



Rosette of care for children with zika congenital syndrome: caring attitudes of relatives

A rosácea do cuidado às crianças com síndrome congênita por zika: atitudes cuidativas dos familiares

Esquema del cuidado de niños con síndrome congénito por zika: actitudes de la familia

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ABSTRACT

Objective: To understand family care modeling for children with SCZ from the theoretical contributions of the Rosette of Care in the chronic situation. **Methods:** The study was conducted between October and November 2017 with 11 relatives, exploring in-depth interviews and story-theme design for data production. **Results:** The Rosette of Care can be triggered from self-care or family care, performing care attitudes built on previous family experiences and interactions with care learned in health services. The modeling of care is supported by the family nucleus consisting of mother, father and grandmother, organizing it in four dimensions: Fully care, "Look after", Stimulate, and Access resources and services. The mother recognizes the child's needs, judges the family's abilities and defines the caregiver. **Conclusion and implications for practice:** The modeling of care is very personal due to the epidemic scenario and to the little scientific knowledge at the time, resulting in innovations in care attitudes. It is up to the nurses to support the relatives to recognize the health needs that emerge from the child, as well as to potentiate the division of care tasks, mainly stimulating the adequacy of the workload of the parents.

Keywords: Mother-Child Relations; Family relations; Microcephaly; Zika virus Disabled children.

RESUMO

Objetivo: compreender a modelagem do cuidado familiar à criança com Síndrome Congênita por Zika a partir das contribuições teóricas da Rosácea do Cuidado na situação crônica. **Métodos:** O estudo foi realizado entre outubro e novembro de 2017 com 11 familiares, explorando entrevistas em profundidade e o desenho estória-tema para a produção de dados. **Resultados:** A Rosácea do Cuidado pode ser disparada a partir do cuidado próprio ou do cuidado familiar, desempenhando atitudes cuidativas construídas por experiências familiares anteriores e interações com o cuidado apreendido nos serviços de saúde. A modelagem do cuidado é sustentada pelo núcleo familiar constituído por mãe, pai e avó, organizando-a em quatro dimensões: Cuidar integralmente, "Tomar conta", Estimular e, Acessar recursos e serviços. A mãe reconhece as necessidades da criança, julga as habilidades dos familiares e define o responsável pelo cuidado. **Conclusão e implicações para a prática:** A modelagem do cuidado é personalíssimo devido o cenário de epidemia e de pouco conhecimento científico à época, resultando em inovações das atitudes cuidativas. Cabe às(aos) enfermeiras(os) apoiar os familiares para reconhecimento das necessidades de saúde que emergem da criança, bem como potencializar a divisão de tarefas de cuidado, estimulando, principalmente, a adequação da carga horária de trabalho dos pais.

Palavras-chave: Relações mãe-filho; Relações familiares; Microcefalia; Zika vírus; Crianças com deficiência.

RESUMEN

Objetivo: Comprender el modelo de atención familiar para los casos de niños con SCZ a partir de las contribuciones teóricas del esquema de atención en la situación crónica. **Métodos:** El estudio se realizó entre octubre y noviembre de 2017 con 11 miembros de la familia, explorando entrevistas en profundidad y el diseño de temas para la producción de datos. **Resultados:** El esquema de atención se puede desencadenar a partir del cuidado personal o familiar, sobre la base de actitudes relacionadas con experiencias familiares anteriores e interacciones con la atención obtenida en los centros de salud. El modelo de atención se apoya en el núcleo familiar formado por madre, padre y abuela, y se organiza en cuatro dimensiones: Atención integral, "Cuidar", Estimular y Acceder a recursos y servicios. La madre reconoce las necesidades del niño, juzga las habilidades de la familia y define al cuidador. **Conclusión e implicaciones para la práctica:** el modelo de la atención es muy personal debido al escenario epidémico y al escaso conocimiento científico de la época, lo que resulta en innovaciones en las actitudes de atención. Corresponde a las enfermeras ayudar a los miembros de la familia a reconocer las necesidades de salud que presenta el niño, como también potenciar la división de tareas de cuidado, estimulando principalmente la adecuación de la carga de trabajo de los padres.

