

The knowledge of the nursing team about autistic disorders in children in the light of the human caring theory

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ABSTRACT

Introduction: Autistic Spectrum Disorders (ASD) or Autistic Disorders (AD) are complex neurodevelopmental disorders characterized by social communication deficits, social interaction, and nonverbal behavior in multiple contexts. **Objective:** To analyze the knowledge of the nursing team about ASD and the approach to the subject during professional training based on the principles addressed in the Human Caring Theory. **Methods:** Descriptive study with a qualitative approach, adopting the Human Caring Theory by Jean Watson as a theoretical reference. Ten semi-structured interviews were conducted with professionals from the nursing team of a Primary Health Center in the ABC Region from São Paulo State, Brazil, in May 2019. Their knowledge about ASD in children was assessed by a 7-question guiding script. Data analysis was performed using Content Analysis Method. **Results:** Four main categories were elaborated: the care based on humanistic-altruistic values, the cultivation of sensitivity for self and the other, the valorization of the feelings expression and the interpersonal relationship, the promotion of intra and interpersonal teaching-learning process. **Conclusion:** The nursing team professionals are not prepared to work in the care of children with ASD. During their training, the subject's approach is poor, making professionals feel insecure and unable to provide care to this child and his family.

Keywords: autism spectrum disorder; autistic disorder; nursing; child care; nursing care; nursing theory.

INTRODUCTION

Autistic Spectrum Disorders (ASD) or Autistic Disorders (AD) are neurodevelopmental disorders characterized by deficits in social communication, reciprocal social interaction, and nonverbal behavior in multiple contexts, in addition to the presence of restricted and repetitive patterns of behavior, interests, or activities^{1,2}.

Although studies on the incidence of ASD are scarce, some research points to an estimate that 500,000 Brazilians had ASD in 2010, with a higher incidence in males, and in 2015, that estimate would be 2 million^{1,3}.

With the relatively high incidence, several researchers are trying to understand the genetic causes of ASD. Some studies point to a relationship of three to more than ten genes, while others point to several specific areas of the genome as probable contributors to its development³⁻⁵.

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Thus, the diagnosis of ASD is essentially clinical, based on the child's observations, interviews with parents, and application of specific instruments such as ADI-R, CARS, ASQ and M-CHAT⁶⁻⁸.

For the diagnosis, some behavioral indicators present in most ASDs are used, such as stereotyped movements, tactile or visual insistence, rigid routines, echolalia, and limited emotional expressiveness⁹.

The objective of assessing children with suspected ASD is not only to establish the diagnosis but also to identify the potential of this child and its family. Thus, this assessment must be carried out by a multiprofessional team since the identification of these potentialities and commitments is paramount in order to draw up a Unique Therapeutic Plan for the best development of the child^{9,10}.

Some studies indicate that the multidisciplinary team must be composed of a psychiatrist, neurologist or pediatrician, a psychologist, and a speech therapist^{6,9}.

However, it is important that nurses and the nursing team are involved in the entire process of diagnosis and interventions for children with ASD since these professionals are at the forefront of care and are the gateway to health services¹¹⁻¹³.

However, there is a lack of knowledge among nursing professionals in relation to ASD in general and the possibilities of assisting children with these disorders and their families¹¹.

Considering this context, the following research questions were defined: what does the nursing team know about ASD? Is this topic addressed during professional training?

Therefore, the objective of this study was to analyze, based on the principles addressed in the Theory of Human Care, the knowledge of the nursing team about ASD, and the approach of the theme during professional training.

METHODS

This is a descriptive study, with a qualitative approach, carried out with the nursing staff of a Basic Health Unit-School in the ABC Region from São Paulo State, Brazil.

The sample consisted of professionals from the nursing team who work in the service and whether or not they provide assistance to children with ASD in the context of global care, totaling ten interviews. All invited professionals agreed to participate fully in the research. After clarifying all doubts, signing the Informed Consent Form, and completing the demographic data form, semi-structured interviews were conducted guided by a guiding script (Table 1).

The reports were recorded during the interviews and then transcribed in full and analyzed according to the Content Analysis technique¹⁴.

After data collection, categories and subcategories were elaborated, interpreted using the theoretical framework of the study, the Theory of Human Care, and other complementary literature.

For a better understanding of the results, some illustrative statements from each category and subcategory were transcribed, guaranteeing the anonymity of the interviewees with the use of the letter "E", referring to "interviewee", followed by the number corresponding to the chronological sequence of the interviews.

