Nursing care to the autistic child: an integrative review

Assistencia de enfermagem à criança autista: revisão integrativa

Asistencia de enfermería al niño autista: revisión integrativa

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ABSTRACT:

Introduction: The Autistic Spectrum Disorder (ASD) configures a neurodevelopmental disorder that involves social interaction, communication and behavior identified generally in pre-school children. The nursing professionals must perform the management and monitoring of the autistic child.

Objective: To examine the scientific evidence about nursing care to the autistic child.

Methodology: An integrative review of the literature, held in databases: CINAHL, Web of Science and LILACS databases using the search terms: “Nursing Care”, “Child”, “Child, Preschool”, “Autistic Disorder” and “Autism Spectrum Disorder”. There were included articles published between the period of 2013 to 2017 in Portuguese, Spanish and English.

Resulted: The articles included were presented in summary table and the analysis of the results was performed descriptively presenting the synthesis of studies through comparisons and highlight of differences and/or similarities. It was identified that is basic to nursing to have empathy, holistic vision and knowledge to perform singular assistance and of quality for the child and family.

Conclusion: Nursing uses the empathy, holistic view and different strategies for the care to the autistic child; however, the professionals refer difficulties in clinical practice. The publications on the subject are scarce being necessary the development of clinical research.


RESUMO:

Introdução: O Transtorno do Espectro Autista (TEA) configura uma perturbação do neurodesenvolvimento que compromete a interação social, comunicação e comportamento identificado geralmente na criança pré-escolar. Os profissionais de enfermagem devem realizar o manejo e acompanhamento da criança autista.
Objetivo: Analisar as evidências científicas sobre a assistência de Enfermagem à criança autista.


Resultados: Os artigos incluídos foram apresentados em quadro sinóptico e a análise dos resultados foi realizada de forma descritiva apresentando a síntese dos estudos por meio de comparações e destaque de diferenças e/ou semelhanças. Identificou-se que é fundamental à enfermagem ter empatia, visão holística e conhecimento para realizar assistência singular e de qualidade para a criança e família.

Conclusão: A enfermagem utiliza a empatia, visão holística e diferentes estratégias para o cuidado a criança autista, no entanto os profissionais referem dificuldades na prática clínica. As publicações sobre a temática são escassas sendo necessário o desenvolvimento de pesquisas clínicas.

Palavras-chave: Cuidados de Enfermagem; Criança; Pré-Escolar; Transtorno do Espectro Autista.

INTRODUCTION

The United Nations (UN) estimates that there are over 70 million of autistic individuals in the world. In Brazil, it is believed that there are a million autistic patients, 90% of them do not diagnosed(1). The Autistic Spectrum Disorder (ASD) configures a disturbance of the human neurodevelopment that commits the areas of social interaction, communication and behavior, usually identified in the pre-school children(2).

In Brazil, healthcare professionals, education, parents and relatives are characters that have earned the achievement of fundamental rights of the person with ASD through a specific policy. Law N 12,764, from 27th December 2012, establishes the National Policy for the Protection of the Rights of the Person with Autism Spectrum Disorder. It ensures to the person with ASD the right to a dignified life, to the physical and moral integrity, the free development of personality, safety, leisure and protection against any form of abuse and exploitation(3).
From this perspective, it is known that the deficits associated with autism result in losses in various aspects of life, be them personal, academic or professional, and vary between specific limitations in the process of learning to global deficits in social skills implying, therefore, the multiprofessional support. The ASD is characterized into three levels based on the support defendant: level 1, requires support; level 2, requires substantial support; and level 3, which implies in extreme support at all times\(^4\).

In this way, the variability of symptoms and therapeutic intervention interferes with the quality of the person and family life, because communication and social relations play an important role in the emotional health of the person\(^5\). In the process of diagnosis of ASD uses the observation, interviews with the parents, the anamnesis, the exclusion of other diseases and above all, the clinical diagnosis, which depends on the observation of the child’s behavior and complaints from the family\(^6\).