Palabras clave: Relaciones madre-hijo; Relaciones familiares; Microcefalia; Virus Zika; Niños con discapacidad.

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Submitted on 09/10/2019.

Accepted on 02/03/2020.

DOI: 10.1590/2177-9465-EAN-2019-0268

INTRODUCTION

On November 11th, 2015, the Ministry of Health (MoH) of Brazil declared a Public Health Emergency of National Importance regarding the increase in cases of microcephaly caused by the Zika Virus (ZIKV).¹ Later on, the MoH stops considering only the reduction of the head circumference and starts to name the abnormalities caused by the virus, including microcephaly, as Syndrome of Congenital Zika (SCZ) virus, also determined by craniofacial disproportion, spasticity, seizures, irritability, contractures muscle, auditory and ocular abnormalities and brain abnormalities identified by neuroimaging.^{1,2}

Caring for children with disabilities is a complex task because they are clinically fragile and socially vulnerable, demanding time, disposition and creating a challenge for the families. Caring for children with SCZ requires holding the child for a long time, that is, being with them in their arms or on their laps for a long period, almost always rocking them, and also traveling through care spaces - rehabilitation centers, for example - and facing prejudice and discrimination when interacting with the general public.³ Because of this, their care requires structuring the family and social network,^{3,4} being so important for the child as it is for mothers to emancipate themselves from the naturalization and imposition of caring for the child as a purely maternal activity.⁵

In this study, the concept of systemic family is adopted, understood as a system composed of family units that live in constant interaction, sharing beliefs, principles and values. Each relative has its relevance in the family system, being responsible for the dynamics and organization of family arrangements.⁶

The Rosette of Care in the chronic situation⁷ represents the interaction between self-care, family care and care in the networks, outlined in Figure 1.

Self-care makes reference to ways of taking care in daily life, expressed from life experiences and interactions between people/collectives, so that individuals accumulate a quantum with qualities and knowledge to take care of. **Family care** encompasses any action aimed at the well-being of the relatives, considering their respective values and beliefs, providing daily attitudes with close and specific meanings, especially for the sick family member. In this regard, families constitute care centers composed of members who enjoy affective proximity and/or

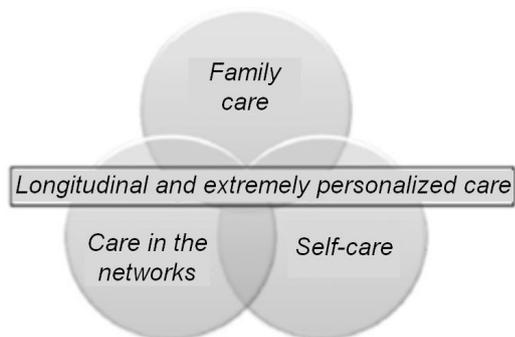


Figure 1 – Rosette of Care in the chronic situation.
Source: Extracted from Bellato et al.⁷

knowledge and/or attitudes to care. The authors understand **care in the networks** as the extended networks that families weave with other people, institutions and entities (neighbors, friends, churches, schools, among others), as well as building themselves when looking for health professionals or services.⁷

Furthermore, the **modeling of the care** is comprised by a handcrafted dimension⁸ constructed from the interactions between relatives and the sick person, allowing for the recognition of their needs and for the organization of care under a **personal mode**.⁹

This article was developed seeking to answer the following question: How family care is modeled for children with SCZ? It aims to understand the modeling of family care for children with SCZ from the theoretical contributions of the Rosette of Care in the chronic situation.⁷

METHODS

An exploratory study, carried out at the Association of Parents and Friends of the Exceptional (*Associação de Pais e Amigos dos Excepcionais*, APAE) located in Feira de Santana (627,477 thousand inhabitants), Bahia, Brazil. The ten study participants were elected for convenience, based on the following selection criteria: being a member of the family system of the child with SCZ, a condition to be confirmed verbally by the study participant; and, being responsible for the child with SCZ during contact with the researcher. There were no refusals to take part in the study.

