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Abstract

Introduction: In consideration of the changes and repercussions on the family dynamics, apart from childcare responsibilities, parents and caregivers of children with chronic disease face frequent stressors, resulting in rising levels of stress. This review thus aims to analyse studies that assessed the efficacy of psychosocial interventions directed at stress management among parents and family members of children with the most prevalent chronic diseases (cancer, asthma, diabetes and cardiovascular disease). **Method:** This study classifies as a scoping review. The literature search included articles published in five electronic databases (EBSCO, b-On, PubMed, Scielo and Web of Science), in line with the inclusion criteria. **Results:** A total of 15 articles were selected. Interventions varied in relation to outcomes, study design, sample, modalities and strategies. Of the 15 studies, 53% found no significant differences in participants stress levels or between the intervention group and the control group, 40% showed a significant decrease in participants stress levels, and 7% presented mixed results with improvements in some emotional dimensions after the intervention. **Discussion:** Despite the mixed results with regards to the levels of stress, the significant results might justify the importance of performing such interventions among this population. Interventions that are personalized and directed at this populations needs might be effective at reducing stress levels.

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INTRODUCTION

Chronic non-communicable diseases (CNCD) are the first cause of death worldwide¹. According to the “Global Status Report on Noncommunicable Diseases 2014”², the four main chronic diseases include cardiovascular disease, cancer, diabetes, and respiratory disease. These are responsible for nearly 70% of all deaths worldwide and for over 80% of all premature deaths³.

CNCDs’ may entail the need for activity restriction, extensive treatments, painful medical procedures and medication-induced reactions. This has a direct impact not only on the child’s health, but also on family dynamics as a whole — since family members need to adapt to the circumstances and face the diseased child’s needs^{4,5}.

In a systematic review about parental stress among caregivers of children with chronic diseases, these caregivers reported significantly higher stress levels, compared to caregivers of healthy children, which was associated with worst psychological adjustment levels⁶. The repercussions of the disease, namely social, interpersonal, emotional and affective may also constitute stressors to the family^{7,8}.

Lazarus and Folkman⁹ define stress as a process which involves continuous interactions between the person and the environment, including stressful experiences, characterized as the mismatch between the person’s resources and the perceived demand.

In consideration of all the changes and repercussions on the family dynamics, besides childcare responsibilities, parents and caregivers of children with chronic diseases face frequent stressors, resulting in greater stress levels⁵.

With this in mind, it becomes important to take into consideration these parents’ and caregivers’ emotional health, not only for the health of the family dynamics, but also for a better management of the child’s disease. As such, interventions involving parents and family members are crucial to help caregivers manage their stress levels effectively and also manage the disease properly, besides contributing to the well-being of both caregivers and children.

Golfenshtein, Srulovici and Deatricks¹⁰ published an integrative review on interventions aimed at reducing parental stress among families of children with diverse pediatric conditions however the review presents differences in the study design.

As such, the present review focus on studies which explore interventions performed with parents and family members of children with cancer, diabetes, cardiovascular disease and respiratory disease.

AIM

This review aimed to analyse studies that assessed the efficacy of psychosocial interventions directed at stress management among parents and family members of children suffering from the most prevalent chronic diseases (cancer,

asthma, diabetes and cardiovascular diseases).

METHOD

This study classifies as a scoping review.

The literature search was concluded in June 2017, including all articles published until that date in five electronic databases (EBSCO, b-On, PubMed, Scielo and Web of Science), using combinations of the following search words: “program” OR “intervention” OR “management” OR “training” OR “treatment” OR “reduction” OR “control” OR “inoculation” OR “therapy” AND “stress”; AND “mother” OR “family” OR “parents” OR “caregivers; AND “cancer” OR “asthma” OR “diabetes” OR “cardiovascular disease” AND “childhood” OR “children” OR “pediatric”.

ELIGIBILITY CRITERIA

The following inclusion criteria were considered: (a) studies with available full-text; (b) studies that presented results for at least one measure of stress and that assessed this variable quantitatively through application of stress measuring instruments at least two moments (pre- and post-intervention); (c) studies that assessed stress in parents/family members/caregivers of children with the designated diseases (cancer, asthma, diabetes and cardiovascular disease); and (d) psychosocial interventions delivered face-to-face or remotely. Case studies, studies that assessed exclusively post-traumatic stress (due to its specific pathological nature) and studies including chronic diseases only in adolescence were excluded from the present review.

Screening and data analysis

Titles and abstracts were examined for potential eligibility and read by one of the reviewers (SCOA), with support from a specialist (FP). After deciding which studies met the inclusion criteria, the studies was then summarized and grouped by one of the researchers (SCOA).

Quality assessment was carried out by two researchers (SCOA and RR).

In order to summarize the information in an accurate and reliable way, the present study built an information extraction framework both based on the recommendations of Levac, Colquhoun and O’Brien¹¹ for scoping reviews and on several recommended items from the PRISMA Statement¹² since this study focused on intervention studies.

Quality Assessment

This task was carried out by two independent reviewers using a verification list adapted from the Cochrane Handbook for Systematic Reviews of Interventions^{13, 14, 15} with 29 questions, including 17 parameters with the following categories: introduction (questions 1, 2), method (questions 3 to 17), participants’ sociodemographic and clinical characteristics

(questions 18, 19, 20), instruments (question 21), statistical analysis (question 22), results (question 23), discussion (question 24, 25, 26) and others (program registration, financing sources and conflicts of interest), (questions 27, 28, 29). A rating scale was used according to the following parameter: present (3 or 2), unclear (1), absent (0), non-applicable (--).

The total quality score varied from 0 to 36 points.

RESULTS

Study Screening and Selection

A total of 10.099 articles were identified in the literature search in the five electronic databases. 6.853 articles duplicates were eliminated using EndNote and 177 duplicates were eliminated manually. The remaining 3.069 articles were screened (title and abstract), resulting in the exclusion of 3.005 articles based on the inclusion and exclusion criteria. Sixty four potential articles were read in full and those that didn't meet the eligibility criteria were removed from the review, which resulted in the elimination of 49 articles (the majority for not measuring stress in a quantitative manner, by means of psychometric instruments). Fifteen studies were selected to be included in the review^{5, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29}. Figure 1 presents the flow diagram of the screening and selection process.

