

Family coping in caring for children with Down syndrome: a scoping review

Coping familiar no cuidado à criança com síndrome de Down: revisão de escopo

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ABSTRACT

Objective: to map the coping strategies that contribute to family care for children with Down syndrome. **Methods:** scoping review, using the JBI method. Six electronic databases and a virtual library were consulted with the support of the Rayyan platform. The criteria for eligibility were studies available and published in full, which addressed coping strategies in family care for children with Down syndrome. Data analysis was of the narrative type. **Results:** 381 records were retrieved and 14 remained in this review. Six coping styles were identified: managing emotions, decision-making, acquiring knowledge about Down's syndrome and situations involving it, seeking support, communicating within the family and with professionals, and practicing spirituality. **Conclusion:** in order to balance the demands presented by the children and the resources available, family members need to adopt cognitive and behavioral strategies to deal with the adversities of caring for a child with Down syndrome. **Contributions to practice:** the study presents evidence to guide nurses and other health professionals to help families use different ways of coping with the stressful events they experience. **Descriptors:** Child; Down Syndrome; Adaptation, Psychological; Family; Pediatric Nursing.

RESUMO

Objetivo: mapear as estratégias de *coping* que contribuem para o cuidado familiar à criança com síndrome de Down. **Métodos:** revisão de escopo, segundo o método JBI. Foram consultadas seis bases de dados eletrônicas e uma biblioteca virtual com apoio da plataforma Rayyan. Os critérios de elegibilidade foram estudos disponíveis e publicados na íntegra, que abordassem estratégias de *coping* no cuidado familiar a crianças com síndrome de Down. A análise dos dados foi do tipo narrativa. **Resultados:** foram recuperados 381 registros e 14 permaneceram nesta revisão. Seis estilos de *coping* foram identificados: manejo das emoções, tomadas de decisão, aquisição de conhecimentos sobre a síndrome de Down e situações que a envolvem, busca de apoio, comunicação intrafamiliar e com profissionais e práticas de espiritualidade. **Conclusão:** para equilibrar as demandas apresentadas pelas crianças e os recursos disponíveis, os integrantes da família precisam adotar estratégias cognitivas e comportamentais para lidar com as adversidades nos cuidados com a criança com síndrome de Down. **Contribuições para a prática:** o estudo apresenta evidências para nortear enfermeiros e outros profissionais de saúde a guiar famílias na utilização de diferentes formas de enfrentamento diante dos eventos estressores vivenciados por estas. **Descritores:** Criança; Síndrome de Down; Adaptação Psicológica; Família; Enfermagem Pediátrica.

Introduction

Coping is seen as the coordination of behaviors and thoughts adopted to solve problems in the face of a stressful event. It has two main functions: to deal with the problem causing the stress and to control the emotional response produced by the stressor⁽¹⁾.

It is known that families of children with Down syndrome experience higher levels of stress when compared to families of children with typical development⁽²⁻³⁾. However, they have the potential to deal with crises and, in this process, they can adopt coping strategies that allow them to manage the situations they experience⁽¹⁾.

Down's syndrome is a genetically determined alteration that is independent of race, ethnicity, or gender. It is not considered a disease, but it is the main cause of intellectual disability in children⁽⁴⁾. It produces a set of alterations in children, changing their living conditions and causing repercussions for their families⁽³⁾. Several stressors can be present: social isolation, financial difficulties, increased anxiety, and marital problems⁽⁵⁾.

To varying degrees, children with Down's syndrome need their caregivers to provide food, hygiene, and access to health, social, and educational services and professionals⁽⁴⁾. Therefore, we start from the understanding that these caregivers and children need to be the focus of professionals' attention and, especially nurses, need to consider their needs in order to provide better care.

Different actions by health professionals can facilitate coping in families caring for children, by meeting the need for information⁽⁶⁾ and carrying out home visits to plan care⁽⁷⁾. Coping strategies can be a predictive factor in reducing parental stress when raising a child with a disability⁽¹⁾. However, when they are dysfunctional, they can contribute to increased stress and depressive symptoms⁽⁸⁾. Greater use of coping strategies among families is associated with fewer unmet demands⁽⁹⁾.