The lead author of this article submitted the research project, received the participants' consent and conducted the data collection stage, sequentially. The participants did not know the researchers before the data collection started, nor their personal objectives, presenting them only to the professional category and linked institution. The number of participants was defined after reading and analyzing the content transcribed by the study authors, when the reach of the theoretical-empirical data saturation criterion was perceived.¹⁰ The participants freely chose a fictitious name for use in this study. The children were between one year and five months old and two years and six months old, with a mean of one year and nine months old.

As a data production technique, the in-depth interview was adopted, held face-to-face, in a private environment (child rehabilitation room) with the presence of the researcher, the study participant and the child. The first interview was considered as a pilot, with no adjustments made after its execution, which allowed for the inclusion of this in the *corpus* of the study.

The interviews were conducted by the responsible researcher, at APAE, in October and November 2017, later to be recorded and transcribed, with a minimum duration of 21 minutes and a maximum of 56 minutes. After transcription, the interviews were delivered to the participants for reading, allowing them to include or remove any information.

After the transcripts of the interviews, the thematic analysis of the relatives' narratives was carried out in six stages: 1) reading and rereading the data; 2) creation of codes for important topics (12 codes); 3) grouping of codes (4 groups); 4) construction of a

mental map identifying relationships between the themes; 5) naming the themes; 6) and production of the analysis synthesis.¹¹ This study complied with Resolution 466/2012 of the National Health Council and was approved by the Research Ethics Committee of the State University of Feira de Santana, according to opinion No. 2,178,649.

RESULTS

The participants declared ages between 18 and 42 years old, with a mean of 27 years old. Six women were single, four declared to live in a stable union and one was separated. As for the occupation, six of the interviewees were housewives, three were farmers, one was a student in a vocational course and one was a supermarket clerk. Among the participants, the Catholic religion predominated, with six practitioners, two were Protestant, one was Candomblecist and two reported having no religion. Regarding schooling, six completed high school, one attended the first year of high school, another had completed elementary school and three did not complete elementary school.

The per capita income of families is predominantly less than half the minimum wage, being at the stage of social vulnerability. Some families have an income lower than the minimum wage, from social programs financed by the federal government and sporadic jobs, known as “moonlights”, usually developed by the parents.

The relatives model various caring attitudes such as taking into the lap, watching, stimulating, scheduling appointments, among others, which allowed the construction of the dimensions of care described in the category “Caring attitudes of relatives to children with SCZ”. Then, in the category “The Rosette of Care for children with SCZ”, we address the interactions between the child’s own care and the facets of care modeled by the family and apprehended in health services.

Caring attitudes of relatives to the child with SCZ

It was possible to group care practices in four dimensions: Fully care; “Look after”; Stimulate; and Access resources and services, as shown in Figure 2. We identified the four dimensions with similar levels of significance, with no distinct emphasis in the reports and, therefore, arranged in the figure in positions of equivalence.

Reports point to the direct relationship between the aforementioned care and the spaces of interaction that allowed for the knowledge and mastery of these practices, therefore, informational channels such as television, websites, social networks and social groups with people in similar health situations were the means of care learning, as Bianca reports:

We see it on the TV and now we have a group of mothers who teaches how to stay with the children, last month they taught how to make modeling dough with wheat flour, and we were already buying it and can't because they take everything to the mouth (Bianca, mother, 22 years old).

The **Fully care** dimension includes measures that seek to remedy the child’s physiological needs, as well as the search for health and therapeutic services. Thus, it is characterized as practices aimed directly at the child, which require physical contact, dexterity and handling of the infant’s body, maintaining constant vigilance to identify unexpected behavioral reactions, avoiding possible complications.

