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Coping with child's disease by children and their parents (guardians) – a systematic review of the literature

Radzenie sobie dzieci i ich rodziców (opiekunów) z chorobą dziecka – systematyczny przegląd piśmiennictwa

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STRESZCZENIE

RADZENIE SOBIE DZIECI I ICH RODZICÓW (OPIEKUNÓW) Z CHOROBĄ DZIECKA – SYSTEMATYCZNY PRZEGLĄD PIŚMIENNICTWA

Wprowadzenie. Choroba jest stresującym doświadczeniem dla chorego dziecka oraz jego rodziców/ opiekunów. Radzenie sobie oraz badanie określonych zachowań radzenia sobie rodziców i dzieci z chorobą są istotnym elementem opieki.

Cel pracy. Przedstawienie dostępnych wyników badań w języku angielskim i/lub polskim realizowanych przez badaczy w zakresie strategii radzenia sobie dzieci i ich rodziców/opiekunów z chorobą dziecka.

Materiał i metody. Przegląd systematyczny został przeprowadzony zgodnie z oświadczeniem Preferred Reporting Items for Systematic Review and Meta Analyzes (PRISMA 2020). Elektroniczne bazy danych przeszukane w maju 2021 r. obejmowały PubMed, Scopus i Web of Science. Ograniczenia metodologiczne wykazano przy użyciu pakietu check-lists przeznaczonego do oceny literatury medycznej (Critical Skills Appraisal Program – CASP). Do analizy zakwalifikowano 42 artykuły.

Wyniki. Analiza publikacji wykazała, że dzieci i ich rodzice najczęściej radzą sobie z chorobą poprzez wsparcie społeczne, aktywne radzenie sobie, radzenie skoncentrowane na emocjach, odwoływanie się do religii oraz unikanie.

Wnioski. Świadome stosowanie strategii radzenia sobie może przyczyniać się do lepszych wyników w podjętym leczeniu i pozwolić dziecku oraz jego rodzicom poczuć kontrolę nad sytuacją stresową w jakiej się znaleźli. Wiedza o strategiach radzenia sobie stosowanych przez rodziców i dziecko może być pomocna w tworzeniu planów opieki nad dzieckiem.

Słowa kluczowe: rodzice, opiekun, dziecko, strategie radzenia sobie, choroba przewlekła

ABSTRACT

COPING WITH CHILD'S DISEASE BY CHILDREN AND THEIR PARENTS (GUARDIANS) – A SYSTEMATIC REVIEW OF THE LITERATURE

Introduction. Illness is a stressful experience for a sick child and its parents (guardians). Coping and studying specific coping behaviors of parents and children with the disease are an essential part of care.

Aim. Presentation of available research results in English and/or Polish, carried out by researchers in the field of coping strategies of children and their parents (guardians) with the child's disease.

Material and methods. The systematic review was conducted in accordance with the Preferred Reporting Items for Systematic Review and Meta Analyzes (PRISMA 2020) statement. Electronic databases searched in May 2021 included PubMed, Scopus and Web of Science. Methodological limitations demonstrated using the Critical Skills Appraisal Program (CASP) check-lists package. In total 42 articles were qualified for the analysis.

Results. The analysis of the publications showed that children and their parents most often cope with the disease through social support, active coping, emotional-focused coping, referring to religion and avoidance.

Conclusions. Conscious use of coping strategies may contribute to better results in the treatment undertaken and allow the child and its parents to feel in control of the stressful situation in which they find themselves. Knowing about parents' and child's coping strategies can be helpful in developing childcare plans.