Health professionals, especially nurses with more contact with family members, are strategically

positioned to offer the support needed for effective coping in stressful situations⁽⁷⁾. Thus, we understand that gathering scientific evidence on coping strategies can support nurses' practices in caring for the families of children with Down's syndrome.

In view of this, the question of this study was: what scientific evidence is available about the coping strategies adopted by families of children with Down's syndrome that contribute to family care? The aim was to map the coping strategies that contribute to family care for children with Down syndrome.

Methods

This is a scoping review, according to the JBI method. This method makes it possible to examine the available evidence when the studies on a given topic are unclear or there is no systematic information on the subject⁽¹⁰⁾. The research protocol was registered with the Open Science Framework doi: 10.17605/OSF.IO/SAED3 and developed in accordance with the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR)⁽¹¹⁾.

The mnemonic strategy PCC (participants, concept, and context) was used to elaborate the research question, in which P (participants) corresponds to the families of children with Down syndrome, C (concept) coping, and C (context) family care. Considering the above, the research question was: What scientific evidence is available about the coping strategies adopted by families of children with Down syndrome that contribute to family care?

The review consisted of five stages: identifying the research question; identifying studies; selecting relevant studies; analyzing the results; and grouping, synthesizing, and presenting the data. The eligibility criteria were complete research studies; published in full in English, Spanish, and Portuguese; which addressed coping strategies in family care for children with Down's syndrome. Letters, editorials, reflection studies, and protocols were excluded.

The search took place in July 2022 and was

updated until July 2023. We did not set a time limit and the filter used was the availability of the full text. In the first search, 370 productions were found; after the update, 381 were found. The following databases were consulted: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature Analysis and Retrieval System Online (MEDLINE) via PubMed, Latin American and Caribbean Health Sciences Literature (LILACS), SCOPUS, Web of Science, Cochrane Library and EMBASE. As this study used data in the public domain, it did not require approval by the Research Ethics Committee.

An initial search was carried out on PubMed and CINAHL to identify the main descriptors used in studies on the subject of interest, using the Medical Subject Headings (MeSH) combination identified for the research mnemonic. For each database, the search strategy was adapted with a similar combination of descriptors and keywords: “Child”, “Family”, “Down syndrome”, “Coping”, “Psychological adaptation”, and the Booleans “and” and “or”. Figure 1 shows the search strategy by database.

Data sources	Strategy
CINAHL	Down syndrome AND Family AND Adaptation, Psychological AND coping AND child
LILACS	Down syndrome OR Trisomy 21 OR Partial Trisomy 21 Down Syndrom OR Mongolism AND Adaptation, Psychological OR Adjustment OR coping skill OR Behaviors, Coping AND child AND Family
SCOPUS	Down syndrome AND Family AND Adaptation, Psychological AND coping AND child
Web of Science	Coping Family AND Child AND Down syndrome
EMBASE	Down syndrome AND Family AND Adaptation, Psychological AND child
PubMed/MEDLINE	Down syndrome AND Family AND Adaptation, Psychological AND coping skills AND child AND Nursing
Cochrane	Down syndrome AND Family AND Adaptation, Psychological AND child AND Nursing

Figure 1 – Database search strategy with Boolean operators. Divinópolis, MG, Brazil, 2023

The titles and abstracts were retrieved from

the search and selected using the Rayyan digital platform⁽¹²⁾ and the articles selected from each database were read in full by two researchers independently. Any inconsistencies or doubts about whether or not to include the study were resolved by consensus between the two researchers who carried out the search and selection. All the relevant studies were analyzed, based on the inclusion and exclusion criteria established to identify the potentially eligible ones, which involved reading each of the selected articles in full, with the aim of: a) confirming the content based on the guiding question of the research and, if so, b) extracting the data of interest.

It should be noted that, in some articles, the study population was not exclusively children, i.e. the sample included children, adolescents, and adults. We chose to keep these as they provided specific information for children stratified by age, as well as coping strategies aimed at children.

The articles selected according to eligibility were read and re-read by the researchers and made up the final sample. The information from the studies was extracted using a structured instrument according to the JBI guidelines⁽¹⁰⁾. The titles, type of study, year of publication, level of evidence according to the JBI classification, country of origin, objective, methodology, sample, coping strategies, and results of the articles were organized in an Microsoft Office Excel 2013 spreadsheet. This was followed by a narrative analysis of the data.