Furthermore, it is important to mention detailed stages of care, such as: the act of nurturing is not only characterized as offering porridge to the child, but also includes making the food itself from the selection of ingredients, definition of flavor, identification of the most appropriate temperature and, mainly, knowledge of the stages swallowing, which will define the consistency of the food to be offered. Therefore, feeding the child with SCZ requires

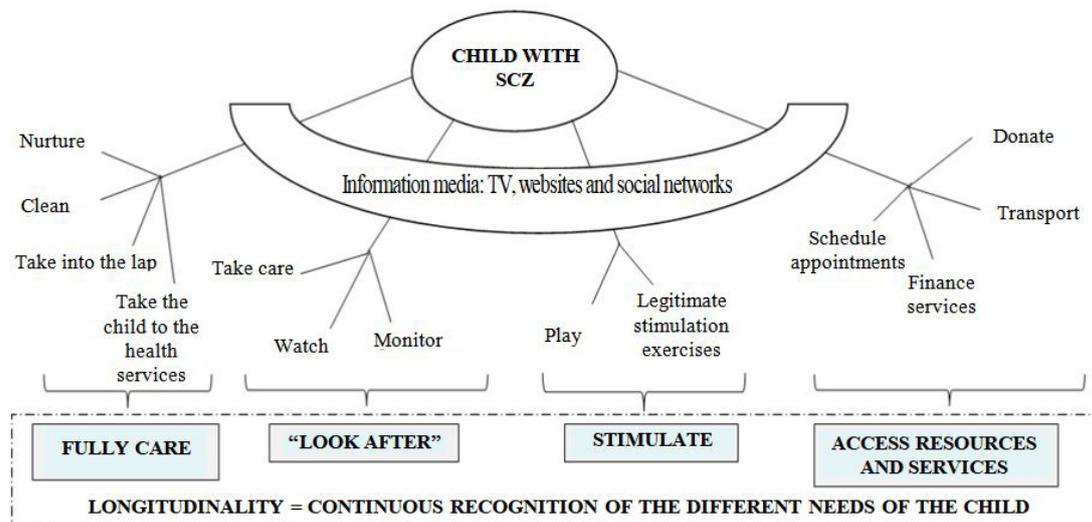


Figure 2 - Caring attitudes of relatives to the child with SCZ. Source: Elaborated by the authors based on data from the in-depth interview.

planning, execution and surveillance, rationalizing the offer and the appropriate positions for this care.

I take their flour for the porridge, then you have to know the right point for this, with little sugar and warm, otherwise the child does not swallow (Bianca, mother, 22 years old).

The relatives also perform specific steps when taking the child into the lap and sanitizing, which involve bathing and changing diapers, as well as taking children to professional care services, consequently adapting their behaviors when interacting with people in public spaces. They experience whirlwinds of thoughts about society's judgment of the child's body, so in order to alleviate malicious interpretations, they use accessories and clothing to hide microcephaly, choose the type of transport, the seat taken on public transport and the modes coping with the discriminatory and prejudiced comments they experience.

On the bus, they would come up to us and say 'how old is she?'. I say that she is one year and three months old, 'because she is one year and three months old and is she that big yet?'. Now I put this tiara on my head and people don't ask so much (Juliana, mother, 27 years old).

“**Look after**” means the act of keeping watch over the child, having a watchful eye for the correct sleeping position, watching over the siblings and “spending time” with the child on their lap or performing other chores, such as household chores.

The act of “looking after” aims at preventing possible accidents, early intervention in episodes of acute complications of SCZ or being with the child while another relative performs activities for the well-being of the child or family.

It is just my oldest (son) who looks for, so if I go to the city fast, agile, he takes care of her, if it were not him there would be no one (Paula, mother, 33 years old).

This report exemplifies the fragility of Paula's social support network, which, when there are no other people to take care of the child, uses the older child, that is, a scenario is formed in which one child needs to take care of the other.

In this dimension, relatives practice being with the child, carrying out the most diverse activities that they do not perform alone, such as playing, telling stories and drawing. Watching means directing attention to the independent activities that the child is able to perform, requiring the family's vigilance, such as watching television, listening to music and playing with dolls and balls, for example. Supervising is essentially a surveillance action that a relative, often the mother, performs over another relative, a condition in which there is a judgment of the family's ability to care for the child.

