



Parents' Coping Strategies in Caring for Children with Special Needs: A Narrative Review

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ABSTRACT

The presence of children with special needs (CSN) causes anxiety in parents who are responsible for their children. Individuals who are stressed are stimulated to do something in response to the stress, which is referred to as coping. Parents of children with special needs employ a variety of coping strategies, depending on the nature of the issues they face. The purpose of this study was to identify parents' coping mechanisms while dealing with children with special needs. A narrative review is a method of conducting a literature review. The keywords coping methods / coping behavior, parents, and special needs children / disabled children were searched in the online databases EBSCOhost, PubMed, and Google Scholar. The search yielded 25 publications that were found to be related to the study's goals. According to the findings of this literature review, parents utilize problem-focused and emotional-focused coping when caring for their children with special needs. When it comes to caring for children with special needs, parents employ a variety of coping mechanisms. The employment of parental coping mechanisms varies from one article to the next. As a result, more comprehensive research on aspects associated to parental coping techniques in managing children with special needs is required. Nurses can help parents deal with stress while caring for children with special needs by acting as educators, counselors, advocates, and collaborators with other health professionals.

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Kata kunci:

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ABSTRAK

Kehadiran anak berkebutuhan khusus (ABK) memicu stres orang tua dalam merawat anaknya. Stres yang dirasakan individu menstimulus individu untuk melakukan sesuatu dalam menghadapi stres, yang dinamakan dengan koping. Orang tua dengan ABK menggunakan perilaku koping yang berbeda-beda tergantung pemaknaan masalah yang dihadapinya. Tujuan penelitian ini yaitu untuk mensintesis penelitian yang telah ada mengenai strategi koping yang digunakan orang tua dalam merawat ABK. Metode studi literatur ini adalah narrative review. Basis data daring yang digunakan yaitu EBSCOhost, PubMed, dan Google Scholar, dengan kata kunci coping strategies / coping behaviour, parents, dan special needs children / disabled children. Hasil pencarian didapatkan 25 artikel yang teridentifikasi dan relevan dengan tujuan penelitian. Hasil studi literatur ini menunjukkan bahwa koping yang digunakan oleh orang tua dalam merawat ABK adalah koping berfokus pada masalah dan koping berfokus pada emosi. Terdapat berbagai jenis strategi koping yang digunakan orang tua dalam merawat ABK. Masing-masing artikel menunjukkan perbedaan penggunaan strategi koping orang tua. Maka dari itu, perlu dilakukan penelitian lebih lanjut

secara komprehensif mengenai faktor yang berhubungan dengan strategi koping orang tua dalam merawat ABK. Perawat dapat berperan sebagai edukator, konselor, advokator, dan kolaborator dengan profesional kesehatan lain untuk memfasilitasi orang tua dalam mengatasi stres selama merawat ABK.

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INTRODUCTION

Care, care, mentoring, and education can help children achieve their potential in areas including language and speech, independence, attitude and conduct, intelligence, mobility abilities, and social emotional well-being. However, for children with developmental disorders or issues, sometimes known as children with special needs or disabilities, doing these activities is difficult. (Rahmitha, 2011). Winarsih, et al. (2013) Children with special needs are defined as children who have physical, mental-intellectual, social, or emotional limitations or specialties that have a major impact on their growth or development when compared to other children of the same age. According to Donley, et al. (2018) children with special needs endure delays in receiving health treatment when compared to children who do not have special needs.

Parents are burdened by the presence of children with special needs according to Widyatno, Atmoko, and Viatrie (2018). Parents find it difficult to care for their children when they exhibit difficult-to-control behaviors such as aggression, hyperactivity, difficulty concentrating, difficult to manage, tantrums, a tendency to hurt themselves, and frequent mood swings (Widyatno et al., 2018; Sefrina, 2007). 2019). Furthermore, one in three parents felt negative feelings (embarrassed, unhappy, and dejected) about their child's condition that was not as expected, according to Faradina's research (2016).