The studies were classified according to the level of evidence proposed by the JBI, namely: level 1 refers to experimental studies, randomized clinical trials, and systematic reviews, level 2 is quasi-experimental studies, level 3 is observational studies, level 4 is reviews of descriptive, cross-sectional and case studies and level 5 is expert opinion⁽¹³⁾.

Results

After reading the abstracts, 52 remained and 14 made up the final sample, as shown in Figure 2.

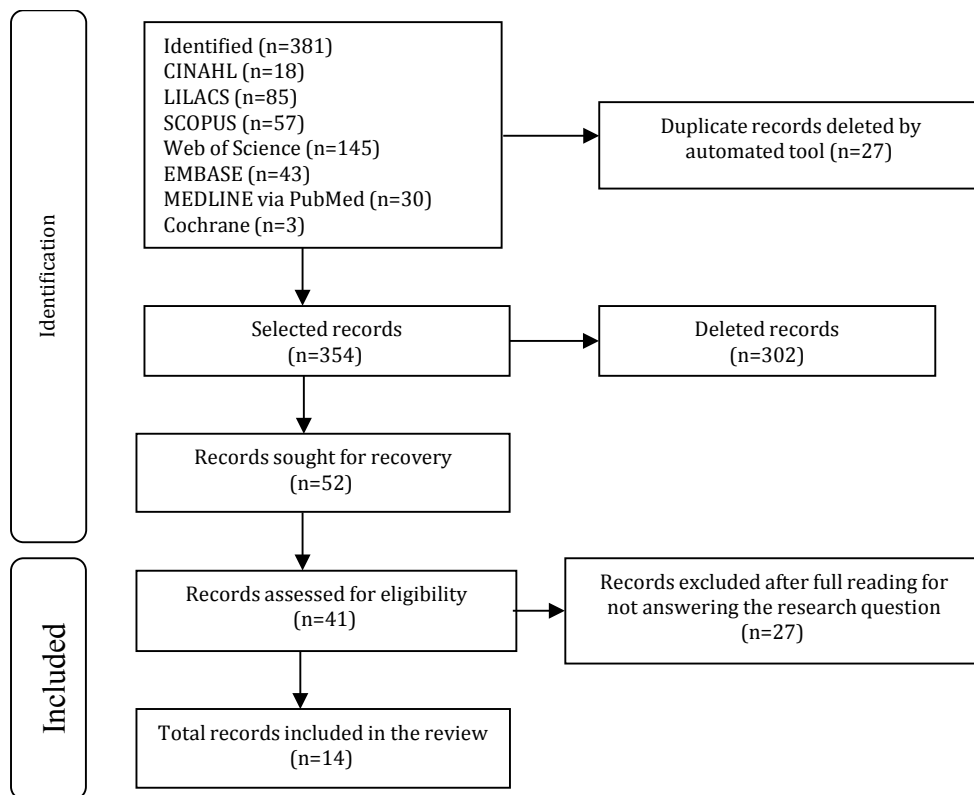


Figure 2 – Flowchart of the review study selection process, adapted from PRISMA-Scr⁽¹¹⁾. Divinópolis, MG, Brazil, 2023

Regarding the studies' statistics, they were published between 2002 and 2022 in the United States of America (n=5), Iran (n=2), Brazil (n=2), and one in each of the following: the Netherlands, Poland, Canada, China, and East Asian countries. Most of the studies were cross-sectional (n=11), experimental (n=1), prospective observational (n=1) and integrative review (n=1). The approach was qualitative (n=7) and quantitative (n=7).

Regarding the participants in the studies, three were carried out exclusively with mothers of children with Down's syndrome, two with fathers, and nine involving fathers, mothers, and siblings. The children's ages ranged from zero to 12 years old.

Based on the studies' results, it was possible to group the coping strategies by similarity and we named them coping styles. Figure 3 shows a summary of the evidence from the included studies.

Analysis of the data revealed that the set of actions, thoughts, feelings, and behaviors adopted by families to manage the adversities surrounding Down syndrome can be grouped into the following styles: managing emotions, decision-making, acquiring knowledge about Down syndrome and the situations surrounding it, seeking social support, communicating within the family and with professionals or the community, and seeking spirituality. Figure 4 shows the coping styles and their respective examples, as cited in the studies.