The **Stimulate** dimension covers the movement of the child's body, cited by women as playing or stimulating, understood as the repetition of exercises learned with health professionals, such as physiotherapists and speech therapists.

Some relatives organize a specific space in the child's home for stimulation, buy or receive rugs, tatami mats and toys similar to those used in professional services, also reproducing the stimulation practices carried out in these spaces.

Playing is understood as any body movement of the child that amuses and stimulates the smile. Thus, the delay in development does not determine the choice of play, it is eligible to promote joy to the child, considering rehabilitation as a consequence.

The caring attitudes that make up the dimensions are progressive and change based on the child's interaction with relatives. It is about recognizing the children's progress and new needs, a longitudinal role exercised meticulously by those who practice care more often.

The fourth dimension, **Access resources and services**, gathers the care practices designed to facilitate the scheduling of consultations and to optimize the waiting time for their performance, fund the health and treatment services, provide resources for the transport of the child and those responsible for the health services, in addition to the donation of materials for the child's use, such as milk and diapers.

Since the suspicion of the diagnosis and even after the prescription of the recommended therapeutic measures, the family's daily routine intensifies with comings and goings to health services regularly; however, for medical consultations with specialists, or even for high-tech exams, concerns about the time and cost of consultations emerge. To this end, seeking to streamline the therapeutic itinerary, the relatives get in touch with friends who can intermediate the scheduling of consultations and shorten the long wait for such services. When it comes to high financial costs, they use campaigns among close people or even on social networks for voluntary contributions of any value, widely known as chip in.

Given the complex therapeutic itinerary, relatives organize themselves to ensure this route, lend vehicles, make themselves available to drive the itinerary, pay for fuel and transport through applications. Various material contributions were also reported by relatives, such as basic baskets, diapers and cash.

The family really helps, if you go to the fair, one brings a packet of milk, one brings a packet of diapers, but it is not right (Maria, sister, 21 years old).

The caring attitudes of this dimension enjoy sporadic, voluntary and, although intermittent, essential character, which can result in anxiety and constant concern on the part of mothers in view of the unpredictability of resources.

The attitudes mentioned in the four dimensions were pointed out as daily practices, understood as actions performed daily or almost daily. In addition, they are caring attitudes performed in the midst of intense crying, agitation, convulsions and body stiffness, characterizing care as specific and singular. Therefore, a care space is permeated by intense stress and emotional appeal to the caregiving mother, who keeps constant vigilance to prevent complications to the child, making her care very special in its conception and execution.

The Rosette of Care for the child with SCZ

The role played by each relative was related to the care dimension, resulting in the illustration in Figure 3. In it, the relative is represented by a specific color, when this color overlaps the columns for each care dimension, it means that the relative models the care included in that dimension. As an example we will use the mother, represented by the red color: the red line over the first three columns means that mothers exercise Fully care, "Look after", and Stimulate. The same interpretation can be made for other relatives. The circles named "self-care", "family care", and "care in the networks" schematically represent the Rosette of Care for children with SCZ.

Despite being understood as interdependent care, the child's own care triggers other care activities. Carla, for example, identifies that her son does not like some foods and therefore cries, so she opts for heated porridge, although this action requires other efforts.

I usually make porridge for him, because he has difficulty eating certain things, there are things he doesn't like and he cries a lot. I wanted him to eat Danone, but when I go out, I only take porridge and have to go warm (Carla, mother, 29 years old).

It is worth highlighting the protagonism and role of coordinator of the care exercised by the mother. Figure 3 represents the maternal activity of interpreting the signs, behaviors and desires emitted by the child, their own care, and then it is up to them to judge the skills of each relative and define the most qualified person to perform the care, which may include themselves.

Juliana and Bianca cite their justifications for restricting the care provided by the father and cousin:

The sole thing he (male parent) does not do is bathing the child, because he doesn't even know how (Juliana, mother, 27 years old).

