

# Social network training: evaluation and applicability to care for children with chronic diseases

Capacitação em rede social: avaliação e aplicabilidade na atenção à criança com doença crônica Capacitación en redes sociales: evaluación y aplicabilidad en el cuidado de niños con enfermedad crónica

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#### ABSTRACT

**Objective:** to evaluate the impact on health professionals of a training workshop on the use of the social network methodological framework and to identify limits and possibilities for applying this framework in care for children with chronic conditions and/or diseases. **Method:** this qualitative study with professionals from family health teams, who participated in training workshops in social networking. Data were collected from October to November 2017, and interpreted using thematic content analysis. The study was approved by the research ethics committee. **Results:** knowledge about the methodological framework was a source of satisfaction and novelty that helped care for children, and for users of other age groups. **Conclusion:** command of the social network framework poses a challenge for care in family health units. Nonetheless, health personnel see this frame of reference as a possible means of optimizing care for children with chronic diseases.

Descriptors: Family Health Strategy; Social Networking; Social Support; Child Care; Chronic Disease.

#### **RESUMO**

**Objetivo:** avaliar o impacto de uma oficina de capacitação sobre o uso do referencial metodológico de rede social junto a profissionais de saúde e identificar os limites e possibilidades para a aplicabilidade desse referencial no cuidado às crianças com condição e/ou doença crônica. **Método:** estudo qualitativo, com profissionais de equipes saúde da família que participaram de oficinas de capacitação em rede social. A coleta de dados transcorreu de outubro a novembro de 2017, sendo interpretado pela análise temática de conteúdo. Estudo aprovado pelo Comitê de Ética. **Resultados:** o conhecimento acerca do referencial metodológico significou satisfação e uma novidade que auxilia a prática assistencial no atendimento de crianças, bem como aos usuários de outras faixas etárias. **Conclusão:** a apropriação do referencial de rede social se constitui em um desafio para o cuidado nas unidades de saúde da família. Ainda assim, os profissionais veem o referencial como uma possibilidade de otimizar cuidado às crianças com doenças crônicas.

Descritores: Estratégia Saúde da Família; Rede Social; Apoio Social; Cuidado da criança; Doença Crônica.

# RESUMEN

Objetivo: evaluar el impacto de un taller de capacitación sobre el uso del marco referencial metodológico de la red social junto a profesionales de la salud e identificar los límites y posibilidades de aplicabilidad de este marco en la atención de niños con afecciones y / o enfermedades crónicas. Método: estudio cualitativo con profesionales de equipos de salud de la familia que participaron en talleres de formación en red social. La recolección de datos tuvo lugar de octubre a noviembre de 2017, siendo interpretada por el análisis temático de contenidos. Estudio aprobado por el Comité de Ética. Resultados: el conocimiento sobre el marco referencial metodológico significó satisfacción y una novedad que ayuda a la práctica asistencial en el cuidado de los niños, así como a los usuarios de otros grupos de edad. Conclusión: la apropiación del marco de redes sociales constituye un reto para la atención en las unidades de salud familiar. Aun así, los profesionales ven el marco referencial como una posibilidad para optimizar la atención a niños con enfermedades crónicas.

Descriptores: Estrategia de Salud Familiar; Red Social; Apoyo Social; Cuidado del Niño; Enfermedad Crónica.

## INTRODUCTION

Chronic diseases or conditions in childhood are a serious public health problem and, in adult life, they represent the main cause of morbidity and mortality worldwide, with emphasis on cardiovascular diseases, tumors, chronic respiratory diseases and diabetes<sup>1</sup>. These and other chronic diseases have imposed challenges to the health system, which needs to assist children with chronic conditions of varied etiologies and different prevalence values. This requires specific treatment, continuous monitoring and integration across the health care network services<sup>2</sup>.

The family routine of children who suffer from these diseases becomes a difficult experience and a challenge that affects family functioning, often marked by continuous hospitalizations, increased demands for health services, cultural

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particularities, family concerns, social isolation, burden in parents or caregivers, conflicts, stress, fear and need for adaptations in the home environment<sup>3-5</sup>. Given these changes, the family needs to have a social network to assist in the care provided to the child.

