REVIEW

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Self-Efficacy of family caregivers for children with autism spectrum disorders: integrative review

Ramírez-Ochoa, Jonathan[1*]; Orellana-Yáñez, Alda[2]

SUMMARY

Introduction: Autistic spectrum disorders in children have a negative effect on their caregivers where the understanding of parental thoughts, such as the perception of self-efficacy, could affect the care provided. **Objective:** Identifying how the perception of self-efficacy of the family caregiver of a child with autism spectrum disorder modifies the care provided. **Methods:** Integrative review performed within four databases using the keywords: caregivers, self-efficacy and child, with Boolean AND; filters by year and language were used. **Results:** 41 articles were selected, which after reviewing and verifying compliance with inclusion and exclusion criteria left us 7 articles to work with that made reference to family caregivers of children with autistic spectrum disorder and their perception of self-efficacy. **Conclusions:** The family caregiver should be considered an essential component of the care system, where strengthening perceptions of self-efficacy allows them to feel capable and empowered in their role, favoring coping skills and the acquisition of tools to implement care.

Keywords: Self-efficacy; caregivers; child; autism spectrum disorder; autistic disorder; nursing (DeCS; BIREME).

[1] Master Degree in Nursing, Collaborator Teacher, Departamento Materno-Infantil, Facultad de Enfermería, Universidad de Concepción, Chile. E-mail: *jonaramirez@udec.cl*

[2] PhD in Nursing. Pediatric Nurse. Directora del Departamento materno-infantil. Director especialidad en enfermería infantil. Facultad de Enfermería. Universidad de Concepción, Chile. E-mail: *aorellan@udec.cl*

*Corresponding author

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INTRODUCTION

Autism spectrum disorders (ASD) on average affect 1 out of every 160 children in the world. US statistics cite 1 out of every 68, while Chile has no updated statistics. ASD is a group of disorders characterized by qualitative alterations typical of social interactions, forms of communication and by a repetitive, stereotyped, and restrictive repertoire of interests and activities, represented by generalized features of the behavior of the individual in his family and social life and in terms of his relationships. In most cases development is abnormal from the pre-school stage and only in rare exceptions do the anomalies first occur after the child reaches the age of five years. However, the norm is that there is some degree of general cognitive impairment, although these disorders are defined by the deviation of the behavior in relation to the mental age of the child(1-3).

In 2011, the "Clinical Practice Guide for the Detection and Timely Diagnosis of Autistic Spectrum Disorders (ASD)" was published in Chile, which proposes an action model for the age range between 0 and 4 years and 11 months, where during the evaluation of psychomotor development in primary care, it is possible to identify signs of retardation or delay in the language and social areas, which will guide the application of the "Modified Autism in Childhood Questionnaire (M-CHAT)" together with psychosocial interventions of accompaniment, to be subsequently referred to a pediatric neurologist for control, who then confirms the diagnosis, stratification within functioning level along with the identification of existing comorbidities within secondary and tertiary levels of health care(3).

In case the comorbidities associated to the ASD suppose the need for attention with at least 4 specialists for more than 12 months, together with special dietary needs, technological assistance, rehabilitation and/or special education (without these necessarily being consequences of the disorder) it is possible to admit them into the care and classification model of children and adolescents with special health care needs (NANEAS by its acronym in Spanish), which implies better monitoring in terms of the type and frequency of care with the different professionals who participate in the program, such as medical specialists, nurses, physical therapists, nutritionist, etc., at secondary and tertiary levels of health care(4-6).

The impact of the diagnosis of a child with ASD on the caregivers and the family subsystem affects them negatively, thus creating a negative feedback cycle, with an emotional and economic burden for the family, since this is a type of care that tends to be demanding and very exhausting over time, and usually it has to be provided by members of the family, usually the mother or father(1, 8).

The search for improving the caregivers' capacity to implement the care will be reinforced when considering the mental health of the parents, as well as understanding of how parental thoughts, such as their perception of self-efficacy, can affect and guide the intervention process, the ability to provide care, and the care provided to their children(8, 9).