Key words: parents, guardian, child, coping strategies, chronic disease

INTRODUCTION

Coping is defined in the literature as „constantly changing cognitive and behavioral efforts to deal with specific external and internal requirements that are judged to burden or exceed a person's resources" [1]. Chronic health problems are common in childhood and can affect the psychosocial well-being of children and their families. The parents' coping with their child's illness allows them to manage everyday matters and ensure proper care for the child [2]. The health condition of children, caring for them, and disease development can cause stress and emotional problems for parents, such as anxiety or depression [3]. Moreover, parents may experience a range of different emotions, such as guilt, sadness, regret, anger or worry [4]. Research on the chronic disease affecting a child has highlighted the relationship between the caregiver's stress and the health outcomes of the patient (child) [5]. Caregivers pay attention to the responsibility for the course of treatment as the main source of stress; in addition, greater parental stress leads to bad adaptation and affects the outcome of the child's illness. In turn, chronically ill children and adolescents may develop emotional and behavioral problems [6]. The way in which parents deal with their child's disease and how they adapt to a sick child is important for their own emotional and physical well-being, but also for the child's own well-being [3]. The coping strategies used by children and adolescents in the studies are described with the use of the range from passive to adaptive. They can include running away, social withdrawal, distraction, problem solving, seeking support, and active coping. Earlier studies on coping mechanisms in adolescents have shown that adolescents mainly use methods of seeking support and distraction, and that they may depend on the individual and the stressor [7]. The research also provides information that spirituality is an important factor which helps to maintain hope and influences parents caring for a sick child. Moreover, spiritual well-being reduces the parents' uncertainty about the future fate of the child [8]. Knowledge of the coping strategies used by parents and the child may be helpful in developing child nursing care plans [2].

AIM

Presentation of available research results in English and/or Polish, carried out by researchers in the field of coping strategies with the child's disease of children and their parents/guardians.

METHODS

The review was submitted to be registered in the PROSPERO system, was positively assessed and received the number: CRD42021265701. The systematic review was conducted in accordance with the Preferred Reporting Items for Systematic Review and Meta Analyzes (PRISMA 2020) [9]. Electronic databases searched in May 2021 included PubMed, Scopus and Web of Science. The search terms included combinations of PubMed MeSH thesaurus terms and textual terms. The terms child * children * coping * illness * disease * parents * are used in conjunction with the Boolean logical operator. The operator used in this systematic overview is the „AND" operator, which is the product of sets (i.e. their common part).

The other criteria for including the publication in the analysis are presented in Tab. 1.

Tab. 1. Criteria for including an article in the analysis and excluding from the analysis

Inclusion	Criteria for exclusion from the analysis
• language of publication: publication in English and/or Polish • years of publication: works published in 2016-2021 • type of publication: original papers, systematic review, meta-analysis, RCT research • access to the full text of the article • compliance with the adopted combination of keywords	• language of publication: publication in a language other than English and/or Polish • years of publication: works published before 2016 • the type of publication is different than: original papers, systematic review, meta-analysis, RCT research • full text of the article is not available • non-compliance with the adopted combination of keywords

The titles and abstracts of the articles identified in the search process were first reviewed to exclude articles out of scope. The authors of this article have independently checked the full texts to identify eligible articles. At this stage of the article evaluation, we used the CART criteria (completeness, accuracy, relevance, timeliness) to exclude studies that focused on the phenomenon of interest to a limited extent. Discrepancies were discussed and resolved. Eligible article reference lists have been manually checked for additional references. Methodological limitations were demonstrated using the check-lists package intended for the evaluation of medical literature [10]. A narrative approach to research synthesis was used due to the methodological heterogeneity of the analyzed results. A preliminary search resulted in 849 records, after

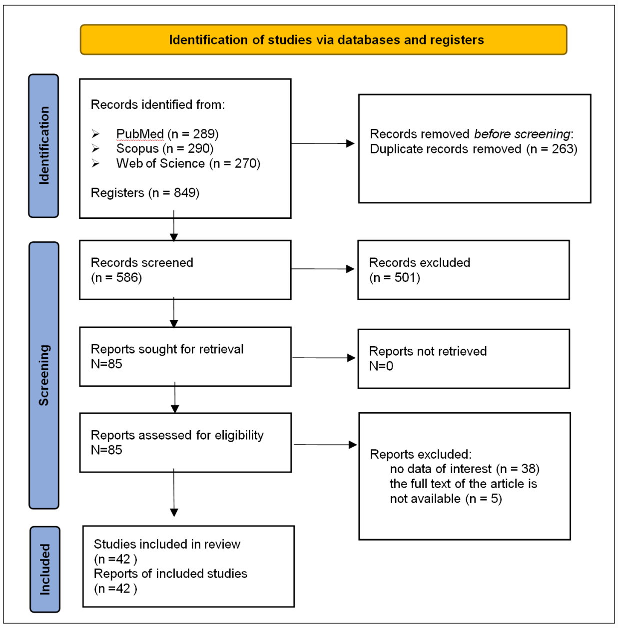

Fig 1. PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers [9]