My five-year-old niece could only walk with Ramon (a child with SCZ) on her lap, it is all the time, we are not afraid to drop it (Bianca, mother, 22 years old).

Still in Figure 3, it is possible to perceive that each representative line of the relatives only reaches the dimensions of care after contact with the column that represents the mother, that is, it is the one who defines the relatives' care attitudes. For this, she uses the strategies of persuasion, guidance and encouragement so that this person takes care of exactly how she thinks she should be.

Ana positively judges the care skills of her sister, who has cared for children in past experiences, and is therefore chosen to develop various caring attitudes. However, in the face of the unknown episode of convulsion in the child, the mother tried to teach her sister how to act, which she learned and conveyed confidence to the family:

My sister is just like me, she bathes, she gives food, she gives meals at the right time, because she knows how to take care of a baby. I trust her, only after she saw Anita having a seizure, she was scared, I explained to her what it was like. There, she became normal. With her I'm trusting to leave, so I can rest a little, so I can sleep a little. With her I have confidence, not with others (Ana, mother, 23 years old).

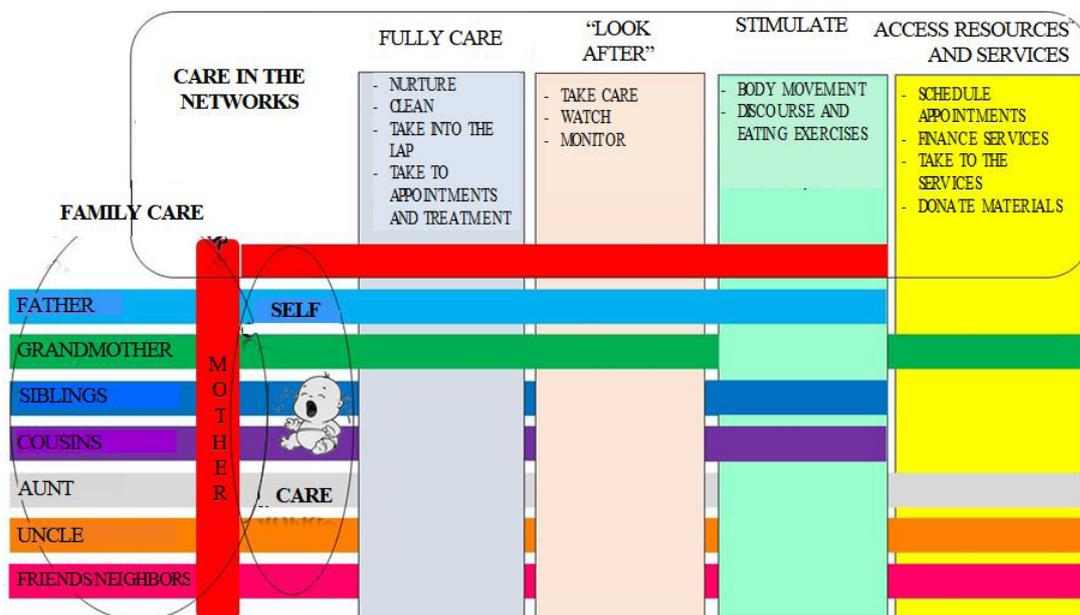


Figure 3 – Rosette of Care of children with SCZ
Source: Elaborated by the authors based on data from the in-depth interview.

Figure 3 also illustrates the family care nucleus consisting of mother, father and grandmother, relatives who participate most in the care. The mothers consider that caring for the child requires a lot of responsibility and, for Carla, she would not have another person better able to care than the mother herself, so she decides, after six months of maternity leave, to quit her job to fully take care of the child.

I stopped working because I had no one to look at him. I think the responsibility is mine, because there is a lot of rush to be at the doctor, to do physical therapy, so I really had to be present (Carla, mother, 29 years old).

When the mother is the sole provider of the family, the daily care is transferred to another relative who maintains a trusting relationship with her. The mother assumes full care of the child only at night, when she returns from work, or in her free time, always with her employer's understanding for some delays or absences in the working day.