Overall Study's Characteristics

Stress management and reduction was the aim of the included interventions, with twelve studies (n=12; 80%) presenting stress as a primary outcome and three (n=3; 20%) as a secondary outcome.

All studies presented at least one measure of stress (e.g., parental stress, general stress, distress, stress related to the parental experience of the child's disease). The most utilized measuring instrument was the PSI - Parenting Stress Index (4 studies); followed by the DASS - Depression, Anxiety, and Stress Scales (3 studies), the PECE - Parent Experience of Child Illness (2 studies), and the PSS - Perceived Stress Scale (2 studies). Eleven studies (n=11; 73%) performed analysis on the variable stress using only one instrument and four (n=4; 27%) included more than one stress measurement.

Regarding study design, ten articles (n=10; 67%) were randomized control trials (RCT) and five articles (n=5; 33%) were not RCTs. Regarding the assessment moments, nine studies (n=9; 60%) performed a minimum of three assessments (pre-test, post-test and follow-up) and six studies (n=6; 40%) reported two assessments (pre-test and post-test).

On sample characteristics, eight interventions (n=8; 53%) evolved parents (mothers and fathers), three interventions (n=3; 20%) focused exclusively on mothers, two interventions (n=2; 13,5%) included parents and family members (one study also included children), and two intervention (n=2; 13,5%) also included the family members (including children). Sample size varied considerably between 5 and 79 participants.

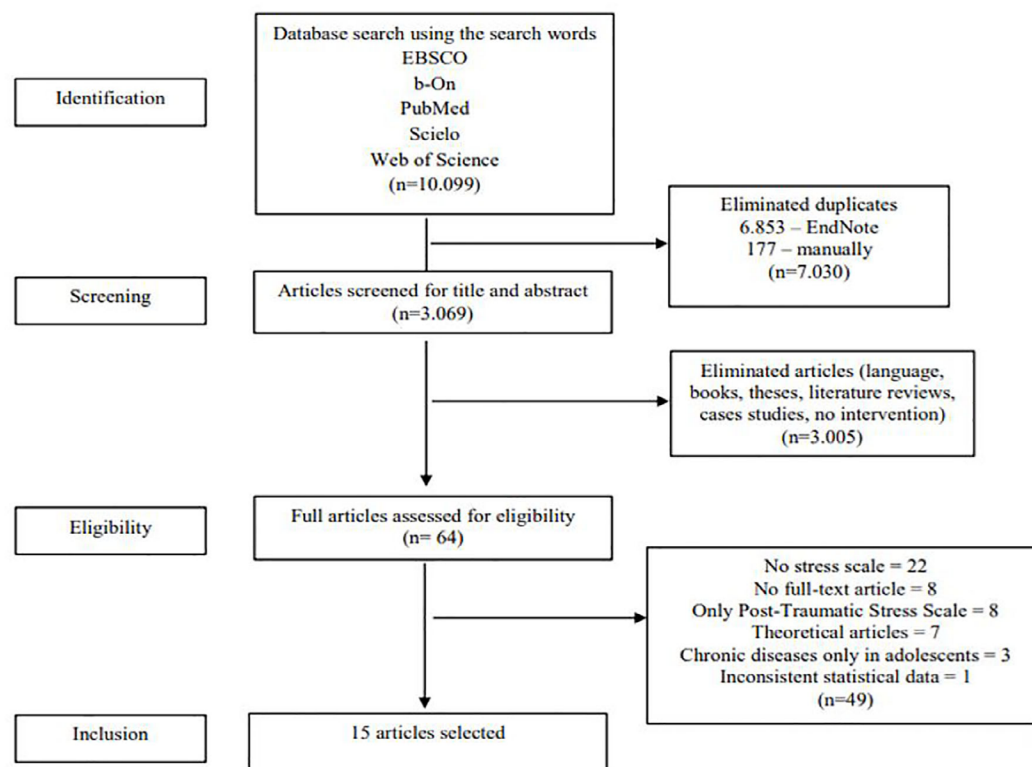


Figure 1. Flow diagram of the screening and selection process of articles

Of the four child diseases included in the review (cancer, diabetes, asthma and cardiovascular diseases), six articles (n=6; 40%) referred to children with a cancer diagnosis, four articles (n=4; 27%) included children with diabetes, two articles (n=2; 13%) included children with cancer or cardiac surgery urgency, two studies (n=2; 13%) referred to children with asthma and one study (n=1; 7%) included children with a variety of chronic diseases, with the most common diagnoses being asthma and diabetes.

Was found a variety in relation to the children's age (between 0 and 18 years), although the search words were limited to childhood, children and pediatric. Given this date, the age included childhood in all studies, but also adolescence in some of them.

With respect to intervention modalities, twelve (n=12; 80%) were delivered face-to-face, in settings such as hospitals and ambulatories, with one of these performed in participants' residences. Three interventions (n=3; 20%) were delivered remotely, using resources such as videoconference and telephone. In some interventions, besides the face-to-face sessions, follow-up telephone connections were established.

Nine studies (n=9; 60%) presented individual interventions and six studies (n=6; 40%) delivered group interventions.

Overall Interventions' Characteristics

Different approaches were used in the interventions. Some interventions included in their programs health promotion, mindfulness, acceptance and commitment therapy, family empowerment, psychosocial models, behavioral theory and stress inoculation. Among the strategies and techniques utilized, the following were identified: psychoeducation (e.g., information about the child disease), breathing and relaxation techniques, communication skills, identification of stressful situations, conflict resolution, parental strategies (e.g., strengthening of disease-related education skills), coping strategies, and parental and caregiver support.

Intervention efficacy in relation to stress

To assess intervention efficacy, the stress measurement instrument used in each study was taken as reference.

Of the 15 selected studies, eight (n=8; 53%) found no significant differences in stress levels or found no significant differences between the intervention group and the control group; six studies (n=6; 40%) showed a significant decrease in participants' stress levels; and one study (n=1; 7%) presented mixed results, with improvements in some emotional dimensions, but not others, which remained unchanged.