The concept of self-efficacy was first introduced by Albert Bandura in 1977, as a pillar in the formation of cognitive social theory, which identifies the inability to ignore the reciprocal interactions between the environment, the individual, and the behavior, the first two being the basis for the formation of human behavior, which in itself is defined as "the manner or form in which individuals behave in their lives and actions, recognizing their freedom to make health decisions"(10). The perception of self-efficacy is capable of modifying the way that family caregivers think, make decisions, and act(11), allowing them to perform the necessary actions to obtain the results expected in relation to the care of the child with ASD.

According to the World Health Organization (WHO), family caregivers of children with ASD are able to play a key role in providing support, which helps to guarantee their access to health and educational services, also facilitating encouragement and continual support in each stage of their growth and development; and in many cases, they are able to participate directly or be a fundamental component in the process of administration of psychosocial and behavioral treatments to their own children(1).

The unfathomable work performed by the family caregiver when supported and monitored by the nursing professional facilitates the development of tools and knowledge towards care. For that, nursing utilizes theoretical support implicit in each of the nursing theories and models, adding value to this review the Nola Pender's Health Promotion Model (HPM), resulting from the work of Bandura who broadly exposes the relevant factors involved in the change of behavior of a person such as the perception of self-efficacy for example, giving rise to attitudes and motivations that these have towards health promotion actions and the generation of new behaviors related to themselves and the people caring for them(12). This development process, which is constantly evolving, requires maintaining up-to-date and consensual knowledge that, through an integrative review immersed in the practice of evidence-based nursing, provides professionals with evidence to support, guide, provide autonomy, and avoid variation in their work (13).

Table 1. Keywords and indexed descriptors

Keywords (Spanish)	*MeSH (English)*	*DeCS (Spanish & Portuguese)*
Cuidadores familiares	Caregivers	Cuidadores Cuidadores
Cuidado	-	-
Percepción de autoeficacia	SelfEfficacy	Autoeficacia Autoeficácia
Niño/a	Child	Niño Criança
Trastorno del espectro autista	Autistic Disorder Autism Spectrum Disorder	Trastorno Autístico Transtorno Autístico

Source: Own development

Based upon the foregoing, the purpose of this integrative review is identifying how the perception of self-efficacy of the family caregiver is able to modify the care provided by family caregivers of children with ASD.

METHODOLOGY

Between the months of September 2017 and January 2018, secondary research was conducted using an integrative review methodology in the databases Scientific Electronic Library Online (SciELO), Virtual Health Library (VHL), Web Of Science (WOS), and US National Institutes of Health (PubMed) to answer the following question: How does the perception of self-efficacy of the family caregiver of a child with autism spectrum disorder modify the care provided? Then the following keywords of the question were identified: family caregivers, care, perception of self-efficacy, and child with autism spectrum disorder, which, according to descriptors indexed in DeCS (Descriptors in Health Sciences) and MeSH (Medical Subject Headings), corresponded to the following terms in Spanish, English and Portuguese (Table 1).

Once the descriptors to be used were defined, the inclusion and exclusion criteria (Table 2) were identified, these being related to the article itself and to the results of the research shown in the article regarding the subject and population of the integrative review. Within this evaluation, submission of each selected article to the criteria of identification of authors, title, year, location of study, where the journal is published, indexed database, web page, keywords, objective, methodology, results and conclusions were included, where the lack of clarity or information in any of the aforementioned points was cause for immediate elimination since the methodological evaluation criteria were not met.

Table 2. Inclusion and exclusion criteria

Inclusion criteria
Age of the child (2 - 12 years old)
Published from 2014 to 2018
In English, Spanish, and Portuguese
Original articles with quantitative or qualitative methodology
Articles with high compliance of the methodological quality criteria
Systematic and integrative reviews
Exclusion criteria
Incomplete articles
Articles that cost
Articles with low compliance of the methodological quality criteria

Source: Own development

Once preliminary aspects were defined, entry was made to begin searching at SciELO electronic library, where the search order used was Self-efficacy AND Caregivers AND Child in Spanish, English and Portuguese respectively, without achieving positive outcomes. Subsequently, a search was conducted with the first two descriptors and the Boolean AND, providing a total of 13 articles in Spanish, 15 articles in English, and 15 articles in Portuguese. Criteria for inclusion of title, year, and summary reading were subsequently applied, and 4 articles in Spanish and 3 articles in English were selected.