The presence of children with special needs triggers parental stress (Cuzzocrea et al., 2016). The results of the research by Pociinho and Fernandes (2018) show that the stress level of parents who have special needs is higher than parents who do not. The stress level of parents with special needs also varies from low, medium and high stress (Widyatno et al., 2018).

The individual's stress motivates him or her to take action in the face of the stress (Nasir & Muhith, 2011). Individuals' responses to stress are referred to as coping mechanisms). Coping is defined as an action or a behavioral and cognitive modification taken to cope with stressful conditions or internal or external demands in one's life (Nasir & Muhith, 2011). Coping is an action or behavioral and cognitive change to overcome stressful situations or internal or external demands that burden an individual's life (Lazarus & Folkman, 1984; Nasir & Muhith, 2011).

Problem-focused coping and emotional-focused coping are the two types of coping methods identified by Lazarus and Folkman (1984). Meanwhile, McCubbin, McCubbin, Nevin, and Cauble (1981) developed Lazarus and Folkman's (1984) theory of coping strategies which are also known as coping patterns. There are three coping patterns that parents use in caring for children with health problems, namely coping patterns I (Maintaining *Family Integration, Cooperation and Optimism*), coping patterns II (Maintaining *Social Support, Self Esteem, and Psychological Stability*), and coping patterns. III (*Understanding The Medical Situation Through Communication with Other Parents and*

Consultation with the Health Care Team (McCubbin, McCubbin, et al., 1981). While McCubbin, Olson, and Larsen (1981) divide the coping strategies of parents who face problems into *acquiring social, reframing, seeking spiritual support, mobilizing family to acquire and accept help*, and *passive appraisal*. Coping strategies affect parenting patterns of children (Novi, Agung, Sutari, & Adriana, 2014), child development (Anam & Nohan, 2017; Santoso, Wibhawa, & Ishartono, 2018), as well as the psychological well-being of parents with special needs (ABK). Bray et al., 2017).

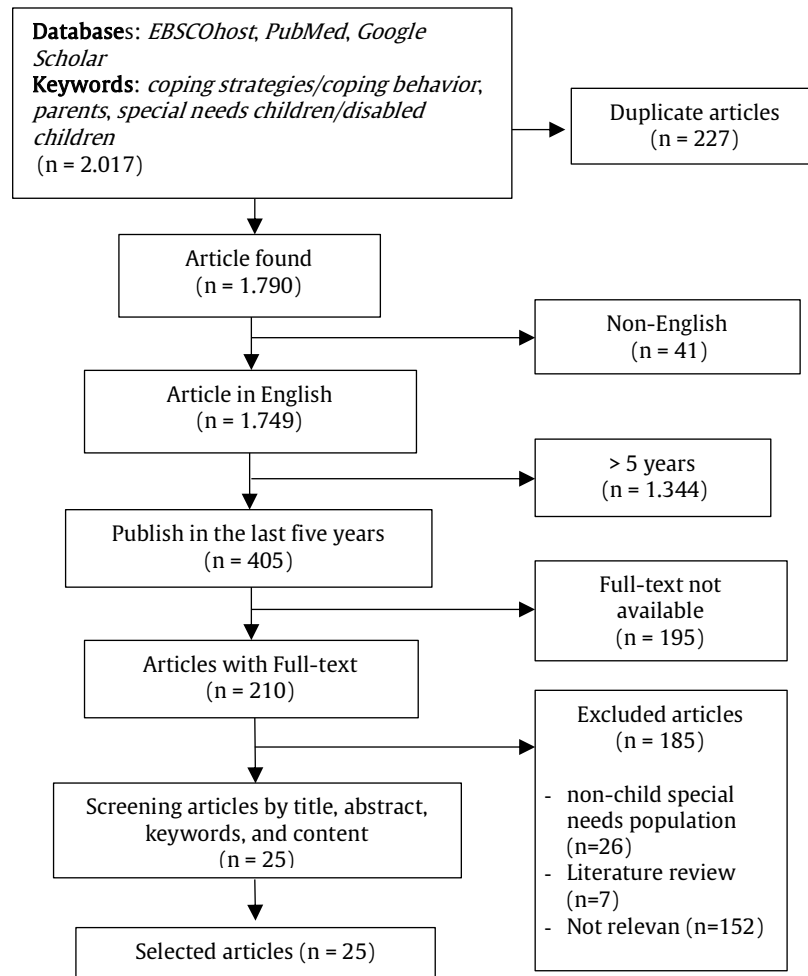
Parents of children with special needs employ a variety of coping strategies, depending on the nature of the issues they face. Other studies have yielded mixed results when it comes to the coping skills of parents of special-needs children. There is currently still lack of literature study that completely synthesizes the coping techniques of parents with special needs children from numerous previous studies. As a result, research on parental coping strategies for children with special needs is required.