removing (n=263) duplicates, 586 items remained. After further analysis of the titles and abstracts, 501 articles were excluded. Then, after analyzing the full texts of the works, 43 items were excluded. Finally, 42 works were qualified for the analysis. The stages of the electronic review of databases are presented in Figure 1. Records that were rejected during the full text analysis did not meet the inclusion criteria.

RESULTS

The collected material and the conducted analysis allowed to define the scope of research related to the coping strategies of the child and its parents/guardians with the disease. Works were qualified in accordance with the inclusion criteria for the analysis, containing the results of research on the coping strategies of children and/or their parents/guardians with the child's disease. Detailed results are presented in Table 2. In the analysis there were qualified 6 articles which employ the use of (structured, partially structured) interviews. Moreover, 3 systematic reviews were qualified, one meta-analysis, in the remaining 32 articles the diagnostic survey method was used. A total of 471 sick children were included in 7 articles (EB-epidermolysis bullosa; congenital heart disease (CHD); cancer; autism; genetic diseases; muscular dystrophy; intellectual disability; Wolf-Hirschhorn syndrome; neurological and neuro-developmental diseases; children undergoing hemodialysis; Thalassemia; haemophilia; bronchial asthma; leukemia; mucopolysaccharidosis); in 25 articles, a total of 2,442 parents /guardians were included; 43 fathers were included in 1 article; 826 mothers were included in 8 articles. The study group size ranged from 10 (articles no. 10) to 275 (articles no. 20) participants. Two studies related to strategies used only by children, 5 articles contained results concerning children and parents/guardians, and the remaining 35 studies contained results concerning only parents'/guardians' coping with the child's disease (Tab. 2.). As already mentioned, methodological limitations were shown using the check-lists package. The methodological quality of each article is represented by the % in Table 2. The results of the first group of articles (systematic review and meta-analysis) ranged from 70% to 90%; M=80%. The methodological quality of the interview articles was then assessed. The lowest score was 70%, the highest was 90%; M=85%. The last and most numerous group of articles were papers containing a diagnostic survey, whose results were in the range of 42%-83%; M=64%.

The following thematic areas were distinguished in the scope of the analyzed works:

1. Social/Psychosocial Support; family integration; understanding the medical situation, consultation with the medical team [articles no. 2, 6, 7, 10, 11, 12, 13, 14, 16, 17, 18, 19, 21, 22, 28, 33, 36, 38, 40, 41] Tab. 2.
2. Active coping; problem solving [articles no. 4, 23, 26, 28, 40, 42]
3. Emotion-focused coping; acceptance [articles no. 1, 5, 8, 9, 10, 14, 15, 17, 20, 21, 22, 25, 28, 30, 31, 32, 34, 37, 42] Tab. 2.
4. Appealing to religion; spiritual support [articles no. 3, 6, 7, 12, 19, 24, 27, 28, 29, 34, 35, 36, 41] Tab. 2.
5. Avoidance; dysfunctional coping [articles no. 1, 5, 8, 9, 14, 22, 25, 30, 31, 34, 37, 40, 42] Tab. 2.