To address the autistic child requires from the health professional the development of skills, knowledge and strategies for individualized care. In this way, the management and the actions should be planned and adjusted to meet the degree of disorder, which requires from a pharmacological intervention to the multiprofessional care centered on the integrality of the person\(^7\).

It is understood that is from the nursing professional the responsibility to cooperate positively in the child’s follow-up during the consultation, not restricting the analysis of growth and development. In this perspective of hosting and comprehensiveness of care, the nursing staff should know how to act before the child, family and community as well; this study aims to analyze the scientific evidence about nursing care to the autistic child.

**METHOD**

The integrative review of the literature, which consists in a strategy of obtaining studies in a systematic way, broad and orderly whose results are related to a specific topic for construction of knowledge\(^8\).

This review was guided by the following guiding question defined considering the population or problem of interest, intervention to be performed and the context of the study: How is nursing care to children with autistic spectrum disorder?

Later, there was defined for the search of primary studies in electronic databases: CINAHL, Web of Science Clarivite Analytics, Scopus and Latin American and Caribbean Literature in Health Sciences (LILACS) via the Virtual Health Library (VHL). From the consultation of Descriptors in Health Sciences (Decs), Medical Subject Headings (MeSH Database) via PubMed and Cinahl Title, the descriptors used, in accordance with the base, were Nursing care; Child; Child, Preschool, Autistic Disorder; Autism Spectrum Disorder. With the aim of ensuring a broad search in CINAHL base, the search terms was performed as a descriptor and keyword. There was performed the intersection between such descriptors, using the Boolean connectives AND and OR. The data collection occurred in March 2018.

The criteria for inclusion were original articles available in full, published in the period from 2013 to 2017, in Portuguese, English and Spanish. There were excluded review
articles, newspaper articles, dissertations, theses, publications that were not available and duplicates. The strategies of searches in each base are described in table 1.

Chart 1: Search strategies used in the databases CINAHL, Web of Science, LILACS through VHL, Scopus.

<table>
<thead>
<tr>
<th>Database</th>
<th>Search strategies</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CINAHL</strong></td>
<td>(MH “Nursing Care”) OR “nursing care”</td>
<td>41,030</td>
</tr>
<tr>
<td>1st Step</td>
<td>(MH “Child”) OR “child”</td>
<td>330,113</td>
</tr>
<tr>
<td>2nd Step</td>
<td>(MH “Autistic Disorder”) OR “autistic disorder”</td>
<td>13,299</td>
</tr>
<tr>
<td>3rd Step</td>
<td>1st AND 2nd AND 3rd</td>
<td>9</td>
</tr>
<tr>
<td><strong>Web of Science</strong></td>
<td>Nursing Care</td>
<td>116,251</td>
</tr>
<tr>
<td>1st Step</td>
<td>Child OR Child, Preschool</td>
<td>1,392,775</td>
</tr>
<tr>
<td>2nd Step</td>
<td>**“Autistic Disorder” OR “Autism Spectrum Disorder”</td>
<td>15,320</td>
</tr>
<tr>
<td>3rd Step</td>
<td>1st AND 2nd AND 3rd</td>
<td>28</td>
</tr>
<tr>
<td><strong>Scopus</strong></td>
<td>**“Nursing Care”</td>
<td>58,341</td>
</tr>
<tr>
<td>1st Step</td>
<td>Child</td>
<td>2,820,068</td>
</tr>
<tr>
<td>2nd Step</td>
<td>**“Autistic Disorder” OR “Autism Spectrum Disorder”</td>
<td>37,901</td>
</tr>
<tr>
<td>3rd Step</td>
<td>1st AND 2nd AND 3rd</td>
<td>13</td>
</tr>
<tr>
<td><strong>LILACS through VHL</strong></td>
<td>Nursing Care</td>
<td>14,152</td>
</tr>
<tr>
<td>1st Step</td>
<td>Child OR Preschool</td>
<td>97,408</td>
</tr>
<tr>
<td>2nd Step</td>
<td>**“Autistic Disorder” OR “Autistic Spectrum Disorder”</td>
<td>81</td>
</tr>
<tr>
<td>3rd Step</td>
<td>1st AND 2nd AND 3rd</td>
<td>2</td>
</tr>
</tbody>
</table>

Source: Prepared by the authors from the collection in the databases CINAHL, Web of Science, Scopus and LILACS through VHL.