With this classification regarding the results in mind, specific study characteristics follow:

Studies that found no significant differences in stress levels or that found no significant differences between the intervention group and the control group

Were selected 8 studies^{17, 19, 20, 22, 23, 24, 25, 27}.

Five investigations (n=5; 62,5%) presented stress as a

primary outcome and three (n=3; 37%) as a secondary outcome. With regards to design, seven (n=7; 87,5%) were RCTs and 1 (n=1; 12,5%) was not an RCT. Six studies (n=6; 75%) performed three or more assessments (pre-test, post-test and follow-up) and two studies (n=2; 25%) performed only two (pre-test and post-test). On sample characteristics, four articles (n=4; 50%) included parents (fathers and mothers), two (n=2; 25%) included only mothers, one (n=1; 12,5%) included parents and family members, and one (n=1; 12,5%) also included the children as participants, besides the parents and the family members.

With respect to child diagnosis, in four studies (n=4; 50%) the children had a cancer diagnosis, in two (n=2; 25%) the children were diagnosed with diabetes, in one study (n=1; 12,5%) the children had cancer or urgency for cardiac surgery, and in one study (n=1; 12,5%) the children had asthma.

Regarding intervention modalities, five of the interventions (n=5; 62,5%) were performed individually and three (n=3; 37,5%) were performed in group. Intervention format was either face-to-face (n=5; 62,5%) or remote (n=3; 37,5%).

Studies that showed a significant decrease in stress levels

Were selected 6 studies^{5, 16, 21, 26, 28, 29}.

All studies (n=6; 100%) presented stress as a primary outcome. In relation to study design, three (n=3; 50%) were RCTs and three (n=3; 50%) were not RCTs. Four investigations (n=4; 67%) performed only two assessments (pre-test and post-test) and two investigations (n=2; 33%) performed three (pre-test, post-test and follow-up). Regarding sample characteristics, four studies (n=4; 67%) were performed with parents (fathers and mothers) and two (n=2; 33%) with parents and family members.

With regards to child diagnosis, in two studies (n=2; 33,2%) the children presented diabetes, in one (n=1; 16,7%) they were diagnosed with cancer, in one (n=1; 16,7%) they either had a cancer diagnosis or urgency for cardiac surgery, in one (n=1; 16,7%) children had asthma, and in one (n=1; 16,7%) they presented a series of chronic disease (the most common being asthma and diabetes).

With respect to intervention modality, all interventions (n=6; 100%) were delivered face-to-face, with three (n=3; 50%) being delivered in a group format and the remaining three (n=3; 50%) in an individual format.

Study presenting mixed results (improvements in some emotional dimensions and no alterations in others)

Was selected 1 study¹⁸. This intervention had stress as primary outcome and was performed with parents (fathers and mothers) of children with cancer. This study was not a RCT, employed four assessments, and delivered the intervention both face-to-face and individually.

A summary of the studies is presented in Table 1.

Quality Assessment

Inter-rater reliability was explored using Cohen's Kappa, which revealed a substantial reliability ($k = 0,819$).

A summary of the quality assessment of studies is presented in Table 2.

DISCUSSION

With stress measurements as a reference, the selected interventions presented varied results (with reductions in stress levels, no significant differences in stress levels, or mixed results, with some emotional dimensions improved and other unchanged). Studies also varied in relation to: study aim, results regarding the variable stress, RCT or non-RCT, number of assessments, stress measurement instruments, sample characteristics and intervention modalities.

Although the majority of investigations presented stress as a primary outcome, it should be noted that the three investigations which presented stress as a secondary outcome (all RCT) didn't show significant reductions in stress levels. This could indicate that these interventions were designed to affect variables, other than stress, eventually diluting their effect on this symptom.

Of all analysed studies, the majority constituted RCTs, including a control group, participants' randomization and assessments in three or more moments (pre-test, post-test and follow-up). It was thus observed that most non-RCT studies presented positive effects, with decreases in stress levels, while the RCT's did not showed in the majority this stress level reduction. It is relevant to highlight that RCT's allow the assessment of efficacy, given the presence of a control group, essential to compare and discriminate results caused by treatments and interventions³⁰.

Regarding the interventions' design, it was also observed that from all the studies which included two assessments (pre-test and post-test) the majority presented positive effects with reductions in stress levels. Thus, in general, the majority of non-RCTs and studies that applied only two assessments (without follow-ups) presented positive results in stress reduction. Therefore, the evidences about the efficacy of these interventions in reducing the caregivers stress is fragile and insufficient to determine the sustainability of the results in the long term.

Regarding the study samples, interventions included fathers, mothers and family members (and even included the children themselves). However, the majority of participants were female. Although nowadays there's a shift in caregiver gender roles, caregiving is still predominantly delivered by women. According to Silver, Stein and Dadds³¹, in their study on family structure and physical and mental health of children with chronic diseases, stated that mothers are usually more involved in the treatment process, going more often to the hospital and interacting more frequently with the healthcare team.

In relation to child diagnosis, the results of the interven-

tions varied, with studies of children with cancer presenting more frequently non-significant results with regards to the reduction of stress levels on the parents. This could be attributed to the differences between the diagnosis and the associated phenomena. Although the four child diseases selected in this study are classified as chronic, each possesses its own particularities in relation to stages of evolution, risk of death, necessary treatments and caregiving requirements from the parents. As such, it is necessary to consider such specificities in intervention elaboration and delivery, as well as in the analysis of results with regards to reduction/lack of alteration of stress levels among parents and caregivers.

Despite the diversity of the content of the interventions, the majority (80%) approached information on the disease (diagnosis, medical procedures, treatments and parental/caregiver involvement). This emphasizes the importance of knowledge on the disease and its management from behalf of the caregivers. In a review article, Vaz and colleagues³² reported the need for the family to receive information about the disease and highlighted that parents reported as beneficial receiving information about the chronic disease, highlighting the importance of education programs to promote parental understanding and better childcare. Access to information might have, in itself, a positive impact on stress levels, since information sharing promotes coping strategies and develops skills to experience the disease, with information playing a major role in disease management³³.

