

Family Coping Strategies in Autism Spectrum Disorder: An Integrative Review

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Abstract:

Objective: The purpose of this study was to collect and evaluate scientific productions and integrate research results about challenges and coping strategies of families with people with Autism Spectrum Disorder (ASD).

Method: Through the integrative review, the data collection was performed using the descriptors "autistic disorder", "autism", "autistic disorder", and "family" in the databases SCIELO, BDNF, LILACS, PubMed and MEDLINE.

Results: Four articles were selected for the final sample of this work. The main challenges identified by the families were the impact of the diagnosis and educational difficulties. Coping strategies used were social media, blogs creation, searching for different health professionals, family adaptability, looking for support in faith, and involvement in parents' associations.

Conclusion: Few articles were found, which highlights the importance of the study in this topic and gives relevant information to facilitate health care and coaching of health professionals.

Descriptors: Autistic disorder, Family, Nursing, Coping.

Introduction

The Autism Spectrum Disorders (ASD) are Pervasive Developmental Disorders (PDD) characterized by problems in language, social interaction and behavior - restricted and repetitive - which includes changes in movement patterns that may occur before 03 years old. The ASD includes Autism, Asperger Disorder, and PDD ^{[1]-[2]}.

Cases diagnosed as ASD correspond approximately 1 to 5 in every 10000 children, with a proportion of 4.2 men to 1 woman. In Brazil, epidemiological studies are limited, but based on the 2000 Census, the prevalence estimated is 500000 people with ASD in national level ^{[1]-[3]}.

Early identification of ASD is extremely important to make interventions as soon as possible. This identification is made initially by parents which report that their children isolate themselves, do not like affection, do not cry, and cannot keep eye contact ^[4].

The autistic person changes the relationships among family members. The social life of families can become embarrassing and limited, and their social relations can be broken. The families often get another position in the society due to expensive treatments, difficulty to access

social benefits, and usually one of the parents needs to leave his/her job to take care of the autistic child.

The three most important reasons of parental stress are: low acceptance of autistic behaviors by society and by other family members, necessary maintenance, and lack of social support ^[5].

Whereas that Autism Spectrum Disorder (ASD) brings a lot of challenges and changes for the family background, this study aimed to gather, evaluate, and integrate the results of scientific studies published between 2003-2013 that inquired about challenges and coping strategies of families with people with ASD.

Method

The integrative review is a specific method of review that summarizes the available information in scientific literature about a particular subject in order to allow a better understanding of health problems. This method consists of five steps, which were observed in the development of this study: problem identification, literature research, data evaluation, data analysis, and review presentation ^[6].

An integrative review was carried out in national and international literature through electronic search of articles indexed in the databases: SCIELO (Scientific Electronic Library Online), BDEFN (Base de dados em Enfermagem - Nursing Database), LILACS (Latin American and Caribbean Health Science Literature), PUBMED (US National Library of Medicine) and MEDLINE (US National Library of Medicine), by crossing Health Sciences descriptors (DECs) and Medical Subject Headings terms (MeSH): "autistic disorder", "autismo", "transtorno autístico", "família", interrelated by Boolean operator "and".

The review was led by the following guiding question: What are the challenges and coping strategies used by families with people with Autism Spectrum Disorder (ASD), according to the publications available in the literature?

The inclusion criteria for the sample composition were: a) publications included in the national and international literature b) languages Portuguese, English and/or Spanish; c) full texts available on electronic databases d) articles that discuss about challenges and family coping strategies in Autism Spectrum Disorder e) studies published from 2003 to 2013 f) publications written by health professionals.

The bibliographic survey was carried out from August to October 2014, considering the steps of the integrative review, the guiding question, and the inclusion and exclusion criteria. After the initial reading of the 8652 titles and abstracts, 14 articles were pre-selected for full reading. The final sample of this review amounted to 4 studies. For

data collection, it was applied an instrument that had as reference another instrument validated by Ursi^[7].

Results

We obtained 8652 articles by crossing the descriptors "autistic disorder", "autismo", "transtorno autístico" and "família" in databases: SCIELO, BDEFN, LILACS, PUBMED and MEDLINE. The BDEFN database did not show any articles related to the study subject.

Using the guiding question as reference and respecting the inclusion and exclusion criteria, we read carefully titles and abstracts of all 8652 articles. After this initial evaluation, we choose only 14 articles. To minimize mistakes on the next step of the integrative review, the articles were characterized by title, language, publication year, database, journal, and professional area of the authors.

The 14 selected articles were read entirely considering the inclusion and exclusion criteria; among them, 4 articles were chosen as sample for this study. For each article included in the sample, a letter of the Roman alphabet was assigned to it to facilitate discussion.

The analysis of the selected articles was organized considering the following dimensions: database, article title, journal title, author, country, and year of publication - as shown in Table 1. Among these articles, one was produced in Brazil, three were published in nursing journals, and one was produced by psychologists.