(*) In the databases Web of Science, LILACS and Scopus the quotes were used between the compound terms to get publications with exact sentences.

For the selection of publications, there was performed applying the search strategies, inclusion and exclusion criteria sequentially. Thus, the resulting studies were analyzed based on information from the title and abstract, and then read it in its entirety. Each selected scientific publication was identified with the letter “A” in descending
chronological order and organized in synoptic table with the following information: databases, journal, and authors/year of publication, article title and objectives. The analysis of results was performed descriptively presenting the synthesis of studies by means of comparisons and highlight the differences and/or similarities.

**RESULTS**

In total, after the inclusion criteria, 52 publications were found, of which 7 were unavailable for free, 25 not approached the proposed theme, 3 were narrative reviews, 3 were newspaper articles, 4 were duplicated and 1 was a note. Thus, to exclude 43 publications, the remaining 9 articles to be read in its entirety of which 4 did not meet the objectives of this study and, therefore, only 5 were included in the integrative review, as shown in Figure 1.

**Figure 1**: Flowchart of the process of selection of the publications.

It was observed that 60% of the publications belong to the database Web of Science, Scopus 20% and 20% to LILACS. In relation to journals, 60% were published in national journals, they were Text & Context Nursing, Journal Care is Fundamental Online, and Anna Nery School and 40% were published in international journals, which were Journal of Pediatric Health Care and The Journal for Nurse Practitioners. In 2017, there were 20% of the publications, 40% in 2016, 20% in 2015 and 20% in 2014.
In addition to the databases, journals and year of publication, the articles were also characterized according to authors, article title and objectives, as shown in Chart 2.

**Chart 2:** Characterization of the articles concerning databases, journals, authors/year of publication, article title and objectives.

<table>
<thead>
<tr>
<th>N</th>
<th>Databases</th>
<th>Journals</th>
<th>Authors/year of publication</th>
<th>Article title</th>
<th>Objectives</th>
</tr>
</thead>
<tbody>
<tr>
<td>A2</td>
<td>Web of Science</td>
<td>Journal of Pediatric Health Care</td>
<td>FRYE, L. 2016&lt;sup&gt;(10)&lt;/sup&gt;</td>
<td>Fathers’ experience with Autism Spectrum Disorder: nursing implications</td>
<td>Describe the experience of parents of children with autism spectrum disorder by using their own words and identify the resources necessary to help them to engage actively in their role as a parent of a child with autism spectrum disorder</td>
</tr>
<tr>
<td>A3</td>
<td>Scopus</td>
<td>Text&amp;Context Nursing</td>
<td>FRANZOI, M. A. H. et al., 2016&lt;sup&gt;(11)&lt;/sup&gt;</td>
<td>Musical intervention to nursing care strategy for children with autism spectrum disorder at the psychosocial care center</td>
<td>Reporting the experience of applying music care technology to these children in a day-care center for children and adolescents</td>
</tr>
<tr>
<td>A4</td>
<td>Web of Science</td>
<td>Journal Basic Care Online</td>
<td>SENA, R. C. F. et al., 2015&lt;sup&gt;(12)&lt;/sup&gt;</td>
<td>Practice and knowledge of nurses on the infantile autism</td>
<td>Analyzing the practice and knowledge of nurses of the family health strategy about autistic disorder</td>
</tr>
<tr>
<td>A5</td>
<td>Web of Science</td>
<td>The Journal for Nurse Practitioners</td>
<td>WILL, D.; BARNFATHER, J.; LESLEY, M. 2013&lt;sup&gt;(13)&lt;/sup&gt;</td>
<td>Self-Perceived Autism Competency of Primary Care Nurse</td>
<td>The objective of this study was to examine how the primary care nursing professionals understand their level</td>
</tr>
</tbody>
</table>
The Nurse’s Assistance to the person with autism is pointed out as crucial in the performance of the work process of nursing. Reveals the need for a careful look, devoid of preconceptions, attentive to the needs of others and their suffering, since most of the times there is the difficulty of oral expression on the part of the autistic, it is up to the nurse to listening and provision of holistic care\(^{(12)}\).