Afterwards, an entry to VHL, WOS, and PubMed was made; advanced searches with the three descriptors in the order previously used in SciELO were conducted, and language and year filters were used obtaining a result of 84, 278, and 140 articles, respectively. The title was read and after that the summary, having a total of 11, 12, and 11 articles selected, respectively.

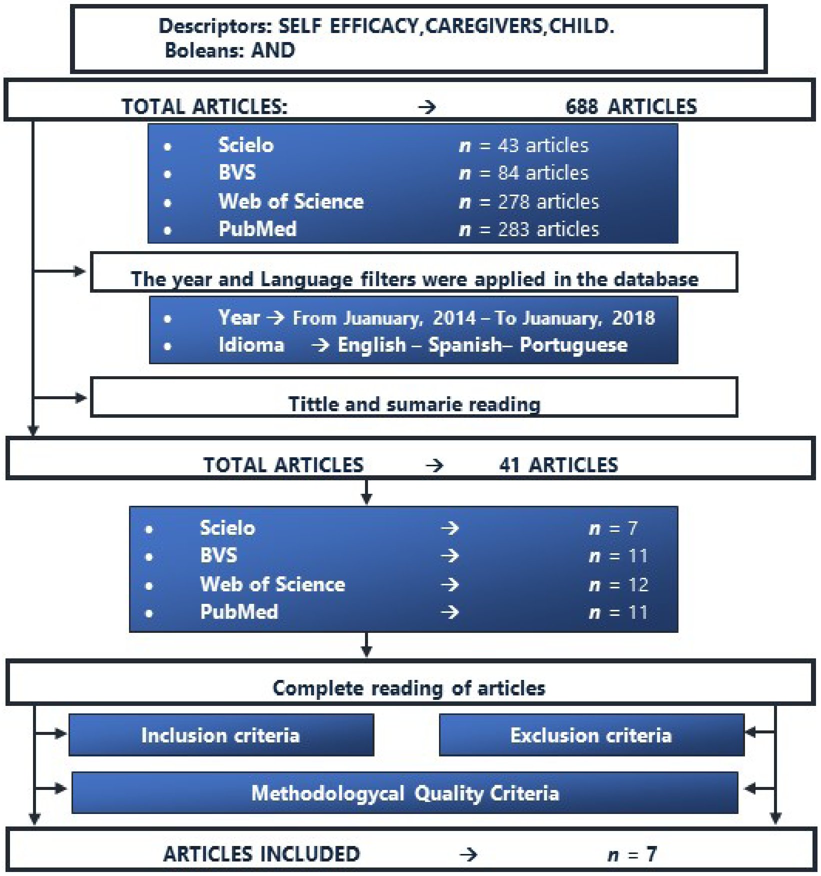
The 41 articles were fully read in pursuit of information regarding the objective of the research, and a critical analysis and confirmation of the inclusion and exclusion criteria was made, in addition to the application of the methodological evaluation criteria of the articles, and 7 articles were selected for this review (Figure 1).

RESULTS

Regarding the distribution by year of the selected articles, three are from 2014(10 - 12), two from 2015(13, 14), and two from 2017(11, 16), but no available articles from 2018 were found in the databases at the time of this search. Regarding the distribution by continent of the selected articles, three are from the American Continent and four from the Asian Continent, one of which was developed in Brazil, two in China, one in India, and one in Pakistan. Two European articles were found, one from Spain and the other from the Netherlands. In relation to the research design of the articles, it was found that five are descriptive-correlational, one is quasi-experimental, and another one is experimental.