Social network, which can be primary or secondary, comprises a set of interpersonal relationships that determine the person's characteristics, such as: habits, customs, beliefs and values, and that, from this network, the person can receive emotional and material help, services and information<sup>6</sup>.

The primary social network consists of the family, relatives, neighbors, friends and colleagues; and the bond established is one of trust and reciprocity. The secondary social network, on the other hand, can be formal, informal, external from the third sector, market-related and mixed, which are distinguished by the way in which they originated and the types of exchange that the members establish among themselves, such as: reciprocity, law, money or a combination of these<sup>6</sup>.

A stable social network is considered a protective factor for a variety of chronic diseases as it can help minimize pain and stress, as well as psychological distress, and also improve self-management<sup>7</sup>.

Thus, even facing adverse situations, such as in a chronic condition and/or disease, the experience becomes less painful when the child has an effective social network, capable of offering support in all phases of the disease<sup>8</sup>.

In addition, the literature shows that interventions with an emphasis only on the biomedical model have been insufficient to understand the real needs of the population. Therefore, there has been growing interest in the research studies that address the sociocultural conditioning factors, such as knowledge of the social network and support of the population<sup>9-11</sup>.

Among the components of the social network of children with chronic conditions and/or diseases, primary health care professionals stand out because they work closer to the homes where the children live. Thus, for support to be effectively implemented, it is necessary that these professionals have a conception of networking, in a way that encompasses the context of the family, the community, the hospital and the school, with a view to strengthening the intersectoral relationships and bonds established between the various members of the network<sup>11-12</sup>.

In this sense, a person's social network can be identified by drawing up a map, where it is possible to graphically visualize the structural dimension of the primary and secondary networks, as well as the type of relationship that the members establish with each other. Therefore, according to the methodological framework employed in this study, for the representation of a person's social network map, frames with geometric figures are used to represent the network members, as well as the types of links established between such members<sup>6</sup>.

Several authors emphasize that providing assistance to children with chronic diseases in primary health care services has been a challenge for the professionals who work there, due to the fact that the care model of these services often privileges assistance for acute conditions, in addition to the lack of qualification for this type of care and of articulation with the other services of the health care network<sup>13-14</sup>.

This study assumes that, the greater the support offered by the components of the social network of the family that has a child with a chronic condition and/or disease, the greater the resources that the child will have available to face the situation of vulnerability and respond positively to their condition. Thus, the use of the Sanicola's approach on social networks as methodological framework by professionals from the primary health care network may prove to be a resource for strengthening the relationships established between these professionals, families and/or other network members, and contribute to expanding and enriching the assistance provided.

In this context, this study aimed at assessing the impact of a training workshop on the use of the social network methodological framework with health professionals and to identify the limits and possibilities for the applicability of this framework in the care of children with chronic conditions and/or diseases.

# **M**ETHOD

This is a descriptive-exploratory and qualitative study, carried out from October to November 2017 with thirteen professionals from Family Health units in a municipality in northeastern Brazil. The inclusion criteria for the study participants were as follows: working in a Family Health team, having participated in a training workshop for the use of the social network methodological framework<sup>6</sup> and having applied the method in the care of children with chronic diseases.

A total of 16 professionals from seven Family Health units in the municipality of of João Pessoa – PB participated in the aforementioned training workshop. Of these, meeting the inclusion criteria in this study, 13 professionals were selected who, after the training, applied the social network framework method proposed by Sanicola<sup>6</sup> in the care of families of children with chronic conditions and diseases in their work context.



Thus, one month after the training workshop, the researchers conducted semi-structured interviews with those professionals based on the following guiding question: In the care of children with chronic conditions and/or diseases, what has the use of the social network framework meant to you?

The interviews were recorded in MP3 format and lasted a mean of 35 minutes. After transcribed in full, the empirical material was interpreted by two authors using the thematic content analysis proposed by Bardin<sup>16</sup>, according to the following stages: pre-analysis, exploration of the material and elaboration of an interpretative synthesis, which allowed identifying central themes, which were aggregated in three categories.

In the pre-analysis phase, the ideas contained in the statements were organized and systematized, by means of floating reading. Exploration of the material consisted of procedures for identifying the sense nucleus evidenced in the excerpts from the statements, as well as identifying the thematic units that resulted in the elaboration of the categories. In the interpretative synthesis of the results, it was sought to understand the meaning of the reports evidenced in each category, through the interpretation of the results in light of the theoretical framework pertinent to the study theme<sup>15</sup>.