METHOD

The study used a make method approach, with a sample of 75 informed consent documents, selected purposively from the 5 most common types of disease (gangrene, hernia, cataract, mammary tumor, and coli tumor), 15 each. Data collection was done by means of a checklist. To complete the descriptive results, 2 (two) informants were deepened through in-depth interviews. Analysis of the data from the document review is descriptive (%) while the results of in-depth interviews are content analysis.

RESULT AND DISCUSSION

The narrative review design is used in the literature study. The type of literature study used in this research is *narrative review*. The sources of information used to search for articles in this research are the online databases of *EBSCOhost, PubMed, and Google Scholar*. The following criteria were used to select articles for this study: (1) they were written in English; (2) they were published within the last five years (2015–2020); (3) they were full-text articles; and (4) the article's purpose was to identify the coping strategies of parents of children with special needs. The research subjects of parents with children with chronic diseases (cancer, etc.), papers employing the literature review approach, and articles not relevant to the research aims were all excluded from this study. The search keywords for articles in this study were "coping strategies" AND "parents" AND "special needs children". In addition, the keywords "coping behavior" AND "parents" AND "disabled children" are used in *databases* that do not contain the previous keywords.



Scheme 1. Article Search and Filtering

RESULTS AND DISCUSSION

Articles come from the United Kingdom, Turkey, Egypt (1), Jordan (1), the United States (7), Italy (1), Saudi Arabia (1), Canada (1), Serbia (1), Singapore (1), Israel (2), Pakistan (1), Spain (1), Malaysia (2), India (1), Kuwait (1), and Iran (1).

(1). The types of articles include descriptive correlational, quasi-experimental, descriptive comparative, prospective studies, cross-sectional studies, cohort studies, qualitative single case studies, and mix-method studies. Each article depicts various parental coping strategies based on the characteristics of special-needs children.

**Table 1
Parental Coping Strategies based on Characteristics of Children**

No	Title	Type of crew	Gender	Age (years)	Parental Coping Strategies
1.	Coping Strategies in Mothers of Children with Intellectual Disabilities Showing Multiple Forms of Challenging Behavior: Associations with Maternal Mental Health (Adams et al., 2017)	Intellectual disability	- Male (n=57) - Female (n=32)	≤15 (n=89)	positive coping, problem focused coping, religious, and avoidance coping
2.	An Evaluation of Anxiety in Parents with Disabled Children and their Coping Strategies (Akturk & Aylaz, 2017)	- Physical disability (n=97) - Mental disability (n=231) - Physical and mental disabilities (n=77)	- Male (n=224) - Female (n=181)	- 0 – 6 (n=125) - 7 – 14 (n=171) - 15 – 24 (n=109)	problem focused coping, seeking social support, and avoidance coping
3.	Relationship between Parent Stress, Psychological Well-Being and Coping Strategies among Parents with Down Syndrome	Down syndrome	- Male (n=26) - Female (n=24)	- 1 - < 5 (n=12) - 5 - < 10 (n=28) - 10 - < 15 (n=7) - 15 - > 20 (n=5)	positive coping, problem focused coping, avoidance coping, and religious