Table 1 - Identification of the studies of the review. Uberlândia. MG, Brazil. 2014

| | Database | Article Title | Journal | Authors | Country | Year |
|----------|-------------------------|---|---|---|----------|------|
| A | Scielo | The family with autistic child: nursing support ^[8] | Portuguese Journal of Mental Health Nursing | Nogueira, M.A.A; Rio, S.C.M.M. | Portugal | 2011 |
| B | Scielo Lilacs | Children and young people with autism: impact on their parents and family dynamics ^[9] | Archives of Clinical Psychiatry | Marques, M.H.; Dixe, M.A.R. | Portugal | 2010 |
| C | Lilacs | Experiences of parents to care for her autistic son ^[10] | Revista Enfermería Herediana | Anita, BH; Maria, CG; Monica, PZ, Zulema, SM. | Peru | 2012 |
| D | Lilacs, Pubmed, Medline | Maternal experiences in the reality of having an autistic son: an understanding for nursing ^[11] | Brazilian Journal of Nursing | Monteiro, CFMS; Batista, DONM; Moraes, EGC; Magalhães, TS; Nunes, BMVT; Moura, MEB. | Brazil | 2008 |

From the categorical analysis of the sample, the themes were clustered in 2 categories: challenges identified by families with people with ASD and family coping strategies^[12].

Families that face conditions requiring special care - which tends to cause changes in the structure and routine of the family like ASD - find many challenges daily. Through the analysis of the selected studies, it was possible to verify the main challenges of families with people with ASD, as shown Table 2.

Table 2 – Challenges faced by families with people with ASD. Uberlândia. MG, Brazil. 2014.

| Challenges | Number of articles | Articles that mentioned the challenges | Research attendant population |
|--|--------------------|--|---|
| Impact of diagnosis | 3 | A, C, D | 15 mothers and 30 parents of autistic children. |
| Educational problems | 2 | A,B | 1 mother and 50 parents of autistic children. |
| Financial problems | 2 | A, B | 1 mother and 50 parents of autistic children. |
| Lack of information about the disease and services | 2 | A,B | 1 mother and 50 parents of autistic children. |
| Lack of support from health professionals | 2 | A, B | 1 mother and 50 parents of autistic children. |
| Renunciation of work and personal desires by parents | 2 | C,D | 14 mothers and 30 parents of autistic children. |
| Communication disability between the parents and their autistic children | 1 | D | 14 mothers of autistic children. |
| The barrier to find a caregiver to share the care of autistic person | 2 | B,C | 80 parents of autistic people. |

The impact of ASD diagnosis in families – which is often followed by feelings like pain, pity, frustration, anger, refusal, etc. – was appointed as main challenge in 3 sample articles, which had samples with a significant number of parents of autistic children.

The difficulty to discover a prepared school able to integrate autistic person, financial problems due to high cost of treatment, lack of information about the disease and services, demand of support from health professionals, renunciation of work and personal desires to take care of person with ASD, were identified as challenges in 2 articles of the sample.

The communication disability between the parents and their autistic children – related to the difficulty of the person with ASD to find ways to express themselves, limited emotional

Table 3 - Relation between challenges faced and coping strategies proposed by families with people with ASD. Uberlândia. MG, Brazil. 2014.

| Challenges | Coping strategies |
|--|---|
| Lack of information about the disease and services | Use of social media |
| | Blog creation |
| Lack of support from health professionals | Looking for different health professionals |
| Impact of diagnosis | Family adaptability |
| | Appeal in faith and trust on a supernatural being |
| Impact of diagnosis, lack of information about the disease and services, lack of support from health professionals, renunciation of work and personal desires by parents | Participation in parents association |

The use of social media in order to families with people with ASD tell their experience and emphasize their needs, and blog creation for assisting families to find help and information about ASD, were coping strategies proposed to

expressivity, speech and words without contextual sense, or immutability – was a challenge presented in 1 article.

The barrier to find a caregiver to share the care – due to rigorous and peculiar care required by an autistic child and the stigma that society attaches to this disorder – was identified in 2 of the sample articles. Although it does not represent most of the sample articles, this is a challenge that must be emphasized because the population used in these studies consisted in a considerable number of parents of autistic children (80 parents of children with ASD).

After the diagnosis of ASD, considering all implications and repercussions, the family tends to organize ways to face the challenges. In the sample articles were proposed some coping strategies for the challenges faced by families with people with ASD, which are shown in Table 3.

overcome the difficulty of accessing information about the diagnosis and available services.

Due to the lack of support from health professionals, the parents start a constant investigation to different health professionals expecting to find a qualified professional who

can clarify all doubts and uncertainties that arise from ASD diagnosis. This also consists in a coping strategy. This attitude is taken by several parents that want to get other opinions and professional point of views about their children to make sure that there was no mistake on the diagnosis. Usually, families do not have a pattern regarding this research. They randomly seek for services and professionals until they find an opinion that is more convenient to them.