Of the ten articles selected, three were identified in PubMed (14,18, 19), three in WOS (15, 16, 17), and one in BVS (11).

Figure 1. Search methodology and selection of articles included in this integrative review.



Source: Own deveploment

Table 3 details each article selected for this review in chronological order of publication, which allowed us to establish a comparative reading between each, with respect to objectives, results, and conclusions by author.

DISCUSSION

Of the articles considered for this review, one is indexed in a journal of Nursing(14) while six others in different journals of the area of psychology(14, 16-19). The selected articles mention that women are typically the family caregiver for children with ASD(14-16, 19), and must fulfill a function for which they have not been trained or guided and this care is additional to other socially assigned roles, such as the role of wife, mother of other children, homemaker, among others. A preference for the abandonment of their source of employment was also identified, in order to become fulltime caregivers(14, 16). The aforementioned gives us an idea of the self-sacrifice of the family caregiver, postponing personal and family projects, often sacrificing their own mental health, which favors over time the development of parental stress associated to care, increased level of perception of work overload as caregiver, and decrease in the understanding of the care they must perform and how it is in line with their own life (16).

The literature reviewed recognizes the following risk factors for the deterioration of the mental health of family caregivers: the low quality of their relationship with their mates, low resilience level, taking care of more than one child with ASD, lack of perceived social support, low perception of self-efficacy, severity of the symptoms of the specific disorder of the child with ASD, and other risk factors such as the perception of self-efficacy and the severity of the deterioration of the child as significant predictors of parental stress(17).

The low perception of self-efficacy is directly related to the inability of family caregivers to rest, producing an increased level of anxiety and work overload, decrease in the quality of life related to mental health, locus of control, and resilience level(16). Additionally, the perception of self-efficacy is the intrinsic determinant that best allows us to understand how mothers of children with ASD feel capable of providing care, allowing them to have greater expression of feelings along with the generation and recognition of a environment that could favor social support; in the case of fathers, as family caregivers, a good level of self-efficacy(18) makes them able to control and solve situations that pose problems for them or for the family nucleus.

By generating interventions that include both the professional team and the family caregivers, where they are taught to adequately deal with crises, it helps family caregivers to empower themselves and strengthen their own perception of self-efficacy, feeling useful within the care system, favoring the quality of life as related to their mental health, generating a greater perception of trust in the decisions they make and actions they implement, as well as competence and ability to care(14, 15).

It is necessary that the professionals in charge of working at any stage of the development of the child with ASD are able to establish collaborative partnerships with families, focusing on the training of family caregivers, including them as an integral part of the team that is working towards the development and integration of the child with ASD. This process will be favored by facilitating the development of their own perception of self-efficacy as caregivers, which will strengthen personal and family well-being, through the synergy established with the care they provide(15, 19).

CONCLUSIONS

At present, the care model, which permeates the entire clinical guide available in Chile, focuses on the management of the child with ASD, downplaying the added value that the caregiver places on them, even with errors in the delivery of specific guidelines regarding the management and actions that caregivers should apply in the various stages they must live with their children, in order to facilitate their coping and adaptation to this new life taking care of children with ASD, unless they fall into the category of some chronic concurrent condition or a severe condition within ASD, which allows them to be part of the NANEAS program(3-6).

The lack of inclusion and accompaniment of family caregivers in this task, full of challenges, fears, and duties, both from the individual and family point of view, translate into carelessness towards them and a lack of consideration of individual needs that may arise after the diagnosis of their children.

The strengthening of the self-efficacy that the family caregiver perceives about himself, manages to improve his own quality of life, which has a positive impact in his individual life project as well as in his family life project; in addition to providing tools to be a key player in the process and actions necessary to take care of a child with ASD. It is crucial to facilitate the generation of instances that enhance the self-efficacy of parents or families, increasing the well-being of the caregivers and giving them the added value to make them capable and empowered of their new role as caregivers, where they can perceive themselves capable of providing the care and generating an impact both in the life of the child with ASD and in the decisions they will make throughout

Table 3. Summary of articles to carry out the implementation of the integrative review after applying the inclusion and methodological quality criteria.