4.	Children (Barakat & Mohamed, 2019) Stress and Coping Strategies in Parents of Children with Physical, Mental, and Hearing Disabilities in Jordan (Bawalsah, 2017)	- Physical disability - Mental disability - Hearing disability	Not mentioned	Not mentioned	problem engagement, focused engagement, problem focused disengagement, and emotion focused disengagement
5.	Hope, Coping, and Relationship Quality in Mothers of Children with Down Syndrome (Cless et al., 2017)	Down syndrome	- Male (n=184) - Female(n=167)	Not mentioned	religious coping, seeking social support, dan internal coping
6.	Parental stress, coping strategies and social support in families of children with a disability (Cuzzocrea et al., 2016)	Developmental disability	- Male (n=28) - Female(n=22)	Mean = 7,82	religious coping, avoidance coping, seeking social support, dan problem focused coping
7.	For fathers raising children with autism, do coping strategies mediate or moderate the relationship between parenting stress and quality of life? (Dardas & Ahmad, 2015)	Autism spectrum disorder	- Male (n=85) - Female (n=16)	2 – 13	positive reappraisal, confrontive coping, planful problem solving, seeking social support, distancing, self-control, avoidance, accepting responsibility
8.	Developing and Evaluating Counseling Program for Caregivers to Cope with their Children Suffering from Autism at Makah Al Mukramah (El-Magd et al., 2016)	Autism spectrum disorder	- Male (n=65) - Female(n=32)	- < 6 (n=55) - > 6 (n=42)	reframing, acquiring social support, passive appraisal, mobilizing family to accept help, dan seeking spiritual support
9.	Parental attitudes and personality traits, self-efficacy, stress, and coping strategies among mothers of children with cerebral palsy (Jankowska et al., 2015)	Cerebral palsy	Not mentioned	Not mentioned	emotion focused coping, problem focused coping
10.	Support Needs and Coping Strategies as Predictors of Stress Level among Mothers of Children with Autism Spectrum Disorder (Kiami & Goodgold, 2017)	Autism spectrum disorder	Not mentioned	Mean = 9,7	maintaining family integration, cooperation, and optimism, maintaining social support, self esteem, and psychological stability, dan understanding the medical situation through communication with other parents and consultation with medical staff
11.	Coping Strategies and Resolution in Mothers of Children With Cerebral Palsy (Krstić et al., 2017)	Cerebral palsy	Not mentioned	2 – 7	reframing, social support, passive appraisal, institutional support, dan spiritual support
12.	Coping and Well-Being in Parents of Children with Autism Spectrum Disorders (ASD) (Lai et al., 2015)	Autism spectrum disorder	Not mentioned	10 – 14	problem focused coping, avoidance coping, positive coping, dan religious
13.	Ways of coping and mental burnout of Bedouin mothers compared to Bedouin fathers of children with ASD (Manor-Binyamini & Abu-Ajaj, 2017)	Autism spectrum disorder	- Male (81%) - Female (19%)	- 5-10 (3%) - 11-16 (79%) - 17-21 (18%)	avoidance, self-control, positive reappraisal, confrontive, planful problem solving, seeking social support, accepting responsibility, dan distancing
14.	Comparing Parents of Children With Down Syndrome at Different Life Span Stages (Goff et al., 2016)	Down syndrome	- Male - Female	- Early childhood (< 5) - Middle childhood (5 - 11) - Adolscence (12 – 18) - Chronological adult (> 18)	acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, dan passive appraisal
15.	Families of Adolescents with Autism: Facing the Future	Autism spectrum disorder	- Male (84,5%) - Female (15,5%)	13 – 22	reframing, social support, family support, spiritual