The study was approved by the Research Ethics Committee of the Centro Universitário FMABC (CAAE 08214919.0.0000.0082 and process 3,259,504).

RESULTS AND DISCUSSION

Ten professionals from the nursing team were interviewed: four nurses, a nursing technician, and five nursing assistants. Eight professionals reported experiences with children with ASD, while two professionals reported having no experience.

With the transcription of the speeches, four categories were elaborated, each with two subcategories (Table 2), based on the elements of the Clinical Caritas Processes, a re-reading of the original charitable factors of the Human Care Theory (Table 3)¹⁵⁻¹⁷.

The Theory of Human Care was chosen as a theoretical framework for the study, as it aims at nursing as a human science, considering the individuality of each being in promoting quality, dignified and personalized assistance.

These issues are relevant when it comes to the child with ASD since, for each individual, the disorders manifest themselves in a way, and the professional must be prepared to have a humanistic view and identify the main demands of that child.

Care is the most precious attribute that nursing has to offer humanity, despite receiving less emphasis than other factors of nursing practice¹⁵.

Watson incorporated in his theory in 2005, the elements of Clinical Caritas Processes that consider the being who receives the care as divine^{16,17}.

According to these elements, the person receiving the care must be welcomed with sensitivity and love, while the person offering it must establish a help-trust relationship, transcending the professional role and placing himself entirely in the care¹⁵⁻¹⁷.

Thus, care is the essence of nursing and denotes the reciprocity between the professional and the person, helping them to take control and promote changes in their health¹⁵.

Care based on humanistic-altruistic values

Care is based on humanistic values and altruistic behaviors, which are developed by examining the person's views, beliefs, interactions with various cultures, and personal growth experiences^{15,16}.

In order for nursing to respond to society's needs and contribute to its roots, both teaching and health care provision must be based on humanistic-altruistic values¹⁵.

Therefore, as these values are based on experiences, it is necessary to understand the professionals' point of view about "being autistic", as illustrated in the following reports.

"[...] I know that it is a special child who has difficulty interacting with the environment... with people... who will be more closed in its world [...]" (E2).

"[...] as far as I know, it's a deficit... where the person isolates himself... it's as if you were hitting, and the person was not listening [...]" (E10).

From these observations, it is presumed that ASD are disorders that go beyond their complexity, far from being precisely defined, as there are no ways in which they can be tested or measured¹⁸.

However, ASDs are part of Global Developmental Disorders, which show commitment in three areas of development: communication skills, non-verbal behaviors, and reciprocal social interaction skills^{2,18}.

Children with ASD usually show signs in the first months of life, such as difficulty maintaining eye contact, echolalia, repetitive and stereotyped behaviors, and rigid routines¹⁹.

Behaviors that are clear in the speeches of the participants in the reports of experiences that follow.

Table 1: Guiding script for semi-structured interviews of the research "The knowledge of the nursing staff about autistic disorders in children, in the light of the Human Care Theory"

<ol style="list-style-type: none"> 1. What do you understand by Autism or Autism Spectrum Disorder? 2. Do you believe that all children with autism are biologically, psychologically, and socially equal? Why? 3. Do you know what Sensory Disorders are? Could you identify them during your professional practice? 4. Have you had any experience with children with ASD? <ol style="list-style-type: none"> a) If yes: How was that experience? b) If not: How do you think the nursing care provided to this child should be? 5. What difficulties do you think the professional has when caring for a child with ASD? 6. During your training, was the topic addressed in any discipline? 7. Do you think this approach is necessary during professional training? Why?

Table 2: Categories and subcategories developed through the analysis of charitable factors and clinical caritas processes of Jean Watson's Theory of Human Care.

Categories	Subcategories
Care based on humanistic-altruistic values	- The professional's point of view about "being autistic" - Experience reports
The cultivation of sensitivity for oneself and the other	- Congruence, empathy, and warmth - Sensory Processing Disorders
Valuing the expression of feelings and interpersonal relationships	- Feelings about "being autistic" - Limitations in establishing the relationship
The promotion of intrapersonal and interpersonal teaching-learning	- Approach to the theme during the vocational training - Essentiality of this approach during professional training

Table 3: The ten original charitable factors and their re-reading in clinical caritas processes of Jean Watson's Theory of Human Care.