Author/Year/ Country	Design/ LE*	Journal	Participants (age/Number)	Coping styles
Lam; Mackenzie/ 2002 ⁽¹⁴⁾ China	Cross-sectional 4B	Qual Health Res	18 mothers of children with Down's syndrome aged 0-6	Emotion-focused coping strategies, such as self-confidence and avoidance, and seeking social support.
Poehlmann et al/ 2005 ⁽¹⁵⁾ USA	Cross-sectional 4B	Ment Retard	11 families of children with Fragile X Syndrome and 10 families of children with Down syndrome aged 11 to 23	Family support, especially from the spouse, and social support from friends, relatives, and church members.
Riper et al/2007 ⁽¹⁶⁾ USA	Cross-sectional 4B	J Pediatr Nurs	76 families of children with Down's syndrome aged 7 to 14	Effective communication between family members. Family resources were significantly associated with family adaptation, as was a higher level of communication and problem-solving.
Veek et al/ 2009 ⁽¹⁷⁾ The Netherlands	Observational 3E	Intellect Dev Disabil	440 families (861 people) of children with Down's syndrome < 18 years old	Coping strategies based on recognizing emotions, positive and/or negative. Among the positive ones were acceptance and positive re-evaluation and, among the negative ones, bad thoughts about having a child with Down's syndrome.
Pourmohamadreza-Tajrishi et al, 2015 ⁽¹⁸⁾ Iran	Experimental 2D	Iran J Public Health	64 mothers of children with Down's syndrome < 12 years old	Problem-focused coping strategies using behavioral approaches with resolution planning had a positive effect on promoting the mental health of mothers of children with Down syndrome and reducing symptoms such as phobia, depression, psychosis, somatic complaints, aggression and anxiety in the group studied.
Choi; Riper/ 2017 ⁽¹⁹⁾ East Asian countries	Integrative Review 4A	J Adv Nurs	Varies from 7 to 155 participants aged between 1 and 48 years old	Individual resources of family members with clear communication, as well as the management of positive and negative emotions. Social support and resources, relationships with families experiencing similar situations, and up-to-date information on Down's syndrome.
Cless et al/ 2017 ⁽²⁰⁾ USA	Cross-sectional 4B	J Marital Fam Ther	350 mothers of children with Down's syndrome aged 1 to 40	Religious coping and control of emotions. The greater the use of religious coping strategies based on hope, the better the quality of the relationship between the spouses. In addition, the search for social support was used, which in this study was not related to an improvement in the relationship.
Marshak et al/2019 ⁽²¹⁾ USA	Cross-sectional 4B	J Intellect Disabil	311 fathers of children with Down syndrome < 3 years and > 3 years	Support from parents who experience similar situations in having a child with Down's syndrome. Social support and affectionate personality of the children.
Gashmard et al/ 2020 ⁽⁷⁾ Iran	Cross-sectional 4B	Medicine (Baltimore)	Families of children with Down's syndrome (20 people) < 18 years old	Searching for information about Down's syndrome, spirituality, seeking support and communication within the family and with professionals or the community.
Pisula; Banasiak/ 2020 ⁽²²⁾ Poland	Cross-sectional 4B	J Intellect Disabil Res	162 parents of children with Down's syndrome aged 2 to 6 years	Emotion-oriented and problem-oriented coping: the former was a predictor of parental stress, while the latter showed a lower level of stress.
Lee et al/2021 ⁽⁹⁾ Canada	Cross-sectional 4B	Res Dev Disabil	152 fathers, mothers, and caregivers of children and adults with Down syndrome	Planning for the future, community, and professional support. Greater use of coping strategies was associated with lower levels of stress.
Braga et al/ 2021 ⁽²³⁾ Brazil	Cross-sectional 4B	Rev Esc Enferm USP	39 mothers and 3 fathers of children with Down syndrome aged 1 to 7 years	Belief in God. Set of actions, communication, and decision-making between family members. Seeking information and support from professionals, relatives, and friends.
Faught et al/2022 ⁽²⁴⁾ USA	Cross-sectional 4B	J Appl Res Intellect Disabil	76 parents of children with Down syndrome and 62 parents of children with typical development	Parents of children with Down's syndrome reported more social and family support when compared to parents of children with typical development. Parents with poor emotional skills are more permissive of their children's attitudes.
Duarte et al/2022 ⁽²⁵⁾ Brazil	Cross-sectional 4B	Healthcare (Basel)	39 mothers and three fathers of children with Down syndrome	Spirituality has been described as a critical coping resource in times of crisis. In addition, hope, trust, and loving connection have been cited.