Tab. 2. Qualitative thematic analysis of articles qualified for systematic review

No	Article Title	Research method; research tool	Study group	Analyze results	References No. and Ranges:	Methodological quality
1	The relationship between quality of life and coping strategies of children with EB and their parents [11].	Method: diagnostic survey Research tool: Pediatric Quality of Life Inventory; TNO-AZL Questionnaire for Adult's Health- related Quality of Life; Coping with a Disease Questionnaire.	Study group: 55 children; 48 parents	Both children and parents often used acceptance and wishful thinking strategies, while emotional responses and cognitive-palliative strategies were the least frequently used strategies.	42 1984-2020	50%
2	Effect of resilience-based group therapy intervention on coping in mothers of children with cancer: A randomized clinical trial [12].	Method: diagnostic survey Research tool: General Health Questionnaire (GHQ 28); Coping Health Inventory for Parents (CHIP).	Study group: 48 mothers	Running a home and integrating a family is very stressful for families and reduces their ability to cope with their children's disease. Improvement was observed among mothers undergoing group therapy in the applied strategies for family integration, social support and understanding of the medical situation.	27 1980-2018	67%
3	Emotional state of parents of children diagnosed with cancer: examining religious and meaning-focused coping [13].	Method: diagnostic survey Research tool: Brief Scale of Religious Coping (Brief RCOPE)	Study group: 147 parents	Respondents turned to religion and positive coping. Positive emotions of parents were associated with positive re-evaluation and negative coping with religion.	49 1985-2018	75%
4	The contribution of maternal executive functions and active coping to dyadic affective dynamics: children with autism spectrum disorder and their mothers [14].	Method: diagnostic survey Research tool: Brief COPE; Social Communication Questionnaire Current Version (SCQ-Current); Vineland Adaptive Behavior Scales, Second Edition Interview Form (VABS-II)	Study group: 40 dyadies of mothers with children	Mothers who used more active coping strategies, and those who had increased sustained attention, were more involved in mutually positive interaction with their child.	120 1968-2018	50%

■ cont. Tab. 2. Qualitative thematic analysis of articles qualified for systematic review

No	Article Title	Research method; research tool	Study group	Analyze results	References No. and Ranges:	Methodological quality
5	Parenting stress and depressive symptoms in the family caregivers of children with genetic or rare diseases: the mediation effects of coping strategies and self-esteem [15].	Method: diagnostic survey Research tool: Pediatric Inventory for Parents (PIP); Brief COPE; Rosenberg Self-Esteem Scale (RSES); Center for Epidemiological Studies Depression Scale	Study group: 100 family caregivers	Family caregivers use dysfunctional coping strategies (withdrawal, denial, distraction, blaming themselves, substance use).	31 1986-2019	58%
6	Mental health and coping strategies in families of children and young adults with muscular dystrophies [16].	Method: diagnostic survey Research tool: Coping Orientation to the Problems Experienced (COPE-NVI); Wechsler Intelligence scales; Achenbach System for Empirically Based Assessment (ASEBA); Strength and Difficulties Questionnaire (SDQ); Development and Well-Being Assessment diagnostic interview (DAWBA); Autism Diagnostic Observation Schedule (ADOS)	Study group: 112 patients	Patients used fewer problem-solving strategies and turned to religion less often; less often they used social support from their parents and less focusing on the problem.	75 1984-2018	67%