Type of Study	*Objective*	*Results and/or Conclusions*
Descriptive-correlational	Identify the stressors of parents of children with ASD(14).	The higher the level of self-efficacy, the greater the perceived consistence. It allows them to face various factors associated with health care. The training of parents will not only help them accept their child, but also to better use parenting practices with effective stress management, thus favoring success in solving their children's behavior problems.
Quasi-experimental	To determine the effectiveness of a multidisciplinary education program focused on improving the quality of life related to health of caregivers of children with ASD(15).	The application of the multidisciplinary parental education program produced a sustained improvement in the quality of life related to mental health, family functioning, self-efficacy, and positive coping for caregivers. Self-efficacy is benefited with interventions that help personal well-being and their understanding of ASD.
Experimental	Evaluate the early feedback intervention program (video) to promote positive upbringing adapted to Autism (VIPP - AUTI(16).	By applying the program, parents manage to develop an interactive-directive style with their children, being able to enhance their own self-efficacy, thus restoring their own confidence for upbringing and care, which is associated with positive thoughts and feelings about themselves and their role as caregivers for their child with ASD.
Descriptive-correlational	Identify the relationship of the pattern of independence of the child with ASD and the level of self-efficacy of the child's caregiver(11).	Most of the caregivers say they feel unable to get a break, experience feelings of guilt for thinking about taking time for themselves and having to ask a friend or relative to take care of the child. The success of the parents in upbringing contributes to the building of their own self-efficacy.
DDescriptive-correlational	To explore dimensions of post-traumatic growth in caregivers of children with ASD in mainland China, and to identify factors that favor post-traumatic growth(17).	Perceived social support, peer-to-peer learning, application of effective response, and self-efficacy facilitate social support and coping strategies. The increased self-efficacy of parents gives them a greater sense of control and more confidence in their role as parents, becoming less critical, less selfish, more compassionate, more supportive, more patient, and more aware of individual differences in the upbringing of a child with ASD, improving the relationship with their environment and achieving greater family unity.
Descriptive-correlational	Understand the role of coping strategies and self-efficacy expectations as predictors of life satisfaction of parents of children diagnosed with ASD(18).	Self-efficacy is the variable that best explains the level of satisfaction in mothers, while the use of problem solving techniques explains the higher level of satisfaction in parents. Women demonstrate more emotion of higher expression and social support strategies than men. There is a significant relationship between the level of satisfaction of parents of children with autism and the coping strategies developed by them throughout the child's upbringing, as well as the level of expectations of self-efficacy shown by parents with regard to their care tasks, protecting them from developing emotional disorders.
Descriptive-correlational	Evaluate the sociodemographic profile of families of children with autism, as well as parental stress, social support, coping, and resilience(19).	Professionals should establish collaborative partnerships with families within public education, to encourage the development of awareness programs in conjunction with the implementation of family-centered interventions, guiding positive behavioral support services based at home. The training of the caregivers enriches them and makes them an integral part of the treatment team.

Source: Own developtment

their lives.

Considering caregivers as an essential part of the care subsystem requires accepting both their potential and limitations, and requires providing them with the necessary tools to improve their ability to provide care in terms of increasing the capacity for self-efficacy and coping, in such a way that they are capable of satisfying the needs of the person needing care, responding to family issues, maintaining their own health, and promoting a healthy relationship between the caregiver and the person needing care. Furthermore, they must also be able to recognize and establish formal and informal supports, manage feelings of inadequacy or guilt, and plan their own future and that of their family group(20).

After fulfilling the objective of this integrative review, nursing should prepare intervention strategies and programs focused on the family caregiver of children with ASD, contextualized within the Primary Health Care, in continuous cooperation with other disciplines through the Model of Health Promotion(12), trying to identify individual characteristics and experiences of the family caregiver that impacts the conformation of their perceptions of self-efficacy to develop their own care and the care of the child with ASD, searching for the integral development of the family group, reinforced by the achievements associated with caring.

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