In this context, the nursing care to the autistic child is based on qualified listening, once that nurses are the eyes and ears of the health team and the voice for parents. The nurse becomes a link between the multiprofessional team and the caregivers of the autistic child\(^{(10)}\).

In this sense, it is necessary to read the lines, look beyond what is visible to the eyes, because knowing how to care implies worry, look to another, this being the essence of human life. In this way, the care provided by a multiprofessional team should have the objective of a qualified care, by means of guidelines to families about autism and creation of therapeutic plans that aim to the uniqueness of each child or patient, this assistance can provide a better quality of life for all involved\(^{(12)}\).

It is worth mentioning that the assistance of the nursing team in listening to parents requires an approach of concerns that surround them with the purpose of paving the process to educate the families of children with ASD to cope with the challenges and best driving the well-being of all\(^{(10)}\).

In contrast, when considering their own competences in relation to primary care that should be provided to the autistic child, nursing professionals have classified them as significantly lower when compared to provide care to children with medical conditions that include congenital cardiopathy, chronic asthma, cystic fibrosis and early diabetes. This happens because these professionals do not feel prepared to provide primary care for children with ASD\(^{(13)}\).

However, other studies have evidenced that the nursing practice with autistic children has been developed increasingly through strategies that enable the insertion of playful experiences as a way to promote care\(^{(9,11)}\).
A study applied the nursing process based on self-care theory of Dorothea Orem and described as results the use of ludic resources for learning enhances, in children, autonomy, creativity, motor coordination, concentration, patience and the ability to work in a group, in so far as they set goals\(^9\).

In another context, researchers identified that the musical intervention as a technology of caring for children with ASD can provide a moment of creative interaction, stimulate the communication and the change of behavior of these children\(^11\).

However, it is important to consider that a series of barriers are identified by nursing professionals to perform primary care in care for the child with autism, such as the lack of coordination of care, lack of time and lack of guidelines of practice\(^13\).

NOTES

This study had as general objective to analyze the scientific evidence about nursing care to the autistic child. Identified that the holistic assistance performed by the nursing staff to the child with ASD is evidenced by a humanized posture, empathy and qualified listening of professionals able to consider the inclusion of family/caregivers as an indispensable part in caring for these children.

Different strategies are employed in the management of the autistic child with the purpose of promoting successful results in assistance, such as: the musical intervention and the use of ludic resources, which are used by nursing professionals, so as to ensure and enhance the child the development of their autonomy, communication and behavior change through a creative interaction.

However, it was also possible to identify barriers that may compromise the quality and effectiveness of assistance to this audience in primary care, such as the lack of coordination of care, lack of time and practice guidelines, in addition to the deficit in the qualification for caring for autistic children. Composed a limitation of this study the scarce scientific production of assistance to the autistic child in the context of nursing practice, as well as the restriction analysis of publications in only three languages, which may have hindered the knowledge of other realities published.

It is recommended to conduct research with methodological rigor that reflect the practice of nursing care in the primary care setting today. As well as investing in professional qualification, planning and development of protocols and guidelines, that guide the clinical practice of care.

REFERENCES