The evidence indicate that interventions which only provide information on the child disease are effective in reducing stress, and that interventions which focus exclusively on relaxation techniques also reduce these symptoms in parents, however, it was observed is this research that studies which combine both approaches (relaxation training and information about the disease and its treatments: 5 investigations) were not efficient in reducing stress. Namely, it should be noted that 4 of these 5 studies included parents of children with cancer, which again brings up attention to the specificity of this diagnosis and to the possible difficulty in attenuating these symptoms, due to this disease's characteristics. This result demands, in future studies, a reflection on the nature of interventions adequate to these families, given that these might require tailored intervention, specifically considering the diseases' particularities, for example, crises intervention³⁴. Another result that stands out is the fact that, of the seven investigations that focused on parents of children with cancer, only two presented attenuation of stress levels.

In our analysis, the majority of interventions was delivered face-to-face, with most of these (58%) presenting significant results and one mixed result. Of the three interventions delivered remotely, none found significant differences on the levels of stress over time. Group interventions didn't show differences in relation to their efficacy (50% positive results, 50% non-significant results). Conversely, 56% of the interventions performed individually didn't present significant results

Study (Author/Year)	Sample (N) (Gender/Age)	Diagnosis (Time/Age of the child)	Design	Intervention	Measure of stress	Pre-intervention stress levels	Outcomes (stress)
Burke et al., 2014 ¹⁶	11 parents Age: n/p	Children with cancer diagnosis or life-saving cardiac surgery and had passed the acute adjustment period (3 months) after diagnosis or surgery. Time since diagnosis (months) M(SD) Oncology - 25.5 (25.3) Cardiology (time since surgery) - 8.2 (2.9) Age: n/p	Non-RCT Assessment: pre-post design with a 6-month follow-up	Take A Breath (TAB), for parents of child diagnosed with a life-threatening illness (LTI) Sessions: Session 1: Overview of the program, the rationale and learning objectives. Personal story sharing (child's diagnosis and treatment). Session 2: Information, skills and exercises designed to increase the Awareness. Core ACT (Acceptance Commitment Therapy) processes. Exploration of the current coping strategies. Session 3: Core ACT processes. Identification of Values and Values-related goals setting. Session 4: Problem Solving. Action planning to implement during the 1-month break before the next session. Session 5: Progress assessment and actions setting and plans for continuing to practice what they have learnt. TAB strategies and ideas application to their current challenges.	Parent Experience of Child Illness (PECI)	M(SD) Guilt & Worry - 2.36 (0.54) Emotional resources - 2.30 (0.43) Unresolved Sorry & Anger - 2.28 (0.45) Long-term uncertainty - 2.20 (0.49)	Parent's distress decreased significantly from pre- to post-intervention assessment, namely, guilt and worry, unresolved sorrow and anger, and long-term uncertainty decreased; on the other hand, emotional resources increased.
Celano et al., 2012 ¹⁷	41 families (children and caregivers) 85% mothers Intervention group (n=21)	Children with poorly controlled asthma Time since diagnosis: diagnosed with asthma for more than a year.	RCT Baseline assessments occurred on average of 11 weeks later in the family's home. Families were randomly assigned to the HBFI or the control group by blocked randomization within age group (8 to 10 vs. 11 to 13). Assessments: baseline, post intervention (4 months following the first home visit) and a 6-month follow-up.	Content on asthma management was adapted from the National Cooperative Inner City Asthma Study intervention. The Home-based Family Intervention (HBFI) consisted of four to six meetings (conducted at the home of the participants), over a period of 4 months, and the content included an introduction, eight modules on asthma management, and another eight modules on psychosocial dimensions (e.g., caregiver stress, rules and discipline, communication). The intervention promoted control over asthma triggers at the first visit and provided feedback on the child's respiratory function and MDI/spacer technique at all visits. The existence of a written asthma action plan was implemented. Furthermore, families were asked to choose three to four goals corresponding to the prepared modules (at least two should be focused on asthma management, and one to two related to psychosocial domains). In the following sessions, the chosen modules served to work the family's specific goals. The Enhanced Treatment as Usual (ETAU) consisted of one single home visit, during which a trigger control examination, feedback on the child's lung functioning, and metered dose inhaler (MDI)/spacer technique, and implemented the written asthma action plan.	Parenting Stress Index-Short Form (PSI-SF) Brief Symptom Inventory (BSI)	PSI (SF) Intervention group - 82.4 Control group - 82.6 BSI Intervention group - 58.0 Control group - 55.0	Caregiver stress improved both from baseline to post-intervention assessment, and from Baseline to follow-up. This decrease was observed in both groups (intervention and control) and there were no differential treatment effect.

Henricks-Ferguson et al., 2017 ¹⁸	13 parents of 11 children Mothers - 85.7% Fathers - 14.3% Age: n/p	Cancer (brain tumour diagnosis with poor prognosis). Time since diagnosis: overall survival rate of less than 50% at 3 years after diagnosis.	Non-RCT The study was prospective, longitudinal and single-group pilot study.	"Communication Plan: Early through End of Life (COMPLETE)" The program was delivered to parents of children newly diagnosed with a brain tumour. The framework includes information/components such as: 1 - Clinical information related to Stress Events (Brain Tumour Diagnosis; Prognosis - Treatment Plan;	Parent Experience of Child Illness - Short Form (PECI)	Guilt & Worry - 2.75±0.14 Unresolved Sorry & Anger - 2.51±0.15 Long-term uncertainty - 2.48±0.22 Emotional resources - 2.20±0.17	Mixed responses to parents' distress were found, with parental guilt and worry showing a decreasing trend over time at a marginal level of significance, but with unresolved sorrow and anger showing no significant difference over time. On the other hand, participants' self-reported long-term uncertainty decreased significantly and hope increased significantly over time.
Mackey et al., 2016 ¹⁹	30 mothers Intervention group (n=16) Control group (n=14) Age M(SD): 33.64 (6.66)	Type 1 diabetes Time since diagnosis: diagnosed for less than 6 months Age M (SD): 4.49 (1.71)	RCT - Baseline questionnaires via phone. Participants met with one of the study counselors for an introduction session, in which the investigation procedures were discussed. There was the realization of an interview.	2 - Parental Appraisal of Stressors (e.g., Preferences for Receiving Information; Emotional Resources and Emotional Needs) 3- Communication through the COMPLETE Intervention (e.g., Tailored Discussions based on Preferences to Receive Information; Ongoing Review of Treatment Options and Goals of Care); - Outcomes - Parents (e.g., distress; uncertainty; hope); - Outcomes - Providers (e.g., RN/MD Satisfaction with COMPLETE; RN/MD Perceived Competence in PC/EOL Communication).	Pediatric Inventory for parents (PIP)	M(SD) Intervention group - 94.66 (24.36) Control group - 85.93 (24.36)	The results of the study show that the intervention had no significant effects on parenting stress.