7	Maternal coping strategies in response to child's oncological diseases in Sri Lanka [17].	Method: diagnostic survey Research tool: Coping Health Inventory for Parents (CHIP)	Study group: 200 mothers	Family support, maintaining family integration, cooperation, optimistic definition of a situation are the most helpful coping strategies.	34 1987-2018	75%
8	Family adaptation among parents of children on the autism spectrum without a comorbid intellectual disability: A test of the Double ABCX model [18].	Method: diagnostic survey Research tool: Social Communication Questionnaire, Lifetime form (SCQ); Social Readjustment Rating Scale (SRRS); Positive Contributions Scale from the Kansas Inventory of Parental Perceptions (KIPP); Brief COPE; Family Quality of Life Scale (FQOLS); Life Scale (SWLS); Social Desirable Response set (SDRS)	Study group: 104 parents	The respondents used problem-focused coping strategies and coping with the emotional approach.	102 1983-2018	58%
9	Parental illness representation of intellectual disability and parental emotional distress and coping [19].	Method: diagnostic survey Research tool: Illness Perception Questionnaire-Revised (IPQ-R); Brief COPE; Depression, Anxiety and Stress Scale (DASS-21)	Study group: 91 parents	Coping methods such as self-blame and substance abuse, and behavioral engagement were positively associated with emotional despair. Adaptive coping methods such as problem-focused, emotional, and friendly humor did not contribute to reducing emotional stress.	45 1986-2018	58%
10	The role of acceptance in parents whose child suffers from cancer [20].	Method: Interpretative Phenomenological Analysis (IPA) Tool: structured interviews	Study group: 10 parents	Parents of children with cancer usually "were with their children and used problem-focused coping strategies" and acceptance.	35 1984-2020	90%
11	Parental coping with childhood cancer and its relationship with self-construal: A survey in southeast Iran [21].	Method: diagnostic survey Research tool: Coping health inventory for parents (CHIP)	Study group: 127 parents	In the study, the highest score for coping strategies was for social support, self-esteem, and mental stability.	44 1983-2018	67%
12	Parental experiences of their infant's hospital admission undergoing cardiac surgery: A systematic review [22].	Method: systematic review	Study group: 8 studies	Parents tried to successfully adapt to this situation by using coping strategies such as: religion, social network support, medical team care and family life history.	37 2001-2020	80%
13	Individual and dyadic coping and fear of progression in mothers and fathers of children with hematologic cancer [23].	Method: diagnostic survey Research tool: Fear of Progression Questionnaire - parent version (FoP-Q-SF / PR); Coping Health Inventory for Parents (CHIP); Dyadic Coping Inventory (DCI)	Study group: 44 pairs of families corporeal	Mothers used coping strategies, i.e. family integration, cooperation and an optimistic definition of the situation, maintaining social support, self-esteem and mental stability, as well as understanding the health situation through communication with other parents and consultation with the health care team.	56 1988-2018	67%