Original Charitable Factors	Clinical Caritas Processes
1. The formation of a humanistic-altruistic value system.	1. Practice loving-kindness and equanimity in the context of caring awareness.
2. Stimulating faith-hope.	2. Be authentically present, strengthening, sustaining, honoring the deep belief system and the subjective world of being cared for.
3. Cultivating sensitivity for yourself and others.	3. Cultivate one's own spiritual practices and the transpersonal self and go beyond the ego itself.
4. The development of the help-trust relationship.	4. Develop and sustain an authentic relationship of care, help and trust.
5. The promotion and acceptance of the expression of positive and negative feelings.	5. Being present and supporting the expression of positive and negative feelings as a deep connection with one's own spirit and that of the person being cared for.
6. The systematic use of the scientific method of problem solving to make decisions.	6. Creatively use the self and all paths of knowledge as part of the care process, engage in artistic practices of healing-reconstruction.
7. The promotion of interpersonal teaching-learning.	7. Engage genuinely in teaching-learning experiences that meet the whole person, their meanings, trying to stay within the referential of the other.
8. The provision of a supportive, protective, and (or) corrective mental, physical, sociocultural and spiritual environment.	8. Create an environment of reconstitution (healing) at all levels (physical and non-physical), a subtle environment of energy and awareness, in which totality, beauty, comfort, dignity and peace are enhanced.
9. Assistance with gratifying human needs.	9. Help with basic needs, with intentional awareness of care, administering essential human care.
10. Acceptance of existential-phenomenological forces.	10. Opening up and attending to the spiritual mysteries and existential dimensions of life-death, taking care of your own soul and that of being cared for.

“[...] there are children who just swing. I've seen children tearing paper [...]” (E4).

“[...] my cousin is closed in his world, he takes a toy, usually spins and swings it... Sometimes we say something you notice that he is listening, but he does not answer [...]” (E6).

Grandin illustrates in his work a case described by Leo Kanner in 1943, in which a child remained “totally oblivious” to everyone around it, did not answer when it was called by name, and found rotating objects infinitely fascinating⁵.

The pattern illustrated is similar to that found in the interviews conducted with the study participants, which shows the timelessness of what was described by Leo Kanner.

Although the child with ASD has its individuality, some pattern of behavior is presented by these children, which helps recognize ASD and its early diagnosis. Despite this, it is understood that health care must have an individualized approach, aimed at the person who integrates all parts into a unified and significant whole¹⁵.

The process of caring for individuals is an important focus for nursing, not only due to the dynamics of human to human but due to the required knowledge, values, and personal, social, and moral commitment of the nurse¹⁵.

The relationship between nurse and child with ASD is one of the most important, since this child may have difficulty communicating and the nurse must exercise differentiated assistance, with a careful eye and active listening, in addition to being a consensus in the addressed literature that nursing assistance is essential in monitoring children with ASD from diagnosis to therapeutic interventions^{6,11,13,20}.

It is up to the nurse, together with the nursing and multiprofessional team, to assist the child and the family to face and adapt to the pressures caused by ASDs¹².

Therefore, this professional must observe and interpret the child and his/her family, seeking to plan the assistance to be offered and constantly evaluating it throughout the entire process¹².

The cultivation of sensitivity for oneself and the other

In addition to relying on his beliefs and experiences, the professional must develop a sensitivity guided by congruence, empathy, and warmth since, as the professional struggles to increase his sensitivity, he becomes more authentic¹⁵.

Nursing professionals who are sensitive to patients are better able to learn about their worldview and care more for the patient's comfort, recovery, and well-being, improving the care provided¹⁶.

Such practice is observed in the following report.

“[...] The patient I attend, her level of autism, I don't have much knowledge, you know, but this level is very deep... now we are going to work with the family... Because she is like a 'pet'... and we

understand that this is not the way, so we are seeking to work in another way to bring her back here closer to us [...]” (E10).

In the care of this child, there is a need for a multidimensional, non-stereotyped and individualized view, as children with ASD cannot be expected to approach voluntarily, as the presence and voice of someone on the team can be very invasive¹⁰.

However, it is possible to accompany these children in their actions and mannerisms, which can serve as gaps for entering a dialogue to achieve a possible and transformative approach and promotion of bond with the child with ASD¹⁰.

The more sensitive the nursing professional is to the particularities of this child, the more strongly the care process affects them, and the faster the experience of fully caring is made¹⁵.

However, people with ASD can provoke different reactions in the professionals, whether they feel unable to attend them or put themselves in an omnipotent way towards families, devaluing the history and experience of those who seek help¹⁰.

So that these conflicts do not occur, the professional must offer welcoming attitudes and, together with family members, identify strategies to be shared to enable the development of this child¹⁰.