Marsland et al., 2013 ²⁰	37 primary caregivers (mother, father, and grandmother) Intervention group (n=23) Female -91.3% Standard care control (n=14) Female -100%	Children newly diagnosed with non-central nervous system (non-CNS) cancer that required chemotherapy, had a life expectancy of >4 months. Time since diagnosis (days)M(SD): Interventions: 24 (15.4); range: 5-56 Standard care control group – 25 (14); range: 4-55	RCT Assessments pre-intervention (T1 – mean = 24 days post-diagnosis) and post-intervention (T2 – mean=165 days post-diagnosis)	Session 4: Group phone call with other participants to provide additional social support to parents. Session 5: Review of the previous calls and discussion on the importance of parental self-care and well-being. The comparison group received 5 phone calls that focused on physical activity and general child safety while being physically active.	Perceived stress scale (PSS)	Intervention group – 28.4 (7.2) Control group – 29.3 (9.4)	There was no significant effect of the intervention, on participants stress levels at T2.
Méndez et al., 1997 ²¹	38 parents Experimental group (n=19) Treatment as usual group (n=19) Age: Experimental group: 38,421 ± 5,092 years Treatment as usual group: 36,053 ± 5,532 years	Diabetes mellitus insulin dependent Time since diagnosis – At least 1 year Age: GE – 8,652 ± 3,059 TAU – 8,359 ± 3,046	RCT Experimental treatment vs. Treatment as usual Assessments: pre- and post-test	The intervention entailed 6 weekly group sessions (60 minutes each). 1 st session: information regarding the stress response and particular stress related with their children diabetes. Relaxation techniques. 2 nd session: Progressive muscle relaxation, in-depth breathing and imagnetic technique. 3 rd session: Tension-distension of 4 body groups with breathing and imagnetic techniques. Self-instructions training: identification of negative thoughts emerging in stressful situations, and their disputing and successful change. 4 th session: Tension-distension of 4 body groups technique. Discussion of daily stressful situation and possible coping responses 5 th session: Overall body relaxation and role-play of stressful situations management related with diabetes. 6 th session: Overall body relaxation incorporating the identification of a relaxation sign. Imagnetic self-instructions training.	Escala de Contratiempos Cotidianos en la Diabetes – translation and adaptation Diabetic Hassles Scale (DDHS)	Experimental treatment -	There was a decrease in both the number of (general and treatment-related) stressors identified, and perceived severity of these stressors, when comparing the pre- with the post-intervention assessment.

Minor et al., 2006 ⁵	44 caregivers (parents and one grandparent) Male – 6 Female – 38 M(SD): n/p. Age classes: Age (years) (%): 19-30 (9.3%) 31-45 (69.8%) 46-60 (18.6%) above 60 (2.3%)	Diabetes and asthma (which were the most common), epilepsy, Down's syndrome, Crohn's disease, colitis, irritable bowel syndrome, cancer, and attention deficit disorder. Time since diagnosis: 7 years Age (years) (%): 13-18 (39.5%) 3-6 (30.2%)	Non-RCT Seven cohorts of participants were run over the study duration. Assessment: interview (T1) and the last class, eight weeks later (T2)	The program was modelled on the Mindfulness-Based Stress Reduction (MBSR) program, with the addition of the primary yoga series. 8 weekly group sessions with 2-hour duration. Content: Week 1: Introduction; Mindfulness attitudes, meditation technique body-scan and sitting meditation. Week 2: Introduction of walking meditation and eating meditation. Week 3: Lying yoga; longer sitting meditation. Week 4: Visualization meditation; use of stress symptoms self-assessment. Week 5: Responding mindfully to stressful situations. How to work with fear, panic, and anxiety. Visualization-based meditation. "Difficult Communication" checklist. Week 6: Mindful attitude within stressful communication. Exploration of feelings of helplessness or uncertainty. Standing yoga. Week 7: Mindfulness in everyday life, in addition to the techniques implementation. Week 8: Meditation supported by a minimum of instructions, add contents the previous sessions. A program manual, and two CDs were produced. Participants were instructed to practice for 45 minutes, 6 days a week, during the program.	Symptoms of stress inventory (SOSI)	110.11 (58.85)	The MBSR program for caregivers of chronically ill children was successful in significantly decreasing stress symptoms. Therefore, there was a 32% decrease in SOSI total score; additionally, all stress-related symptoms assessed (e.g., gastrointestinal, muscle tension, emotional irritability) have shown a significant attenuation.
Othman et al., 2010 ²²	79 parents (60% mothers) Intervention group (n=41) Control group (n=38) Age: n/p	Cancer (leukemia in majority; 66%) Time since diagnosis: period of 7-36 months. Age M: 8.03	RCT Parents attending programs in the first month of the study period - intervention group. Attending in the latter months - wait-list/control. Two assessments: a pre and a post (4-8 weeks after the program/pre-assessment).	The Psycho-educational Program (PeP) consisted of 4 group psycho-educational sessions with a 50-minute duration. Aimed to improve parents' knowledge on childhood cancer; increase parents' psychological awareness and acceptance to diagnosis; recommend coping strategies and decrease their levels of anxiety and stress. Domains/Content: Introduction: definition, types, causes, and symptoms. Treatment: types, side effects, and management. Parental reactions: stress and grief symptoms, coping strategies. Children reactions: strategies directed to children to promote a better coping. Relaxation technique: deep breathing. Groups: Intervention group - standard care + 4 sessions. Control group - standard care.	Strain Questionnaires (SQ)	M(SD) Intervention group - 81.0 (20.5) Control group - 95.2 (36.5)	The PeP showed significant effects at reducing stress.
Rayner et al., 2016 ²³	12 parents Female - 8 Male (partners) - 4 Age M (SD): Female: 40.2 (6.7) Male (partners): 36.0 (3.6)	Cancer diagnosis (5) or requiring life-saving cardiac surgery within the first month of life (3). Time since diagnosis (months) M(SD): 43.9 (34.4)	Non-RCT Inclusion criteria: parents who had elevated psychological distress within 4 weeks of their child's initial hospital admission.	"Take A Breath" (TAB) is a five-session group intervention, delivered online. Content as described in article above (Burke et al., 2014).	Depression Anxiety and Stress Scales (DASS) Parent Experience of Child Illness (PECI)	DASS - M(SD) 12.42 (8.86) PECI Worry - 1.62 (0.85) Emotional resources - 2.74 (0.66)	Changes were significant for guilt and worry and unresolved sorrow/anger, which showed a decrease in stress symptoms. Parents showed small, non-significant change over time.