Because I only stay home at night, my girl (daughter) does everything for her. When I get home and on days off I take care 24 hours all day long. Sometimes I leave before work, my boss lets me go and says nothing, I get my full salary (Júlia, mother, 42 years old).

Parents' roles are defined by their ability to perform tasks. They are responsible for playing and stimulating, while others avoid offering food, due to the risk of regurgitation, and do not bathe, as mothers judge them as little skilled to do it.

To take care of it is to hold it, but to give it a bath, food, juice at the right time, these are my business because I'm afraid of giving it (Ana, mother, 23 years old).

It is worth highlighting that the parents perform the aforementioned care attitudes except accompanying the child to the health services, supposedly due to the incompatibility of their working hours with those of the services, or to the parents feeling they scarcely belong to the settings of these spaces.

Since SCZ was discovered, the protagonism of the grandmothers has stood out. Both in a motivational role and offering emotional support to the family, they accompany the mother during the puerperium and stay there any time the mother needs to be away, as Juliana reports:

"When I go to the street and I don't want to take her (child with SCZ), I leave her with my mother"(Juliana, mother, 27 years old).

The grandmothers offer financial help with the care of the child with SCZ, have a retirement to count on, and help to buy medications, and to pay the rent of the house and the school costs of their grandchildren.

DISCUSSION

Family care for children with SCZ is modeled after the interaction¹² among the child's self-care and the family's caring attitudes. This has arsenals of care practices built by previous experiences, triggered when there is a stimulus of the child's own care.⁷ In summary, self-care is manifested by crying, muscle stiffness, and agitation, among others, that trigger the management of family care.

Therefore, such care is consolidated in the family environment as the previous generations practice it, transmit it inter-generationally and, consequently, ensure the family cultural synthesis.¹³ On the other hand, innovative or little-known care attitudes among relatives are practiced by younger generations and can be consolidated as family care by demonstrating efficiency and effectiveness for all. Therefore, in both situations, what is learned from the interaction with care in the network is barely evident. In this way, specific care for children with SCZ is modeled after the proper caring act, and the previous experiences can be adapted, presenting, nevertheless, an unprecedented nature, since it had never been performed before in similar SCZ situations.

In this study, relatives naturalize the caring attitudes of the "Fully care", "Look after" and "Access resources and services" dimensions, differently from what happens with "Stimulate". Such behavior can be justified by the novelty in stimulating the child, an attitude of care that is hardly performed in previous experiences³ and that, when employed, aims for the best development of the child and awakens the mother's identity as a woman-mother-of-child-angel, who continues to think of the State's negligence as a cause and moves collectively to reduce social inequities.¹⁴

In summary, care absence in the health services would make it difficult to have the "Stimulate" dimension and disqualify the other dimensions. Although mothers did not mention this relationship between professional care and other dimensions, a study proves that they routinely attend the health services, where they apprehend care,⁴ even if they offer services of unsatisfactory quality regarding care humanization.¹⁵

However, the relatives narrated their anxieties and fears about the risk of pulmonary aspiration and seizures, for example, which reflected in recognition of the progress in the child's development and, consequently, adjustments in family care, constituting a myriad of very personal care.

It is understood that self-care and family care trigger the functioning of the Rosette of Care. There are times when the child manifests itself, sometimes with crying or body agitation, indicating discomfort or suffering, sometimes with smiles, expressing well-being.

It is understood that self-care is essentially constituted by the child's real development, that is, tasks that the child can perform alone, such as changing the position to get rid of suffocation, and the potential development that the child can accomplish with the help of an adult.¹² In this regard, the distance between what the child can perform autonomously and potentially with the help of an adult is called the Zone of Proximal Development (ZPD);¹²

therefore, when manifesting itself, the child triggers self-care and matures his ZDP through family care.

Such self-care triggers family care, requiring skills to interpret crying, body movement, looking or any other expression of the child.³ However, family care is also performed in the absence of self-care, such as the planned act of sanitizing, which prevents other illnesses.