cont. Tab. 2. Qualitative thematic analysis of articles qualified for systematic review

No	Article Title	Research method; research tool	Study group	Analyze results	References No. and Ranges:	Methodological quality
14	Determination of burnout, life satisfaction, and stress coping styles of parents with disabled children [24].	Method: diagnostic survey Research tool: Life Satisfaction Scale; Stress Coping Styles Scale (SCSS)	Study group: 191 parents	Parents who had these difficulties with caring for disabled children used a docile approach to coping with stress. Parents used coping strategies such as avoidance, depersonalization and ignoring, and a problem-oriented strategy (by seeking social support and using an optimistic and self-confident approach).	33 1985-2020	83%
15	Coping with Wolf-Hirschhorn syndrome: quality of life and psychosocial features of family carers [3].	Method: diagnostic survey Research tool: WHOQOL-BREF; WHOQOL-SRPB; Zarit Burden Interview - ZBI; Symptom Checklist-90-R - SCL-90-R; Coping Strategies Inventory - CSI; Social Network Questionnaire - SNQ	Study group: 22 guardians of children	The respondents most often used emotional-focused coping and a direct approach to a stressful event.	90 1984-2020	58%
16	Investigating psychological problems in caregiver of pediatrics with cancer: A systematic review.	Method: systematic review	Study group: 15 articles	Studies have shown that parents used coping strategies involving positive reassessment, distancing themselves, seeking social support, self-control, avoidance, confrontation, and responsibility.	57 2002-2019	70%
17	Parental experiences and coping strategies when caring for a child receiving paediatric palliative care: a qualitative study [26].	Method: structured single or multiple interviews	Study group: 42 parents	Four closely related coping strategies have been identified: suppressing emotions, seeking support, taking control to organize optimal childcare, and adapting and accepting the changes taking place.	54 1988-2017	90%
18	Couples dealing with pediatric blood cancer: A study on the role of dyadic coping [27].	Method: diagnostic survey Research tool: Depression Anxiety Stress Scale (DASS-21); Pediatric Inventory for Parents (PIP); Maudsley Marital Questionnaire (MMQ)	Study group: 59 parents (couples)	Research indicates that both positive (i.e. supportive and widespread dyad coping) and negative dyad coping are important for individual outcomes in parents who are dealing with a diagnosis of cancer in their child.	54 1982-2018	50%
19	Power of religious beliefs and coping with cancer: opinions of Iranian parents [28].	Method: diagnostic survey Research tool: Coping Health Inventory for Parents (CHIP)	Study group: 205 parents	„Faith in God" and „Gratitude for His Blessings" and „Social Support" were the most helpful coping strategies among parents.	66 2000-2019	75%
20	Involvement of emotional intelligence in resilience and coping in mothers of autistic children [29].	Method: diagnostic survey Research tool: Schutte Self-Report Emotional Intelligence Test; Way of Coping Checklist (WCC); Resilience Scale (RS)	Study group: 275 mothers	Emotion-focused and problem-focused coping strategies were used in the study groups.	80 1984-2019	75%
21	A qualitative study exploring coping strategies in Chinese families during children's hospitalization for cancer treatment [30].	Method: semi-structured interviews.	Study group: 21 parents	In the study, many parents chose emotional support, optimism, and seeking external support. Healthcare professionals were sources of informational and emotional support for families.	51 1982-2018	70%
22	Coping in parents of children with congenital heart disease: a systematic review and meta-synthesis [31].	Method: systematic review.	Study group: 22 articles	Parental coping fell under four overarching themes: emotional responses, support systems, family management and avoidance. At the time of diagnosis, the parents used strategies for coping with emotions, such as optimism, attachment (or distance), and support.	84 1982-2018	80%
23	Coping with the unfamiliar: How do children cope with hospitalization in relation to acute and/or critical illness? A qualitative metasynthesis [32].	Method: metasynthesis.	Study group: 6 tests	Children dealt with the unknown by transforming their hospital stay into something more like everyday life, using precautionary strategies.	58 1971-2019	90%
24	Coping, attributions, and health functioning among adolescents with chronic illness and their parents: reciprocal relations over time [33].	Method: diagnostic survey Research tool: Brief RCOPE; Multidimensional Measure of Children's Perceptions of Control (MM-CPC).	Study group: 128 teenagers and their parents	The study developed many coexisting relationships between adolescents and parents through the use of religious and spiritual coping strategies.	46 1982-2017	75%