		Age at diagnosis(mon- ths) M (SD): 31.4 (32.6) Age: n/p	Assessment: pre-post designwith 6-month follow-up.			Unresolved Sorry & Anger -1.56 (0.90) Uncertainty -1.52 (0.96)	
Saßmannet al., 2012 ²⁴	65 parents Mothers -33 Fathers - 32 Intervention group (n=37) Controlgroup (n=28) Age M (SD): Intervention 39.1 (3.3) Father: 43.3 (5.5) Control group Mother: 40.4 (3.8) Father: 42.4 (6.5)	Type 1 diabetes Time since diagnosis (years): Intervention group Mean 2.6 (SD 1.6) Control groupMean 2.6 (SD 1.9) Age (years): Intervention group: M=6.4(SD 2.3) Control group: M=5.8 (SD 1.9)	RCT Thirty-seven families were assigned to the DELFIN intervention or to a waiting-list(control group)by simple random- ization (1:1 allocation ratio). Assessments: baseline, post- intervention (3 months later) and the intervention group completeda 12-month follow-up evaluation.	The program DELFIN – Das Elterntaining fürEltern von Kindern mit Diabetes Type 1 (The parenting program for parents of chil- dren with diabetes type 1) is a structured group intervention for parents based on behavioral principles to strengthen their gene- ral and diabetes-related competences. Groups includedup to 7 families (2-hour weekly session, duringa 5-week period). Sessions: First session: focused dysfunctional cognitions,goal setting and communication skills. Second session: strategies to develop a positiverelationship with children; role play exercised to improve communication skills. Homework included among identifying skills to solve family conflicts. Fourth and Fifth Sessions: practical skill training directly related with the management of the chronic disease (e.g., catheter insertion, injection, blood glucose measurement). These sessions also addressed age-specific challenges (e.g., temper tantrums) and role plays were used to practice several strategies.	Depression, anxiety and stress scales (DASS)	M (SD) Intervention group – 25.5 (15.2) Control group –21.9 (15.4)	Parents' stress at the post- intervention assessment (3 mon- ths) did not decre- ased significantly in the DELFIN group, although itimproved surprisingly in the control group. There were no signi- ficant time xgroup. At the 12-month follow-up, no sig- nificant differences were detected, compared to the measures at 3 mon- ths ($p>.05$).