The project was approved by the Ethics Committee under opinion No. 20659448 dated 05/16/2017 and CAAE 66603317.2.0000.5238. The participants signed the Free and Informed Consent Form.

To ensure anonymity, the excerpts from the statements were identified by the letter "P", representing each interviewed participant, followed by Arabic numerals according to the order in which the interviews were conducted.

#### RESULTS

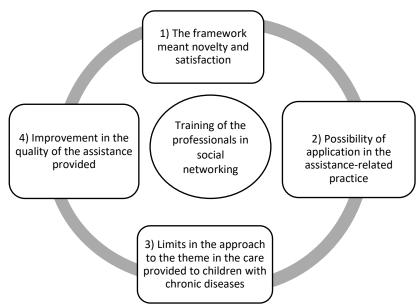
Of the 13 study participants, eight were female nurses, three were Community Health Agents (CHAs), and there was a physician and a female dentist.

Regarding the profile of the children seen by these professionals, their age ranged from one to eleven years old, and with respect to the main caregivers, 11 were mothers and two were grandmothers. Among the types of chronic diseases and/or conditions of the children followed-up, neurological and cardiovascular disorders stood out (Figure 1).

Participants	Professional Category	Child's age (in years old)	Main caregiver	Type of chronic disease/condition of the child
P1	Nurse	9	Grandmother	Cerebral palsy
P2	CHA	7	Mother	Myelomeningocele
P3	CHA	2	Mother	Microchefalus
P4	Physician	4	Mother	Attention deficit disorder and Epileptic syndrome
P5	Nurse	9	Mother	Henoch-Schönlein purpura
P6	CHA	6	Mother	Type 1 Diabetes Mellitus
P7	Nurse	1	Mother	Congenital heart disease
P8	Nurse	10	Mother	Cerebral palsy
P9	Nurse	1	Mother	Congenital heart disease
P10	Nurse	1	Mother	Microchefalus
P11	Dentist	10	Mother	Down syndrome and Autism
P12	Nurse	6	Mother	Nephrotic syndrome and Systemic arterial hypertension
P13	Nurse	6	Grandmother	Cerebral palsy

**FIGURE 1:** Professional category of the participants and characteristics of the children seen according to the social network methodological framework. Municipality of João Pessoa, PB, Brazil, 2017.

In order to better explain the participants' perception/learning after presentation of the social network methodological framework through the training, the researchers synthesized a scheme (Figure 2):



**FIGURE 1:** Clinical representation of the participants' perception about the training on the social network methodological framework. João Pessoa, PB, Brazil, 2017.

From data analysis, three empirical categories were elaborated: Meaning of participating in the social network training workshop; Possibilities to apply the social network methodological framework in the assistance-related practice; and Limits to address the theme of the social network of the family of a child with a chronic condition and/or disease.

## Meaning of participating in the social network training workshop

For the participants of the training workshop, knowledge about the methodological framework to approach the social network of the assisted families meant satisfaction and a novelty that helps primary health care professionals to not see themselves alone in the care provided to children with chronic conditions and/or diseases.

It's a new thing for me. I had never even thought that way, about what a network was, that our knowledge implied a social network and I found it very interesting, because it's a way of seeing ourselves and those around us. [...] I found it very important. [...] sometimes we think that we don't need anyone, even myself, but it's not true. (P2)

It was good, like that, I didn't know any specific social network framework[...] it's a very interesting tool, so much so that I spoke with D. (nurse) for us to collaborate with the staff of the teams (from the Family Health unit) and many found it very interesting. [...] I liked it very much. (P4)

I had never used it (this social network framework). [...] when you do this (design of the social network map), you finally notice that you're alone in the care provided to that child. So I loved that strategy [...] .... this is very important. (P5)

In this perspective, the reflection on the social network was a possibility for the professionals to broaden their perspective and see the relational context of the child/family that lives with a chronic condition and/or disease, in order to identify the support points present in the network, as well as to strengthen the bond with the family.