*LE: Level of evidence

Figure 3 – Main results of the studies. Divinópolis, MG, Brazil, 2023

Coping styles	Examples
Managing emotions	Use of positive emotions, such as acceptance, positive reassessment, self-confidence, and optimism; and reframing of negative emotions, such as bad thoughts about having a child with Down syndrome and avoidance ^(9,14-15,17,19,22) .
Decision-making	Behavioral approaches with decision planning to solve problems ^(9,16,19,21-22,24) . Parents feel confident in defining the resolution of the problem in a positive way ⁽⁹⁾ . Financial reorganization, reducing expenses, increasing working hours ⁽¹⁸⁾ , and treating health problems ⁽⁷⁾ .
Acquiring knowledge about Down syndrome	Information about Down's syndrome at the time of diagnosis ^(19,23) , internet searches ^(15,23) , dialog with health professionals, with parents experiencing similar situations, searching for the child's rights and available resources ^(7,14) .
Seeking social support	Help from the family, especially the spouse, relatives, friends, church members, members of parents' associations, and health professionals. People close to the family who can share their concerns and difficulties ^(7,9,14-16,19) . Searching for social resources such as stimulation centers and other institutions that help children with Down syndrome. Participation in special education groups and Down syndrome community councils ^(14,21) . Sharing experiences with families experiencing similar situations ^(19,21) .
Communication	Effective communication between family members, in a clear and affectionate way ⁽¹⁶⁾ , sharing opinions and concerns with relatives and friends ^(7,16) . Communication of the diagnosis by nurses and/or pediatricians with a clear and objective explanation of Down syndrome ⁽¹⁹⁾ .
Spirituality practices	Belief in divine power, belonging to a religion and having faith in God ^(7,9,15-16,23,25) .

Figure 4 – Coping styles and examples, as cited in the studies. Divinópolis, MG, Brazil, 2023

Emotion management is characterized by the use of individual cognitive approaches by family members. The articles indicate that the use of positive emotions, such as self-confidence, acceptance, and positive re-evaluation, can encourage family members to adopt attitudes of optimism and confidence in the face of stressful events^(9,16-17,20).

However, negative emotions such as denial, guilt, rejection, and avoidance are also used as a coping style^(9,14-15,22). Because of this, coping focused on emotion management was found to be a predictor of stress in families who used this way of dealing with problems⁽²⁰⁾.

Decision-making refers to coping focused on the problem, the stressful event, in which family members use behavioral approaches to deal with situations. It is based on the search and immediate resolution of adversity, where the individual tries to control the threatening issue within themselves and thereby strengthens family ties^(9,21-22).

Acquiring knowledge about Down's syndrome and the situations surrounding it refers to the search for information and is a coping style since knowing

about Down's syndrome predisposes parents to safety in caring for their child and understanding their needs^(7,15,18-19) and knowing their rights can help families look for resources to meet their expectations^(14-15,19).

Seeking social support is a coping style based on interaction with other individuals or institutions that provide some kind of help or service. The results showed support among family members, such as sharing care, help from relatives, friends, and people who belong to the same faith and other parents of children with Down syndrome^(9,14-16,19-21,24).

The type of communication found in this review, as a coping style, is verbal communication between two or more individuals. This begins at the moment of diagnosis and how the news is passed on makes a significant difference to these children's parents' lives. There are indications that there is greater security and understanding when the news is delivered by nurses or doctors, in the presence of the spouse, in a clear, assertive manner, and with up-to-date information about Down's syndrome^(19,23).

In addition, intrafamily communication calmly and affectionately to find solutions helps families in

the process of adapting to crises^(16,23), as does sharing experiences with parents going through similar situations^(14-15,19).

The practice of spirituality, based on hope, is expressed by the feeling that the situation will improve^(20,25). We identified that spirituality and the belief in a divine force make up this coping style. Religious coping was related to faith and support from members of the same religious faith^(7,15-16,20,23).