Streisand et al., 2000 ²⁵	22 mothers Intervention group (n=11) Standard Care (n=11) Age M(SD): Intervention group: 37.2 (5.2) Standard Care: 36.5 (8.5)	Children scheduled to undergo inpatient BMT (bone marrow transplantation) Time since diagnosis (months): Intervention -11.0 Standard Care -10.8 Age: M (SD) Intervention 9.4 (4.5) Standard Care 8.0 (5.2) Range: 2-16 years	RCT Controlled pilot study (intervention groups vs. Standard care) Assessment Pre-admission, day -7, day 0, day +7, day +14, and day +21	A one-session treatment format (90-minute duration), typically held within 1 week of the child's admission to the bone marrow transplantation unit (range 0-30 days prior to admission). The intervention followed a stress inoculation model, including three main components: education, relaxation, and communication. Participants received handouts illustrating the components of the intervention through concrete examples, as well as a tape-player headset to increase their likelihood of practicing the relaxation training. DSI Intervention group Impact - 26.0 ± 20.2 Event - 11.1 ± 6.1 Control group Impact - 234.9 ± 36.3 Event - 12.8 ± 9.2	Daily stress inventory (DSI) Parenting stress index (PSI) Semi-structured Interview (SSINT)	DSI Intervention group: Impact - 26.0 ± 20.2 Event - 11.1 ± 6.1 Control group Impact - 234.9 ± 36.3 Event - 12.8 ± 9.2 Specific stress - 16.5 ± 7.5 Control group Frequency - 9.5 ± 6.8 Specific stress - 12.0 ± 5.2	There were significant changes in stress over time, with highest stress levels being reported at pre-admission. Mothers in the intervention condition reported using more stress management techniques than in the standard care. However, there were no significant differences in stress between the intervention and standard care groups.
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Tsiouli et al., 2014 ²⁶	44 parents Intervention group (n=19) Women - 15 Men - 4 Control group (n=25) Women - 20 Men - 5 Age M (range): Intervention group 43.95 (36-65) Control group: 42.60 (31-56)	Type 1 diabetes Time since diagnosis: more than six months Age: Children/adolescents younger than 18 years old	RCT The 80 participants who met the criteria were first randomized (by using the web random number generator) and then assigned to intervention and control groups. The final sample of the study consisted of 44 individuals. Assessments: Baseline and two months after the intervention.	Stress management program included progressive muscle relaxation combined with diaphragmatic breathing, with the support of an audio CD, and performed during individual sessions (with a duration of 37 min). The subjects were given material containing instructions on exercising the relaxation techniques and were asked to practice them twice a day, during eight weeks. A weekly telephone call was planned to assess adherence. In this session, participants were instructed to adapt a healthy lifestyle (healthy diet and physical exercise). They were also asked to perform positive health behaviors for the following two months (based on the Hellenic Cardiologist Society and the Hellenic Dietetic Association guidelines). Information about the connection between stress and lifestyle was given. Participants in the control group were instructed in implementing a healthy lifestyle (healthy diet and physical activity) and a written support was given, similar to the intervention group. Their adherence during the two-month period was not assessed (by weekly telephone call). Nonetheless, could call the research team, if they wish.	Salivary Cortisol (5 cortisol samples) Perceived stress scale (PSS) Parenting stress index - short form (PSI-SF)	Cortisol (8.00-21.00) M(SD) Intervention group - 0.203 (0.109) Control group - 0.205 (0.151) PSS - M (SD) Intervention group - 27.21 (7.65) Control group - 27.24 (7.70) PSI-SF - M(SD) Intervention group - 85.79 (18.08) Control group - 79.76 (20.21)	A significant decrease in both perceived stress and parenting stress was observed in the intervention group. The two groups (intervention and control) showed a significant difference in perceived stress at the second assessment. No significant difference was detected between or within the groups in cortisol levels.
Wakefield et al., 2016 ²⁷	45 parents Intervention group (n=23) Male - 2 Female - 21 Control group (n=22) Male - 4 Female - 18 Age M(SD): Intervention group: 42.00 (5.76) Control group: 42.77 (5.21)	Cancer Time since diagnosis (years): M (SD) Cascade: 2.93 (2.14) Waitlist control: 2.25 (1.06) 15 years or younger who had completed cancer treatment with curative intent in the past 5 years.	RCT Recruitment took place during 4x12-week blocks, with approximately 50 parents being invited 4 weeks before the first week of each block. Blinding occurred only for statisticians. Parents of the same families were enrolled in different groups, in the same condition. Assessment: Baseline, 1-2 weeks and 6 months post-intervention.	The Cascade programme (Cope, Adapt, Survive: Life after Cancer) consists of three weekly 120-minute online sessions delivered via WebEx (Cisco WebEx, USA). Cascade consists on a synchronous e-mental health intervention, since it is delivered "live", in real time, by a psychologist, and it derives from the models of Uncertainty in Illness and Family Systems-Illness. As such, it focuses specifically on intra- and interpersonal psychological processes relevant to illness adaptation, including constructive appraisal (or acceptance) of uncertainty, practical problem-solving, and mobilization of social support resources. These central mechanisms of change were targeted using evidence-based cognitive-behavioral therapy (CBT) strategies, tailoring each recommended strategy cancer-specific concerns. After a period of 6 months, parents enrolled in the waitlist group were invited to participate in cascade. Technical equipment and Internet access were provided to parents who expressed such needs.	Depression Anxiety Stress Scales short form (DASS-21)	Intervention group - 14.89 (8.15) Waitlist control - 13.88 (8.18)	No significant main effect was found for group (i.e., waitlist vs. intervention) or time (i.e., baseline vs. post-intervention vs. follow-up) on the measures of psychological functioning (stress).

Warner et al., 2011 ²⁸	5 parents Mother – 4 Father – 1 Age: n/p	Children with acute lymphoblastic leukemia and one with neuroblastoma Time since diagnosis: children were an average of 3.5 months post-diagnosis (SD = 2.7 months, range = 1-8 months) Age M (SD): 6.3 (6.3)	Non-RCT Assessments: the evaluations were completed prior to and immediately after the program.	The intervention was mostly based on Surviving Cancer Competently Intervention Program – Newly Diagnosed (SCCIP-ND). However, minor modifications were made. Summarily, caregivers were trained to identify and reframe their beliefs about cancer adversities with the goal of modifying undesirable emotional, behavioral and relational consequences. The intervention also aimed to assist parents in anticipating the impact of cancer on their family over time and the ways in which the skills developed throughout the treatment would be integrated in the future. In order to normalize parents' reactions and foster discussion about their beliefs, three sessions incorporated a multiple-family discussion group video that displayed a group of parents of children with cancer discussing their experiences and responses to cancer diagnosis.	Distress thermometer (DT)	M (SD) 6.5 (1.7)	Results showed decreased level of parents' distress. Four of the 5 participants exhibited reduced overall distress levels, with scores on the distress thermometer decreasing significantly after the intervention.
Yeh et al., 2016 ²⁹	65 families Experimental Group (n=34) Father – 7 Mother – 26 Others – 1	Moderate-to-severe asthma Time since diagnosis: at least six months prior to the study.	RCT Assessment: baseline, and 3-month and 1-year follow-ups.	The Asthma Family Empowerment Program. In the 16 weeks, AFEP was delivered in a four-monthly session format (each session 50 min) to a primary family caregiver. The research initiated each individual family to address problem themselves after the dialogues. The families were encouraged to choose alternatives or problem solving ideas after family discussions. Finally, the nurse reinforced their decision making, confirming	Parental stress index (PSI)	M (SD) Intervention group - 229.88 (46.018) Control group - 220.13 (25.98)	The average score of the PSI was significantly reduced from baseline, to three months, to one year in the experimental group compared with the
	Comparison Group (n=31) Father – 2 Mother – 27 Others – 2 Age (y/o): Experimental Group: 25-35 – 11 36-45 – 20 ≥46 – 3 Comparison Group: 25-35 – 12 36-45 – 18 ≥46 – 1	Age (y/o) - n Experimental Group 6 – 13 7 – 6 8 – 4 9 – 3 10 – 5 11 – 2 12 – 1 Comparison Group 6 – 10 7 – 2 8 – 5 9 – 7 10 – 2 11 – 3 12 – 2	RCT Assessment: baseline, and 3-month and 1-year follow-ups.	successful family asthma management, and helped the family member to test and act out their solutions. Sessions / Aims: Session 1 - Family identification. Session 2 - Posing problems and conflict in the family. Session 3 - Engaging in dialogue and critical thinking. Session 4 - Implementing knowledge and acting out. Both groups participants (experimental and control) received an asthma self-management educational pack with the asthma diary, the asthma education booklet, a CD about asthma, and a peak flow meter. The families in the comparison group only received the regular asthma self-management in the asthma clinic.			comparison group at baseline, and three months and one-year follow-up. The family empowerment program decreased parental stress.

assessment of studies using a verification list adapted from the Cochrane Handbook for Systematic Reviews of Interventions.