cont. Tab. 2. Qualitative thematic analysis of articles qualified for systematic review

No	Article Title	Research method; research tool	Study group	Analyze results	References No. and Ranges:	Methodological quality
25	Coping, stress and negative psychological outcomes in parents of children admitted to a pediatric neurorehabilitation care unit [34].	Method: diagnostic survey Research tool: Parenting Stress index short form (PSI-SF); Coping inventory for a stressful situation (CISS); Hospital anxiety and depression cale (HADS).	Study group: 124 parents	Emotional and avoidance-oriented coping style and socioeconomic status are key factors in the adaptation process of parents of children with neurodevelopmental disorders	43 1975-2018	67%
26	Quality of life in adolescents with chronic kidney disease who initiate haemodialysis treatment [35].	Method: diagnostic survey Research tool: The "Vécu et Santé Perçue del ,Adolescent et l' Enfant" questionnaire; Kidcope questionnaire.	Study group: 32 teenagers	Active coping and avoidance strategies were used by almost all participants in the study.	41 1984-2018	58%
27	The relationship between psychological distress and religious practices and coping in Malaysian parents of children with thalassemia [36].	Method: diagnostic survey Research tool: General Health Questionaire-12 (GHQ-12), Duke University Religion Index (DUREL) and Brief RCOPE.	Study group: 162 parents	Parents used rather positive, religious coping methods.	32 1984-2013	58%
28	Coping and psychopathology in children with malignancy and bronchiectasis [37].	Method; diagnostic survey Research tool: Coping orientation to problems experienced (COPE); Kid - coping; Social support appraisal scale (SSAS).	Study group: 114 children and their parents	The mother's coping styles were religiosity, positive interpretation, growth and use of instrumental social support in the HO (malignancy) group, and planning, use of emotional social support, and active coping in the B (bronchiectasis) group.	34 1987-2014	67%
29	Uncertainty, hope, and coping efficacy among mothers of children with Duchenne / Becker muscular dystrophy [38].	Method: diagnostic survey Research tool: Parental Uncertainty of Children's Health scale (PUCHs); Parent Hope Scale (PHS); Daily Spiritual Experience Scale (DSES); Coping Self-Efficacy Scale (CSES).	Study group: 202 mothers	In the study, hope, uncertainty, and spirituality influenced mothers' ability to cope with their child's DBMD. Uncertainty and hope are independent predictors of coping effectiveness.	35 1984-2018	67%
30	Mental health and coping in parents of children with autism spectrum disorder (asd) in Singapore: an examination of gender role in caring [39].	Method: diagnostic survey Research tool: Depression, Anxiety, Stress Scales (DASS); Brief COPE; Autism Treatment Evaluation Checklist (ATEC); Strengths and Difficulties Questionnaire (SDQ).	Study group: 203 parents	Active avoidance (i.e., giving up coping, blaming and criticizing oneself, and expressing negative feelings) plays a moderate role in experiencing stress and depression in both parents of children with ASD. Engaging in emotional-centered coping styles plays a greater role.	152 1967-2018	75%
31	Self-reported anxiety, depression and coping in parents of children with phenylketonuria [40].	Method: diagnostic survey Hospital Anxiety and Depression (HAD) scale and the Brief COPE..	Study group: 65 parents	In the study, mothers had higher scores on emotional-focused coping ($p<0.001$), especially in acceptance ($p=0.017$), humor ($p<0.001$), religion ($p=0.011$), denial ($p=0.003$), substance use (0.028), no behavioral involvement ($p=0.049$), and self-blame ($p=0.001$) than fathers.	67 1983-2017	67%
32	Executive functioning mediates the relationship between pain coping and quality of life in youth with sickle cell disease [41].	Method: diagnostic survey Research tool: Behavior Rating Inventory of Executive Function Parent Form (BRIEF); Pain Coping Questionnaire (PCQ); Pediatric Quality of Life Sickle Cell Disease Module (PedsQL-SCD).	Study group: 100 children and parents	Subjects used emotion-focused pain coping strategies (i.e., internalization / catastrophization and externalization), and these were predictors of lower HRQL. Moreover, involvement in emotion-focused coping predicted executive dysfunction.	51 1988-2017	58%
33	Care-giving coping strategies among mothers with chronically ill children [42].	Method: diagnostic survey Research tool: Coping Health Inventory for Parents (CHIP).	Study group: 15 mothers	In the study, most mothers indicated maintaining family integration, cooperation, an optimistic definition of the situation, maintaining social support, self-esteem, mental stability, faith in God as the most useful coping strategies in caring for their chronically ill child	75 1961-2017	50%
34	Burden experience of caregivers of acute lymphoblastic leukemia: impact of coping and spirituality [43].	Method: diagnostic survey Research tool: The brief COPE; The spirituality scale; The caregiver burden inventory.	Study group: 100 guardians	Mothers used religious, emotional and instrumental support more often than fathers, while fathers used psychoactive substances and acceptance of the situation more often than mothers.	33 1989-2017	42%

cont. Tab. 2. Qualitative thematic analysis of articles qualified for systematic review

