# STRUCTURE OF THE SOCIAL NETWORK OF MOTHERS/CAREGIVERS OF HOSPITALIZED CHILDREN

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**ABSTRACT:** Objective: Analyze the structure of the social network of mothers/caregivers during the hospitalization of their child. Method: Qualitative study in a pediatric hospital in Rio de Janeiro. Ten mothers/caregivers were interviewed from February to December 2015. A theoretical-methodological framework and social network analysis by Lia Sanicola were used. Results: The primary networks were medium-sized, with strong bonds, particularly the networks for children being hospitalized for the first time. They were more numerous than those for children who had been previously hospitalized. The following secondary networks were mentioned: formal, third sector and market. No mixed and informal networks were mentioned. Conclusion: Extended and frequent hospital stays of children affect the dynamics of social networks. Over the course of hospital stays, they become smaller, but the bonds within them are strengthened. The primary healthcare network was not mentioned, due to the fact that the children had been diagnosed with chronic diseases since birth.

**DESCRIPTORS:** Social support; Social networking; Family; Hospitalized child; Pediatric nursing.

# A ESTRUTURA DA REDE SOCIAL DA MÃE/ACOMPANHANTE DA CRIANÇA HOSPITALIZADA

**RESUMO:** Objetivo: Analisar a estrutura da rede social da mãe/acompanhante durante a hospitalização da criança. Método: pesquisa qualitativa, em hospital pediátrico do Rio de Janeiro. Foram entrevistadas dez mães/acompanhantes de fevereiro a dezembro de 2015. Utilizou-se o referencial teórico-metodológico e a análise de rede social de Lia Sanicola. Resultados: as redes primárias configuraram-se de tamanho médio e laços fortes, principalmente as redes das crianças que estão na primeira hospitalização, pois se mostraram mais numerosas comparadas com aquelas que já tiveram outras hospitalizações. Das redes secundárias, foram mencionadas: redes formal, terceiro setor e mercado. Não foram citadas as redes mista e informal. Conclusão: hospitalizações prolongadas e frequentes da criança interferem na dinâmica da rede social, tendo em vista que, ao longo das hospitalizações, ela se torna menor, porém com laços mais fortalecidos. A rede de atenção primária não foi mencionada e é justificada através do diagnóstico de doença crônica desde o nascimento.

**DESCRITORES:** Apoio social; Rede social; Família; Criança hospitalizada; Enfermagem pediátrica.

### ESTRUCTURA DE LA RED SOCIAL DE LA MADRE/ACOMPAÑANTE DEL NIÑO HOSPITALIZADO

**RESUMEN:** Objetivo: Analizar la estructura de la red social de la madre/acompañante durante la hospitalización del niño. Método: Investigación cualitativa, en hospital pediátrico de Rio de Janeiro. Fueron entrevistadas diez madres/acompañantes, entre febrero y diciembre de 2015. Se utilizó referencial teórico-metodológico y análisis de red social de Lia Sanicola. Resultados: Las redes primarias expresaron dimensión mediana y lazos fuertes, particularmente las redes de niños en su primera hospitalización, mostrándose más numerosas comparadas con las de niños previamente hospitalizados. De las redes secundarias, fueron mencionadas: red formal, tercer sector y mercado. No fueron citadas la red mixta y la informal. Conclusión: Las hospitalizaciones prolongadas y frecuentes del niño interfieren en la dinámica de la red social, considerando que, a lo largo de las hospitalizaciones, se hace menor, aunque con lazos más fortalecidos. La red de atención primaria no fue mencionada, justificándose por el diagnóstico de enfermedad crónica desde el nacimiento.

DESCRIPTORES: Apoyo Social; Red Social; Familia; Niño Hospitalizado; Enfermería Pediátrica.

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## INTRODUCTION

The social network approach first emerged in the area of social sciences and has been increasingly used in the field of health. The use of social networks, as a means of investigating the population's health conditions, is based on the understanding that health is a result of complex relationships among biological, psychological and social factors<sup>(1)</sup>.