Discussion

In managing emotions, the individual cognitively reformulates the situation they are experiencing, based on their feelings and meanings. Cognitive efforts and actions to experience crises more positively are shown to be strategies that contribute to family care for children with Down's syndrome⁽²⁶⁾. These cognitive efforts are the emotional response to the stressful event and generate attitudes of optimism with thoughts that the situation will improve, or the opposite, such as avoidance of bad feelings⁽²⁷⁾.

The ability to assess one's own emotions and identify what they cause, trying to find a positive way of behaving, is considered emotional intelligence. This ability allows us to enhance correct thinking in search of alternatives to solve problems⁽²⁸⁾. Understanding and knowing how to use this strategy to achieve the expected results can lead to personal satisfaction and reduced stress⁽²⁹⁾.

There are indications that the development of socio-emotional skills can help families in adverse situations involving the care of children with Down's syndrome. We identified that nurses can support families by encouraging these coping strategies, as they are the professionals who are closest to them, from the moment of diagnosis, at birth, and throughout the child's growth and development⁽⁵⁾.

Positive reappraisal has been shown to be a technique in which the individual reframes the situation to see it in a pleasant light. As in this review, other researchers have found that using this strategy impro-

ved the psychological well-being of caregivers of children with autism spectrum disorder⁽²⁶⁾.

Individuals can also use negative emotions such as rejection, guilt, denial, and avoidance to deal with problems, but this review's results showed that this form of coping does not contribute to the balance of family function. Emotional dysregulation is associated with parental stress, both in families of children with Down's syndrome and in families of children with typical development⁽²⁾.

Decision-making refers to the individual's practice of resolving situations that arise in everyday life and, according to the results of this review, it was shown to be an opportune way of coping. The set of thoughts and actions that enables the individual to resolve demands reduces the negative consequences of the situation⁽³⁰⁾. Coping with a focus on problem-solving indicated the perception of the challenge and the need to adapt in coping strategies used by children and adolescents with sickle cell disease. This coping style was characterized as a cognitive response of accommodation to stress⁽³¹⁾.

Examples of decisions that have become opportune coping strategies include financial reorganization with a reduction in spending, changing jobs, increasing working hours, changing from private to public schools, and changing homes to make it easier to go between school, home, and rehabilitation facilities. These attitudes contributed to good family adaptation⁽²³⁾. Given this, it is necessary to understand that directing attention and behavioral actions toward resolving the adversities involving the family of children with Down's syndrome can have a favorable outcome.

The acquisition of knowledge has been shown to be an individual's quest to understand information on a given subject. In the case of Down's syndrome, this interest begins after the diagnosis is suspected or confirmed. Obtaining information gives families the security to care for their children and to know how they will grow and develop in order to seek self-care and autonomy⁽²³⁾.

It is clear from the literature that, in order to

make health decisions, Health Literacy is relevant, understood as the individual's ability to acquire knowledge and make assertive decisions to deal with social demands. Health literacy is an important skill for improving the health and well-being of individuals and their families, as it can shape behavior in relation to health-related choices⁽³²⁾.

Health Literacy empowers parents to care for their child, helping to enhance growth and development. It helps parents make decisions about their child's health, including how to administer medication correctly, prevent illnesses, practice good child-care practices, eat properly, and engage in physical activity. It also helps them to better share the situations they experience with health professionals, facilitating diagnosis and treatment⁽³³⁾.

Therefore, the acquisition of knowledge is a coping style that can lead to the empowerment of family members, allowing them to take greater control over their health and assume responsibility. Health Literacy aims to reduce the gap between what is passed on by health professionals or other means of information and what is actually understood by users⁽³²⁾. We infer that investing in Health Literacy strategies, so that families are aware of and make decisions about the care of their child with Down's syndrome, is a coping strategy to be encouraged by nurses and other health professionals.

A relevant example of how coping strategies involving communication between professionals and family members can be adopted is the provision of correct and reliable information at the time of diagnosis of Down's syndrome. It must be recognized that this period generates feelings of uncertainty and sadness in the parents and some even experience a process of mourning⁽³⁴⁾, but when the diagnosis is made during prenatal care, with assertive communication and appropriate information, there is evidence of better coping and the opportunity to plan and prepare for the changes that will take place^(18,34). However, the majority of cases are reported in the post-natal period⁽¹⁵⁾

and, in this sense, health professionals should adopt communication practices and pass on information that can help reduce suffering and build realistic expectations about the child's future.