No	Article Title	Research method; research tool	Study group	Analyze results	References No. and Ranges:	Methodological quality
35	Taking refuge in spirituality, a main strategy of parents of children with cancer: a qualitative study [44].	Method: structured interviews	Study group: 15 parents	Three coping themes were identified: “spiritual strategy,”“spiritual escape,” and “spiritual development,”, which parents of sick children tried to use in coping with their child's illness.	42 2009-2017	90%
36	Perceptions of stress, coping, and intervention preferences among caregivers of disadvantaged children with asthma [45].	Method: interviews (focus groups and individual interviews).	Study group: 30 parents	Parents used coping strategies that involved spending time away from their children and overcoming barriers that limited their ability to cope with stress. Prayer, talking to family and friends, and deep breathing were used by parents.	37 1983-2016	80%
37	Coping strategies, stress, and support needs in caregivers of children with mucopolysaccharidosis [46].	Method: diagnostic survey Research tool: Pediatric Inventory for Parents (PIP) and Brief COPE.	Study group: 93 parents	Caregivers used more problem- and emotion-focused coping and acceptance. Dysfunctional coping strategies, including ventilation, distraction, self-blame, withdrawal, and denial, were correlated with stress.	15 1983-2017	58%
38	A study of the stressors and coping behaviors of parents of Chinese hemophilic children [47].	Method: diagnostic survey Coping Health Inventory for Parents (CHIP)	Study group: 158 parents	The most helpful coping behaviors are: maintaining family solidarity, cooperation and an optimistic attitude; family members working together as a whole; regularly taking the child to hospital for examination and treatment.	22 1983-2017	83%
39	Coping strategies of parents with chronic ill children hospitalized in educational hospitals, Ahvaz-Iran [48].	Method: diagnostic survey Research tool: Coping Inventory for Stressful Situation (CISS).	Study group: 252 parents	The results of the research showed that parents who had children with chronic disease used problem-focused coping strategies (52.3%), and in 54% emotional-oriented coping strategies.	34 1988-2016	67%
40	The relationship between optimism, coping, and depressive symptoms in Hispanic mothers and fathers of children with autism spectrum disorder [49].	Method: diagnostic survey Research tool: Brief COPE; Center for Epidemiological Studies Depression Inventory (CES-D); The Life Orientation Test-Revised (LOT-R)	Study group: 46 mothers and 43 fathers	Three coping strategies were identified: positive coping (active coping, positive reformulation, and planning), coping support (using emotional support, using instrumental support, and using religion), and avoidance (denial, self-blame, disengagement, and substance use).	74 1967-2015	58%
41	Psychological distress and coping strategies in parents of children with cancer in Lebanon [50].	Method: diagnostic survey Coping Health Inventory for Parents (CHIP); General Health Questionnaire version (GHQ-12).	Study group: 124 parents	The most common coping mechanisms reported by the majority of surveyed parents are faith in God, regular observation of the child in the clinic / hospital; the belief that the child is receiving the best possible medical care and that the medical center / hospital is for the welfare of the family, talking to medical staff and believing that the child will recover.	40 1983-2014	67%
42	Coping strategies used by children and adolescents born with esophageal atresia - a focus group study obtaining the child and parent perspective [51].	Method: interview; standardized focus groups with children and their parents.	Study group: 30 Families	Nine coping strategies have been identified: problem solving, avoidance, recognition of responsibility, confrontation, positive reassessment, seeking social support, emotional expression, acceptance and distance.	37 1984-2015	90%

SUMMARY

In studies involving children or children and parents (guardians), both patients and their caregivers used acceptance strategies and emotional-focused coping [11]. Furthermore, many coexisting relationships between adolescents and religious parents and spiritual coping [33] have emerged. In the study by Clavé S et al., adolescents used active and avoidance coping strategies [35]. In addition, the children dealt with the unknown by transforming their hospital stay due to illness into something more like everyday life, using safety strategies (securing known basic needs such as parents, nutrition, establishing relationships with health professionals, and thus constructing everyday life in hospital through parents, play, imagination and social interaction) [32]. The analyzed articles presented the application of strategies regarding family integration, social support, understanding the medical situation (20 articles) and dealing with emotions focused on and acceptance (19 articles). Religious practice (13 articles), social network support, medical team care, family are common strategies used by parents/caregivers when they have a sick child. It is worth noting that in the work of Tesei A. et al., the respondents less often used strategies of solving problems and referring to religion, moreover, they less often used basic coping control (i.e. social support from parents and focusing on the problem by both patients and their parents) [16]. Perhaps it is a sign of changes in civilization or cultural conditions. In studies, many parents used optimism and optimistic defining of the situation, regardless of the events that took place in their lives [17, 23,24,30,31,33,42,48]. Avoidance and dysfunctional coping also appeared among the coping strategies used. In order to deal with the stressful situation of a child's illness, parents also used stimulants [15,19,40,43,49].

CONCLUSIONS

The disease is a stressful experience for both the sick child and its parents/guardians, due to the different situation related to, for example, hospital stay, tests or reorganization of social and family life. Most parents and children try to deal with this situation using positive coping strategies. Conscious use of coping strategies may contribute to better results in the undertaken treatment and allow the child and its parents to feel in control of the stressful situation in which they find themselves.

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