	(O' Brien, 2016)					support, dan passive appraisal
16	Parental Stress and Autism: Differences in Perceived Stress and Coping Behaviour (Rauf et al., 2017)	Autism spectrum disorder	-	6 – 12		acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, dan passive appraisal
17	The role of coping strategies and self-efficacy as predictors of life satisfaction in a sample of parents of children with autism spectrum disorder (Salas et al., 2017)	Autism spectrum disorder	- Male (85%) - Female (15%)	3 – 14		avoidance, social support, expressing emotions, dan problem solving
18	Stress and Coping in Parents of Children with Prader-Willi Syndrome: Assessment of the Impact of a Structured Plan of Care (Tvrdik et al., 2015)	Prader-Willi Syndrome	Not mentioned	1 – 23		maintaining family integration, cooperation, and an optimistic definition of the situation, maintaining social support, self-esteem, and psychological stability; dan understanding the medical situation through communication with other parents and consultation with medical staff
19	The Relationship Between Optimism, Coping, and Depressive Symptoms in Hispanic Mothers and Fathers of Children with Autism Spectrum Disorder (Willis et al., 2016)	Autism spectrum disorder	- Male (n=73) - Female (n=16)	2 – 10		positive coping, support coping, dan avoidance coping
20	Interpersonal Behavioural Problems in Children with Hearing Impairment: The Parental Experiences and Coping Strategies (Idris & Badzis, 2017)	Gangguan pendengaran	Not mentioned	Not mentioned		seeking spiritual support dan acquiring social support
21	Problems faced and coping strategies adopted by parents of the children with special needs in Pondicherry: A mixed method study (Boovaragasamy et al., 2019)	Not mentioned	Not mentioned	Not mentioned		reframing, acquiring social support, mobilizing family to acquire & accept help, seeking spiritual support dan passive appraisal
22	The Correlation between Coping Mechanism Score and Quality of Life Score among Parents Living with Disabled Children in Kelantan, Malaysia (Izani et al., 2015)	Not mentioned	Not mentioned	2 – 18		problem focused coping and emotion focused coping
23	Brief Report: Social Support and Coping Strategies of Mothers of Children Suffering from ASD in Kuwait (Al-Kandari et al., 2017)	Autism spectrum disorder	- Male (n=150) - Female (n=39)	- < 2 (n=74) - 2.1 – 3 (n=69) - > 3.1 (n=39)		religious, acceptance, positive reframing, planning, active coping, use of instrumental support, venting, self-distraction, self-blame, behavioral disengagement, denial, dan humor
24	Bedouin Hearing Parents of Children with Hearing Loss: Stress, Coping, and Quality of Life (Levinger & Alhuzail, 2018)	Hearing disorder	Not mentioned	6 – 18		redefining the crisis situation, obtaining social support, dan passive coping
25	Do Psychological Characteristics of Mothers Predict Parenting Stress? A Cross-Sectional Study among Mothers of Children with Different Disabilities (Najmi et al., 2017)	- Sensory-motor mental disability (21.2%), - Psychological disability (49.3%) - Chronic physical disability (29.5%)	- Male (50%) - Female (50%)	6 – 12		avoidance-oriented coping, task-oriented coping, and emotion-oriented coping

Problem Focused Coping

Problem focused coping is a coping strategy used to solve problems in dealing with stressful situations (Lazarus & Folkman, 1984). This coping strategy is the most widely used coping strategy by parents of children with special needs (Akturk & Aylaz, 2017; Izani et al., 2015) and parents with autism spectrum disorder children in Singapore (Lai et al., 2015). Meanwhile, in the research of Jankowska, Włodarczyk, Campbell, and Shaw (2015) it was found that this coping strategy was the least used coping strategy by mothers with children with *cerebral palsy* in Canada.

Another term for *problem focused coping* is *task oriented coping*. This coping strategy is used more by mothers with children with sensory-motor disabilities and less by mothers with children with mental disabilities in Iran (Najmi et al., 2017). In Egypt, 24% of parents of children with down syndrome employ high-level problem-focused coping techniques, 6% moderate-level coping strategies, and 70% low-level coping strategies (Barakat & Mohamed, 2019).

Positive coping can be defined as problem-focused coping action that has a positive effect on people. Mothers of children with intellectual disabilities in the United Kingdom (Adams et al., 2017), parents of children with Down syndrome in Egypt (Barakat & Mohamed, 2019) Parents of children with ASD in the United States (Willis et al., 2016) and Italian parents (Cuzzocrea et al., 2016). Mothers use *positive coping* better than fathers (Willis et al., 2016).

Problem-focused coping, such as confrontational coping (efforts made by a person to change the situation by daring to take risks with his actions), planned problem solving, supportive coping, encouraging families to seek and receive help, problem solving, and problem solving are just a few of the other types of coping. sustaining family cohesion, cooperation, and optimism, maintaining social support, self-esteem, and psychological stability of parents, and comprehending medical situations through communication with other parents and consultation with health staff.