Parents are usually the people who have the greatest contact with the child, so they are usually the first to observe atypical behaviors and seek health services. When this does not happen, teachers can perceive them and communicate to parents for referral of that child²⁰.

Thus, it is important that the nursing team also communicate with family members and other professionals who are part of this child's daily life in order to map and understand their behaviors and habits, promoting the early diagnosis of ASD.

In addition, it is important to understand that in caring for this child, there is a need for a diversity of care offerings and personalized service, avoiding the reproduction of immediate and standardized responses¹⁰.

It is necessary, then, that the professional understands the sensory processing disorders, dysfunctions that affect the child and compromise his quality of life.

Some common examples are a visual fascination with lights or rotating objects, adverse response to specific sounds or textures, excessive smells or touches, and apparent indifference to pain, heat, or cold²¹.

Respondents were asked about the recognition of these disorders and were unable to define them, as noted in the following reports.

“[...] I think it would be... what, hearing, things like that, talk [...]” (E2).

“[...] So, I don't know if I remember the proper way, but it's like this, she doesn't say she's thirsty, she says 'he's thirsty', she doesn't identify herself as herself, it's something like that, right? [...]” (E8).

It is understood that professionals are not able to recognize the main sensory disorders related to ASD. However, this recognition is necessary since it is a differential for the diagnosis of this child.

Most of the sensory changes in children with ASD are not noticed due to the child's communication difficulties²¹.

According to the DSM-5, this type of symptomatology consists of an increase or reduction in reactivity to sensory input or unusual interest in sensory aspects of the environment^{2,21}.

Although common, these changes do not follow a pattern since the child may present hyperreactivity, hyporeactivity, and sensory search at the same time, each with its intensity²¹.

Due to these sensory dysfunctions, the construction of a personalized and creative Singular Therapeutic Project is recommended, offering proposals that guide the family and the child in the direction of adequate treatment without it becoming a standardized, and repeatable model for all children in the same condition¹⁰.

Some important interventions for children with ASD include the floortime approach, sensory integration, and the act of playing. The implementation of playfulness in the TEA is necessary for the development of the collective imagination and allows the professional and family to enter the child's world, making it interact with the real world²².

Given this, the nursing professional, especially the nurse, must be able to understand and correctly detect the patient's feelings and intimate conditions¹⁵.

In addition to this ability, the professional must be reciprocal as to the subjectivity of this child, which is considered as a whole, as well as that of the professional. When there is reciprocity, it is easier for the child to free himself from some disharmony, becoming freer to direct the energy to its developmental process¹⁵.

Valuing the expression of feelings and interpersonal relationships

During the care of this child, the expression of feelings on the part of the professional should also be taken into account, as this act improves the level of interpersonal communication¹⁵.

Sincerity and individuality go together because if the professional is sincere, it will be able to express the feeling as he experienced or realized it, and the more individual they are, the more the professional extracted them from their intimate and the more genuine they will be¹⁵.

The professionals were asked about their feelings regarding "being autistic", as presented in the following reports.

"[...] we are a little afraid, sometimes, for reasons like that... a little afraid, right? From its reaction, from sketching something more aggressive [...]" (E6).

"[...] I hardly begin the service because it's something I don't feel competent to do it [...]" (E8).

It is observed that fear and incompetence are more evident in the interviewees' statements, creating great difficulty on the part of the professionals in dealing with these children during their care. Therefore, it is essential in this case to strengthen the relationship with the child's family, considering that together they can share the same feelings and both become able to face them¹².

However, the professional's expression of feelings is commonly prohibited. Its presentation in a transpersonal relationship with the patient may conflict with the traditional image of nursing. Thus, health professionals, in general, are warned to avoid personal interactions, with personal involvement being considered as non-professional¹⁵.

In addition, there are no studies that address the expression of feelings on the part of the nursing professional regarding the care of children with ASD, but, as demonstrated in this study, it is understood that this expression in a conducive and appropriate way is essential for the practice of nursing.

The lack of this expression or the repression of these feelings, especially the negative ones, can have direct consequences for professionals, affecting their productivity in the work environment and their social life, resulting in emotional dissonance, repeated stress, and exhaustion²³.

The emotional work must be widely known by the professional because, in addition to being able to understand and work on his feelings, he is also able to do it with the patient, giving him the desired direction for care²³.

With emotional work, the professional also comes to understand and honor the patient's feelings and history, which are important for him and his recovery¹⁶.

However, in the case of ASD, not only are the feelings listed, but the great difficulties presented by professionals in how to start and continue with the assistance to these children, making it necessary to understand the main limitations in establishing the relationship with these patients and their family.