In the context of human life, communication can be understood as one of the dimensions that is affected by physical, sensory, emotional, mental, and spiritual interference, enabling interactions and the production of meaning. In this review, assertive communication was identified as a coping style that can promote spaces for reflection and problematization of reality and contribute to coping with the situations experienced⁽³⁵⁾. It is clear that assertive communication between health professionals and family members of children with Down syndrome is indispensable in care and should be recognized as a coping strategy that allows for the exchange of knowledge and the establishment of interactions.

Social support can be understood as help provided by relatives, friends, neighbors, work colleagues, and others who make up the contact network, to meet the physical, mental, and psychological demands of the individual. It is considered a health protector that provides quality of life and promotes adaptation to the stressful events that arise in everyday life⁽³⁵⁾.

Therefore, social support is considered a coping style that favors family care in the face of negative experiences involving the demands of children with Down syndrome. As a health protector, social support has been identified as a form of coping in different studies^(15,36). Authors have identified that a support network reduces the emotional burden on caregivers of children with congenital malformations⁽³⁰⁾. For mothers, the presence and support of their spouses and other family members was fundamental in their initial and ongoing adaptation to the child's diagnosis^(15,35).

Social support is also a resource that contributes positively to empowering families in their care⁽²²⁾. It also increases parental satisfaction, contributing to practices that influence the child's well-being, as it reduces the burden on caregivers and enables more

interactions between family members⁽³⁷⁾.

Another coping style highlighted in the results is the practice of spirituality, as a positive motivational state related to hope. Spirituality is a subjective element, part of the human dimension in understanding suffering, and should be integrated into healthcare. It is considered an important factor in coping with life-threatening problems⁽³⁵⁾. In this study, it was shown to be a coping style that favors family care for children with Down syndrome.

Faced with health-related events and life-threatening situations, people use spirituality to deal with adversity. Different practices are used in this coping style, such as prayer, attending masses and services, performing novenas, meditation, as well as sacrifice, volunteering at church, among others. The practice of spirituality helps patients cope with different illnesses and stressful situations. Hope was evidenced as a coping mechanism and according to the evolution of the clinical condition in families of children hospitalized in an intensive care unit. The results showed that positive feelings prevailed and minimized family suffering⁽³⁸⁾, and the intensity of acceptance and denial of the diagnosis of Down's syndrome was strongly related to religion⁽³⁹⁾.

The factors that contribute to fostering hope in caregivers of children with chronic conditions are the sharing of experiences with other people, the relationship with the child themselves, the good evolution of the child's clinical condition, and the acknowledgment of other possibilities for the future. This positive outlook can be encouraged by health professionals⁽³⁸⁾.

Study limitations

The search strategy was limited due to the large number of studies found with the broad mapping of terms and limitations of time and human resources. In addition, some studies were inaccessible even after searching the COMUT bibliographic computing program and there was no evaluation of the included

articles using a validated instrument, but it is agreed that this is not a mandatory stage for scoping reviews.

Contributions to practice

The results provide evidence for nurses and other health professionals who assist this group, signaling strategies to be encouraged in these families' lives. The findings serve to guide health professionals to help families use the different ways of coping with the stressful events they experience.

Conclusion

Scientific evidence points to different coping strategies that can favor family care in situations involving children with Down syndrome. These include the use of positive emotion, focusing on solving the problem, seeking knowledge about Down's syndrome, social support, communication and spirituality. This review provides indicators for caring for children with Down's syndrome, especially in preventing stressful elements for the family. Knowing scientifically proven coping strategies can favor family adaptation and improve the quality of life of this population.

Authors' contributions

Conception and design or analysis and interpretation of data; Writing of the manuscript or relevant critical revision of the intellectual content; Final approval of the version to be published; and Agreement to be responsible for all aspects of the manuscript related to the accuracy or integrity of any part of the manuscript being adequately investigated and resolved: Souza MS, Braga PP.

Writing of the manuscript or relevant critical revision of the intellectual content; Final approval of the version to be published; and Agreement to be responsible for all aspects of the manuscript: Romano MCC, Oliveira PP, Duarte ED.

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