The interaction between people and living conditions determine intellectual development and the aspects that can favor children's learning.¹⁶ In this sense, mothers, fathers and grandparents constitute the fundamental tripod of the family to care for the child. These relatives perform essential care, eminently necessary for the children, intercalating and replacing the roles with each other.

Care is socially assigned to women: they are the ones who commonly disengage from formal work to fully care for their children, while men are the home providers.¹⁷ It should be noted, however, that, as this study points out that women maintain their employment relationship when they are the only relative with a fixed income and, therefore, a social division of family activities is evident depending on the family income, it is not possible to interpret it exclusively from the cultural division between the natural caregiver woman and the provider man.

The other relatives such as father, grandmother, sisters (brothers) and aunts (uncles) play a complementary role,^{2,18} which can sometimes generate conflict between relatives, sometimes favor social support for promotion of the family's quality of life, a scenario that is more beneficial for mothers and that reduces their levels of anxiety and depression.¹⁹

The actions planned by the mother tend to prevail even if the child is in the care of another relative. Mothers believe that no relative knows the child better than they do, so they judge the relatives according to their skills, knowledge and care experiences, to later list the care practice that each one can exercise.¹⁷ This behavior can leave them alone for providing care or, even, the fear of exposing the child to society can isolate them and restrict their coexistence to the domestic environment,⁵ resulting in stress and depression. In this sense, mothers need family and professional support to build their individual empowerment process, exterminating the "culture of female silence" and making other relatives responsible for the care.⁵

Parents of children with SCZ have low levels of mental health and satisfaction with life, in addition to emotional disturbances and high levels of fatigue and negative effects.²⁰ These levels are more pronounced in mothers, with repercussions such as joint pain, headache, asthenia, insomnia, tiredness, anxiety and depression.²¹ Therefore, with the growth of the child with SCZ and the denial of access to appropriate equipment, such as a wheelchair, the illness of the relatives tends to be intensified.

CONCLUSION

This study highlights the very personal care for children with SCZ that differs from the care for children with other anomalies, justified by the epidemic scenario and the little scientific knowledge about SCZ, requiring innovations in care attitudes.

The results indicate the need to qualify the singularity of monitoring child and family care, including relatives in the Nursing Care Systematization. The quality of communication of the diagnosis of the disability and the skills that lead to the understanding by the relatives prevent the yearnings for the establishment of a cure and avoid the agency of exhausting therapeutic itineraries.

It is necessary that nurses from the Family Health Strategy or from the Rehabilitation Centers coordinate child care with the mothers, empowering them. The use is suggested of family assessment instruments such as genograms and ecomaps in order to identify the types of relationships existing in families and encourage parents to adjust their workload, reflecting on the frequent participation of care with a view to reducing the burden of the mothers' tasks. It is important to highlight that the results of this study and the proposals for improving the assistance of the health services must compose the syllabus of the pedagogical projects of the courses in the area of health and social assistance, as well as promote the development of extension projects of higher education institutions in the communities.

The participation of other relatives in this study could show different understandings about the care attitudes of each person, the limitation of this study residing in this aspect. In addition, it is emphasized that research studies with families of children with SCZ should be carried out periodically, as the advancement of the child's growth and development imposes new needs, changes in care attitudes and family reorganization for care. It is also proposed that methodologies for observing family care, such as ethnography, may come to be developed in future studies in order to monitor and understand the evolution of the phenomenon.

AUTHORS' CONTRIBUTIONS

Study conception and design. Data collection, analysis and interpretation of the results. Content writing and/or critical review. Approval of the final version of the article. Responsibility for all aspects of the content and integrity of the published article. Paulo Roberto Lima Falcão do Vale, Evanilda Souza de Santana Carvalho.

Analysis and interpretation of the results. Content writing and/or critical review. Approval of the final version of the article. Responsibility for all aspects of the content and integrity of the published article: Deisyane Vitória Alves, Rita da Cruz Amorim.

ASSOCIATED EDITOR

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