According to the findings of Izani, et al. (2015) stated that problem-focused coping is linked to the quality of life of parents of special-needs children. Parents aged 26-65 years who are supported by a psychiatrist have good *problem-solving skills*. Parents between the ages of 26 and 65 who are assisted by a psychiatrist have good problem-solving abilities. Parents who open up about their problems and are accepted by their peers have reduced anxiety and employ more problem-solving coping mechanisms (Akturk & Aylaz, 2017). Parents that do not discuss their problems with their children utilize less problem-solving techniques (Akturk & Aylaz, 2017). Parents who share their difficulties have lower levels of anxiety and use more coping strategies *seeking social support* (Akturk & Aylaz, 2017). Parents who obtain psychiatric help are more likely to use coping methods to seek social help (Akturk & Aylaz, 2017).

Emotion Focused Coping

Pastor, et al. (2009) said that individuals use *emotion focused coping* if the individual is unable to overcome the problem while circumstances force him to accept the situation. Parents who are unable to control their emotions are upset and let their emotions out (Izani et al., 2015). They will feel a lot of emotional stress and give up easily trying to get what they want. This shows that parents who ignore less beneficial elements in their routine life can maintain a better quality of life in their family (Izani et al., 2015).

Emotion-oriented coping is used by mothers with children with cerebral palsy in Canada (Jankowska et al., 2015), mothers with children with sensory-motor disabilities in Iran (Najmi et al., 2017), and mothers with children with physical disabilities in Iran (Najmi et al., 2017). Several other types of coping include emotional-focused coping, namely expressing emotions, keeping a distance or avoiding the problem at hand, self-control, accepting responsibility, reframing (recognizing stressful events so that they can manage stress), passive appraisal (accepting problems by creating positive meaning), problem focused disengagement (problem avoidance with wishful thinking), emotion focused engagement (expressing emotions with social contact), self-distraction, self-blame, denial, and humor.

Parents of children with special needs will divert their children's attention away from their issues by engaging in other activities and avoiding distractions (Izani et al., 2015). Akturk and Aylaz (2017) found that parents who feel guilty and don't communicate their problems employ greater avoidance coping mechanisms. When confronted with emotions, parents will try to divert their attention away from the situation by acting as if it doesn't exist (Izani et al., 2015).

LIMITATION OF THE STUDY

This literature review only found a description of coping techniques among parents of children with special needs, without evaluating the effectiveness of each research article's coping intervention. As a result, more research based on meta-analysis is required to assess the effectiveness of each coping approach on various outcomes for both parents and children with special needs.

CONCLUSIONS AND SUGGESTIONS

According to the findings of a literature analysis, parents who care for children with special needs have a wide range of coping mechanisms. In this study, parents' coping strategies for caring for children with special needs were separated into two categories: problem-focused coping and emotional-focused coping.

Confrontative coping, planful problem solving, support coping, mobilizing family to seek and accept help, problem-focused engagement, maintaining family integration, cooperation, and optimism, maintaining social support, self-esteem, and psychological stability, and understanding the medical situation through communication with other parents and consultation with medical staff are all examples of problem-focused coping that have been discovered in this study. Meanwhile, several coping strategies used by parents which are included in emotion focus coping are self-control, accepting responsibility, reframing, passive appraisal, avoidance coping, problem focused disengagement, emotion focused engagement, emotion focused disengagement, self-distract, self-blame, denial, and humor.

Several of the 25 articles touched on various aspects of parental coping mechanisms. A modest number of studies investigate the association between parental coping mechanisms and one or more demographic variables of their children. However, there is still a knowledge deficit in regards to factors affecting parental coping techniques in the

care of special-needs children. As a result, more research into the elements that influence parents' coping strategies with special needs children is required.

ETHICAL CONSIDERATIONS

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Conflict of Interest Statement

There are no conflicts of interest between the authors and the information reported in this publication. The authors declare that no ethical issues will arise as a result of this manuscript's publication.

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