Another coping strategy observed was the family adaptability, i.e., the attempt of the parents in adapt to child stereotypes when they come across the diagnosis. The appeal in faith and the trust on a supernatural being also consist in a coping strategy, because the belief on a Supreme Being - which is considered as omnipresent - encourages parents to face the difficulties with autistic child and, in some cases, helps them to accept the diagnoses as they believe that this event was something predetermined by this Supreme Being.

Participation in parents association, which allows socialization and contact with other parents and professionals to exchange experiences, was suggested as a coping strategy for: the impact of ASD diagnosis, the lack of information about the disease and services, the demand of support from health professionals, and the renunciation of work and personal desires by parents

Discussion

Permanent disorders like ASD are conditions that doesn't have cure even with early treatments. However, the quality of life can be improved if adjustments and coping abilities were facilitated^[13].

The diagnosis of ASD is essentially clinical and multidisciplinary. It starts from observations made by parents or caregivers, who can assist health professionals to identify the cases and plan a therapeutic approach. Despite this, a lot of families are still suffering with the lack of preparation of some professionals, which impacts negatively in this stage and make it slow and exhausting^{[11][4]}.

The family journey towards the final diagnosis is a difficult step to overcome because it can last a long time and cause tiredness to parents. For this reason, it is very important that parents receive the diagnosis as soon as possible. This way, family members feel that their search has ended, and then they can be committed to understand the world of the autistic person and seek for alternative treatments^[14].

The difficulties faced by families with an autistic child shows a high familiar stress level, because the parents must deal with the loss of the "ideal son", so they can see the real capacity and potential of their child. Family dynamics are affected by changes, ranging from financial aspects to those

related to the physical, mental, and social aspects of the caregivers. Thus, it is necessary a role redefinition for each family member during the adaptation process of parents and children to this new reality^{[13][15]}.

The autistic child family finds difficulties in their quality of life, especially regarding the access to health and transport services, housing conditions, security, leisure, financial resources, and opportunities to get information and skills. There are difficulties to access specialized medical care and other areas of health, and also a lack of information about access to leisure and education for this people. These difficulties increase the stress and decrease quality of life of these families, giving support to the results of this study which showed that financial and educational difficulties, lack of information about the disease and services, and lack of support from health professionals; are the main challenges faced by families with people with ASD^[15].

The demand for qualified care has been frequent. Therefore, professionals need to be prepared to offer help to the families with people with ASD.

Nurses and other healthcare professionals should offer support, guidance, and education to the families, in order to achieve an appropriate social and verbal development for people with ASD, thus improving their quality of life and autonomy. Since nursing has the care as main action, it should see not only the person with ASD but also the family, helping to find a way to show them the meaning of care in the sense of taking care each other and themselves^{[10]-[11]}.

Nurses must have a prior knowledge about the experiences of parents of autistics to perform a more effective management of the cases in which parents need support to accept and handle the situation. These professionals may also have an important role for these families, helping with the communication process between other health professionals and family. Although nursing is present in the authorship of articles in the sample of this study, it is important to highlight that nursing professionals participate more effectively on the research and production of scientific knowledge about ASD. The objective is to qualify their work for people with ASD and their families^{[9]-[11]}.

The person with ASD that receives care with specialists and appropriate support has greater expectation to live independently, minimizing the family's stress levels. The positive reevaluation and the coping focused on the problem, help to break and overcome stress situations^{[5][9]}.

The marital relationship is an important resource to help mothers and fathers to cope challenges of having an autistic child, a good marital relationship is a source of support. In this sense, interventions to improve the marital relationship

of the parents may be important to reduce the parental duty and improve the relationship with their children. Parents or caregivers of people with ASD may face stresses, therefore, they can benefit from treatments focused on family and family counseling^{[15]-[16]}.

Family counseling comes as a coping strategy with guidance to be provided to the family at the time of diagnosis, which helps parents to be more realistic about the possibilities and limitations of their autistic children. Medications are given in some cases of ASD. Although they do not revert the lack of social and communication skills, they can facilitate the stay of these people at home under their family care^[13].

The use of social media, blog creation and participation in parents associations are also coping strategies. As mentioned in this study, these strategies can be used by families with people with ASD against the challenges found in their lives in order to restore family balance and the quality of relationships.

Final considerations

We can consider that scientific studies which discuss about challenges and coping strategies of families with people with ASD are a small number. Although nursing has participated in most articles in the sample of this study, the production of this category about this topic is still limited considering that these professionals are present in the most of health services; thus it is essential that this issue be part of the subject discussed in the coaching of health professionals, encouraging the search and creation of scientific knowledge.

We highlight the importance of studies of integrative review which contribute to describe the state-of-the-art. They give information, based on the scientific literature, about a particular subject. These studies promote the advance of professional education, and also support the decisions made by health professionals, which improve the care provided by them.

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