It helped to think, to use reason, to see what can be done to contribute. [...] knowing who you can count on, what today, in reality, that family has as an instrument, who can help, who can contribute to that child's care... it's a kind of support really; bond, support. And I think that it opened horizons. (P8)

[...] it was a new horizon. It is possible to identify all the people who are part of the context of this user and the life context itself, in the sense of support, in the sense of better understanding the way that this person lives and everything that surrounds them, which can generate health. (P12)

According to the statements, the training favored a perspective towards the other and the search for strategies to meet the population's health needs.

[...] it served as a reflection for me to ask myself what I can do to help (mother of a child with a disease). Not staying in that comfort zone, seeing if the biggest need is for a psychologist, a social worker, knowing what



else I can do or what a certain type of relationship means... It helps us to have a more special look at everyone. (P9)

Participation in the workshop's practical module also contributed so that the professionals, with the help of community health workers or friends, could identify children with chronic diseases living in the area covered by their unit, who were previously unknown to other professionals at the Family Health teams.

I didn't even know about that case. It was very good, because it was only through the social network training that I learned about the case (that the child had a heart problem), because until then I didn't know. [...] with this work I went to check on her situation (the mother's) and I saw that she's practically alone. (P13)

The elaboration of the map with the families of children with chronic diseases, an activity proposed in the training workshop's practical module, allowed the professionals to perceive the mothers' solitary coping with this problem.

I had this sensation that she (the mother) was alone... it's complicated! What do you say in such situation? We are really going to point out alternatives to further strengthen this network. (P8)

I felt sorry for the mother, I discovered how isolated she is, that she has difficulty even receiving help from her own daughter or husband. (P11)

# Possibilities to apply the social network methodological framework in the assistance-related practice

The workshop sensitized the professionals, who realized the possibility of expanding the use of the methodological framework for users belonging to other age groups and with other health problems, in addition to the child's chronic condition and/or disease.

This (framework) is useful not only for the care of G, (child with a chronic disease), but for all my hypertensive, diabetic users, who have some vulnerability. With this (method), we can help people see who they have in life, who they can count on and who they can't, which resources they have and which ones they don't have, and what needs to be improved. (P1)

It's certainly possible for us to map the social network of other children (with chronic diseases) or of other patients. (P13)

In order to implement this new methodology with the users, the participants shared the knowledge acquired with other members of the Family Health team.

I found it a wonderful strategy. We even shared a lot of great ideas. [...] We passed it on to the rest of the team in a big meeting. (P5)

In the next meeting, I'm going to show this here, have a talk [...] to see how we will really apply it into our daily lives, our practice, our routine. (P8)

Using the framework on the social network also represented the possibility of improving care, through knowledge of the situation experienced by the families, establishing a close relationship and offering support.

I understood in this course that this is not just my thing, that it already exists, that I can improve myself and offer the patient something better, better quality assistance, more .... human: I think that this is being more human. The person arrives, you don't know anything about their life, but with the map (of the social network) you can visualize it quickly. (P12)

I tried to see with her (the mother) what is it that we could do to further improve that network. [...] or put some situations right. (P4)

# Limits to address the theme of the social network of the family of a child with a chronic condition and/or disease

Among the limitations mentioned by the professionals to know the social network of families of children with chronic conditions and/or diseases, their non-attendance to the Family Health unit and the preference for using specialized services or the private network were highlighted.

The mother doesn't bring the child (with myelomeningocele) to the consultation, she only brings him, she only brought him, sometimes, to get the report to receive the benefit (P2)

She (mother of a child with microcephaly) is very resistant to coming to the Family Health unit. She said that she only comes because of S., who is a community health agent. [...] They have a good income and everything they can do through the health plan and the private health service, they do. (P5)

Another factor that hinders access of professionals to children with chronic conditions and/or diseases refers to the child's physical and psychological characteristics, which confines them to their homes or leads them to receiving care only from the physician.



(During the home visit) I saw that the girl is unable to come to the unit, as she's aggressive, kicking and screaming all the time. (P11)

[...] when they come here (children with chronic conditions and/or diseases), when the patient has some complication, we schedule an appointment with the physician, because most of the time it's more a medical appointment, because it's for the renewal of prescriptions. (P1)

## DISCUSSION

The results showed that social network training exerted important impacts for the professionals working in Family Health teams, who were able to expand their knowledge and understand the limits and possibilities of strengthening the bond with caregivers of children with chronic conditions and/or diseases.