Article	Questions																												
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29
Burke et al., 2014 ¹⁶ , Australia.	2	3	2	2	2	0	0	2	2	0	2	-	-	-	0	1	0	3	2	2	2	2	2	2	1	2	0	0	0
Celano et al., 2012 ¹⁷ , USA.	2	2	2	2	1	0	3	0	0	2	2	2	2	2	0	2	2	2	2	1	2	1	2	2	2	2	0	2	0
Hendricks-Ferguson et al., 2017 ¹⁸ , USA.	2	2	2	2	2	0	3	2	0	0	-	-	-	-	0	2	0	3	2	1	3	2	2	2	2	2	0	2	2
Mackey et al., 2016 ¹⁹ , USA.	2	3	2	2	1	0	2	1	2	0	2	0	2	1	2	2	1	3	2	2	3	2	2	2	2	2	0	2	0
Marsland et al., 2013 ²⁰ , USA.	2	3	2	2	1	0	3	2	0	1	2	0	2	2	2	2	1	3	2	2	3	2	2	2	2	2	0	2	2
Méndez et al., 1997 ²¹ , Spain.	2	3	2	2	1	0	2	2	0	0	2	-	-	-	0	2	0	0	2	2	3	2	2	2	2	1	0	0	0
Minor et al., 2006 ⁵ , Canada.	2	3	2	2	2	0	3	2	0	-	2	-	-	-	2	2	-	1	2	2	3	2	2	2	1	2	0	0	0
Othman et al., 2010 ²² , Malaysia.	2	3	2	2	1	0	2	2	2	2	2	-	-	-	2	2	1	0	2	2	3	2	2	2	2	2	0	2	0
Rayner et al., 2016 ²³ , Australia.	2	2	2	2	2	0	3	2	2	0	2	-	-	-	0	1	-	3	2	2	3	2	2	2	0	2	0	0	0
Salzmänn et al., 2012 ²⁴ , Germany.	2	3	2	2	2	0	2	2	2	2	2	2	2	2	2	2	1	3	2	2	3	2	2	2	1	2	0	0	2
Streisand et al., 2000 ²⁵ , USA.	2	3	2	2	0	0	0	1	2	1	1	0	1	1	0	2	2	0	2	2	3	2	2	2	1	2	0	2	0
Tsiouli et al., 2014 ²⁶ , Greece	2	2	2	2	2	0	1	1	2	2	2	2	2	2	0	2	1	3	2	0	3	2	2	2	2	2	0	0	0
Wakefield et al., 2016 ²⁷ , Australia.	2	3	2	1	1	0	3	2	2	2	2	1	2	2	0	2	2	3	2	1	3	2	2	2	0	2	2	2	0
Warner et al., 2011 ²⁸ , USA.	2	2	2	2	2	0	2	0	2	-	1	-	-	-	2	1	-	0	1	1	2	2	2	2	0	2	0	2	2
Yeh et al., 2016 ²⁹ , Taiwan	2	2	2	1	0	2	3	1	2	2	2	2	2	2	2	2	0	3	2	2	3	2	2	2	0	2	0	2	2

Notes: 0 - Not done or not reported; 1 - Done but unclear and/or reported to some extent; 2 - Adequately done and/or adequately report with more information; 3 - Adequately done with more information and/or adequately report with more information.

Source: Hawker et al. (2002)¹³; Higgins and Green (2006)¹⁴; and Higgins and Green (2011)¹⁵.

and 11% presented mixed results. These observations might point to the importance of the therapeutic relationship built in a face-to-face setting and the bond established between the professional and the participant, and also among participants (in the case of group interventions). Studies indicate that group interventions offer emotional support to caregivers, a feeling of universality (perception that other mothers share the same difficulties and suffering) and create a space for dealing with emotional issues and with the burden of caregiving^{35, 36, 37}.

It becomes important to consider that the aim of the present study was to assess the efficacy of programs focused on stress management; in this way, considering the diversity of studies and observations noted, it became possible to analyse the results of interventions focusing only on the variable stress. In order to assess and quantify the efficacy of interventions among studies in a broader way, other analysis would be required, which goes beyond the scope of this review.

Strengths and limitations

A limitation inherent to scoping reviews is that these present a certain theme in amplitude, and not depth. However, this study contributed to the broadening of knowledge regarding interventions among these populations; furthermore, the results presented here might contribute to possible applications of interventions in this area.

The size and diversity of the samples with respect to chronic child diseases and interventions design might influence the result and efficacy of the interventions with relation to the variable stress, focus of the present study. However, the analysis of these interventions potentially contributes to a better knowledge of this theme and informs clinical practice.

Additionally, a wide range of instruments that measured stress was verified, which may have affected the comparison between studies/interventions. Although each instrument was aligned with each study's goal, conceptual differences regarding stress were identified, with such variations as: general stress, parental stress and child disease-related stress. Despite this important conceptual specificity of each study, our research analysed the results based on the measures of stress presented in each study.

A limitation of the study is the variety of the age groups of the participants' children (the age included childhood in all studies, but also adolescence in some of them). Despite considering the specifications and characteristics of the ages, such studies were included because their exclusion would cause losses for our sample.

CONCLUSIONS

The limited number of articles found in this review reflect the need for more studies in this area.

Though this study portrays effective interventions on reducing the levels of stress on parents/caregivers of children with chronic diseases, research that state stress as the main

variable in study is scarce.

The scarce literature emphasises the need to develop RCT's and similar interventions in order to demonstrate their efficacy and, consequently, to become useful in clinical contexts to aid parents and caregivers of children with chronic diseases.

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