Some of these reports are presented below.

"[...] I think part of the difficulty is due to the lack of knowledge ... I also think that in the way of approaching, because without knowing the limitations of that patient, we end up treating them as if they were a normal patient [...]" (E9).

"[...] Look, it is precisely this question of knowledge, of having more knowledge and, thus, how will you get in to talk to a person who is here, but not? I think this is a difficulty, how to access this world, how to access this person actually [...]" (E10).

In line with previous reports, some studies indicate that nursing professionals feel powerless and unprepared to act in the care of children with ASD, mainly due to the lack of knowledge and inexperience in the care directed to these children^{11-13,24}.

In another review study on the topic, 65 articles were used, and only one of the authors was a nurse, evidencing the lack of development of scientific research on the role of nursing professionals with ASD, highlighting the importance of more studies by nursing to guide the practice of these professionals^{11,25}.

In addition, as studies on the topic are developed, professionals will empower themselves with knowledge about ASD and understand their essentiality in the multidisciplinary care of this child¹¹.

Caring, therefore, requires knowledge of human behavior and its human responses to health problems, knowledge and understanding of individual needs, and facilitated actions related to general and specific knowledge of care¹⁵.

The promotion of intra- and interpersonal teaching-learning

Because of this, it is necessary to analyze the approach of the theme during professional training to understand where this lack of knowledge starts, as illustrated in the following reports.

“[...] Yes, there was, but it was like that, very fast, very basic [...]” (E5).

[...] I think I had a class only in the psychiatry discipline ... It was one of the disorders that they gave, but it was extremely superficial, and in an internship, I didn't even have that [...]” (E8).

There is a small or null approach to ASD during the training of nursing professionals, which means that they are not prepared to meet the demands of children with ASD and their families.

Caring is epistemic entrepreneurship, which defines both the professional and the patient. This requires serum studies, reflections, actions for new knowledge¹⁵.

It is important that the nursing team has sufficient knowledge about ASD, especially with regard to the predominant symptoms that characterize these disorders²⁶.

Without the recognition of early signs of ASD, there is no possibility for the nursing professional to assist in the initial investigation of autism. Most of the time, these professionals have some knowledge about ASD. However, they are incomplete and inconsistent information, resulting in health problems for children with ASD and their families²⁶.

The expansion of the knowledge of nursing professionals can be done through dialogue, the exchange of experiences, and teamwork, which help to improve their performance, thus performing a complete and quality work²⁰.

Although the expansion of knowledge is the responsibility of professionals, the base of this knowledge must be provided by educational institutions, as there is a lack of basic knowledge about ASD among undergraduate students in the health field¹.

Thus, a question arises as to whether health courses, in general, treat ASD as a relevant topic to be addressed in the context of health professionals¹.

Thus, the essentiality of this approach is pointed out during professional training, as listed in the following reports.

“[...] I think it's important... I think nursing itself should have more jobs, more... things to read, jobs, meetings for us to know how to take better care [...]” (E1).

“[...] I think it is extremely important. I had the discipline of Mental Health, but nothing about autism was explained [...]” (E9).

It is observed that professionals understand the need for educational support about ASD during their professional training and that it does not occur as it should.

The lack of this thematic approach makes it impossible to participate together with the multiprofessional team in the early detection of ASDs, due to the lack of knowledge and security during care¹.

The preparation of the nursing team, especially the one that works in Primary Care, needs improvement since it is at this level of care that many cases of ASD are detected²⁷.

In Primary Care, the nurse monitors the child's growth and development, recording what is routine and redirecting it to other professionals when it needs greater complexity, playing a fundamental role in the child's early diagnosis. However, this is not always a reality in health services, and cases of ASD are neglected due to the unpreparedness of professionals who usually let them go unnoticed or confuse the case with a shy child^{20,27}.

Thus, with little knowledge and little instruction, the nursing professional will not be able to assist in the diagnosis, delaying interventions and compromising the child's health status^{20,27}.

In order for all factors of care to be applied as interventions for this patient, the nursing professional must have basic knowledge and clinical competence for a thorough evaluation of this child and be able to adapt each value to his/her context¹⁵.

Given the perspective presented, it is concluded that the knowledge of nursing professionals about ASD is scarce, demonstrating unpreparedness and insecurity in caring for these children. Since their professional training, there is no approach to the theme, making it necessary, therefore, the stimulation of this approach and the production of new studies on the theme by these professionals, due to its great relevance in the current health scenario.

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