Corroborating these findings, a study on the planning of permanent education actions aimed at health professionals showed the importance of professional training for the development of new skills and competences with a view to qualification and resoluteness in primary care<sup>16</sup>. In addition to that, permanent education actions or training workshops enable the professionals to constantly improve their work processes, as well as to participate in decision-making with their team<sup>17</sup>.

However, for this to occur, the contents worked on in the training workshop need to have a meaning for the health professionals. According to Ausubel's Theory of Meaningful Learning, it is necessary that the content is related to the individuals' prior knowledge, demanding a favorable attitude from them, capable of attributing proper meanings to the contents they assimilate. Therefore, if the new is incorporated into the learners' cognitive structure, they will be interested in incorporating it to their professional practice<sup>18</sup>.

Thus, understanding the structure of the social network of the assisted family made it possible to broaden the professionals' view of the child's relational and environmental context, as well as to identify the points of social support that the family can count on in view of the demands or needs of long-term and continued care. In addition to receiving social support from their family, neighborhood or friends, children with a chronic condition and/or disease can receive different types of support from the multi-professional team of the health care network at the primary, secondary and tertiary levels<sup>19</sup>.

It is known that the child's chronic condition and/or disease has psychological and social repercussions, as well as on the family dynamics, and that the families' needs are complex. Therefore, these needs must be considered in care planning, and it is essential that the health team perceives the potential, particularities and difficulties faced by each family so that care is more unique and effective<sup>20-21</sup>.

From this perspective, a number of studies have shown that the bond between the multi-professional health team and the family constitutes an important point of support for coping with the child's chronic condition and/or disease<sup>4,19</sup>. Hence, the health team must develop qualified listening and humanized care, aiming to participate in the process of creating support networks so that the child and family enjoy a better quality of life<sup>22-23</sup>.

The monitoring of families of children with chronic conditions and/or diseases, through the use of the social network methodological framework, made it possible to bring primary care professionals closer to the family members who, in most cases, were unknown by all team members of the Family Health strategy, as these families experienced the situation of the child's chronic condition alone.

Among the possibilities of using the framework proposed, the participants highlighted the importance of using this tool in the care of individuals belonging to other age groups or health problems. In addition to that, they address the importance of sharing the knowledge acquired in the training for other members of the Family Health team, with a view to expanding the care provided to different human groups.

Regarding access and care of children with chronic conditions and/or diseases in the health care network units, a number of research studies reveal the limitations in the accessibility of these children due to the gaps in the referral, counter-referral and regulation systems. This entails a long wait for scheduling examinations or appointments with specialists, or even the difficulty obtaining care, medications or the necessary supplies for the treatment<sup>24-25</sup>.

These results indicate that the primary health care network still does not play its role of ordering the care provided to families of children with chronic conditions and/or diseases, exerting a negative impact on the reduction of complications or unnecessary hospitalizations.<sup>22, 26-27</sup>.

# **Study limitations**

This study has as a limitation the fact that the data were collected from a reduced number of professionals who participated in a training workshop offered to teams from seven primary health care units in the municipality of João



Pessoa, which may not ensure generalization of the results to all the professionals working in Family Health units in the city. However, the research expanded understanding of the factors involved in the knowledge and applicability of a methodological framework for approaching the social network in children's health care.

## **CONCLUSION**

Appropriation of the social network framework constituted a challenge for the professionals working in the primary health care units. By participating in the training workshop, they verified the importance of acquiring new knowledge and new technologies in care planning, as well as for monitoring children with chronic conditions and/or diseases.

As possibilities brought about by this study, the following stand out: the intention to implement this new methodology with the users; the fact that the participants shared the knowledge acquired with other members of the Family Health team; the involvement of family members in the elaboration of the social network map, which indicated the potential to identify support points present in the network and for solving intra-family problems; and the professional's satisfaction in being able to use new methods to approach the families.

Non-attendance at the health unit, preference for private health services, the child's physical and psychological condition and lack of knowledge in the professionals were factors identified as hindering the implementation of the social network map.

In this sense, it becomes relevant to prepare these professionals, starting in the undergraduate course, so that they can offer support to the families assisted and perform effective actions aimed at optimizing the care provided to children with chronic conditions and/or diseases.

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