Social networks constitute a significant healthcare resource and can be defined as the set of interpersonal relationships between family members, friends and institutions, among others. Individuals who maintain their social identity receive support, and may also develop other social relationships. These social networks are conducive to understanding how their members tailor their actions according to their specific needs<sup>(2)</sup>.

The presence of mothers/caregivers during the hospitalization of their child is legally supported through the Statute of the Child and Adolescent, since the right of a legal guardian to stay with a hospitalized child or adolescent is guaranteed by Law No. 8069/90<sup>(3)</sup>.

Since the enactment of this statute, which ensures this right of the child, the presence of caregivers has been noted, in most cases the mother<sup>(4)</sup>. When a mother has a child in the hospital and needs to become a caregiver, this detracts from her other duties as a wife, worker, and mother of other children, in order to dedicate herself solely to her hospitalized child<sup>(5)</sup>.

The suffering caused by the sickness and hospitalization of a child temporarily destabilizes the routine of family members and the domestic chores previously carried out solely by the mother, since they start being performed by other family members to enable her to stay at the hospital. Therefore, the hospitalization of a child should not be viewed as something separate from the family, since the latter mobilizes in order to continue operating and creates a new structure for adapting to the new reality that has arisen, and when necessary, it restructures itself to keep moving ahead<sup>(6)</sup>.

Based on this temporary crisis situation, mothers who stay in the hospital mobilize social networks to supply their needs<sup>(7)</sup>. The structure of the social network consists of the set of perceptible bonds that are established between people and networks. When these bonds are activated, they generate connections that shape the networks. The social network approach is a key to accessing the reality of human relations. Networks undergo structural changes over time and according to circumstances, and are set in motion by critical events<sup>(2)</sup>.

During the hospitalization of a child, the social network is composed of family members and friends, as well as the people with whom the mother/caregiver interacts during the child's hospitalization, such as the mothers of other hospitalized children and health professionals. Nursing professionals, therefore, are part of the network built within the hospital environment and can contribute positively to the process of coping with this very difficult time in the life of the child and mother/caregiver, by seeking ways to assist them and/or enable them to use social support networks<sup>(5,8)</sup>.

The construction of a social network for providing support during a child's hospitalization ensures mothers/caregivers that certain needs inside and outside the hospital setting will be cared for, and enables them to remain with the child in the hospital. Intra-hospital needs include emotional, material (clean clothes, personal hygiene products, food) and financial support. Outside the hospital, the needs are primarily related to the care of other children and domestic chores<sup>(7)</sup>.

In the national and international scientific literature, six articles were found that addressed the social network of family members of hospitalized children. These six studies pointed out the importance of social support networks and solidarity between mothers/caregivers built within the hospital setting, primarily due to the absence of family support<sup>(5)</sup>.

Three studies identified that support network structures are primarily composed of the family network and health professionals<sup>(8-10)</sup>. However, the weaknesses identified were related to non-continuity of the support received during the hospital stay and lack of involvement of health professionals<sup>(11)</sup>. In terms of secondary networks, the studies referred basically to tertiary health institutions<sup>(12)</sup>.

The social networks that mothers/caregivers of hospitalized children establish in their surroundings

and the services they provide are a possible means for understanding the situation and orienting professional activities focused on the complexity of the social relationships involved in the hospitalization of a child<sup>(13)</sup>.

Studies on social networks bring benefits to the relationships between individuals and characterize the web of social relationships surrounding them, including the contacts and nature of the bonds that connect them. Understanding the social networks of mothers/caregivers of hospitalized children is important because it enables health teams to identify the members of these networks and what the bonds between them are like. They can also identify the functions of each one and see which elements of these relational networks can be activated to make the support more effective<sup>(14)</sup>.

Although the importance of the social networks of mothers/caregivers has been recognized so that they can remain with their hospitalized child, the structure of these networks and their contributions toward strengthening these individuals in times of crisis, such as the hospitalization of a child, have not been clearly defined. In light of this, the objective of the present study was to analyze the structure of the social networks of mothers/caregivers during the hospitalization of a child.

# METHOD

This was a descriptive qualitative study based on the theoretical-methodological framework of social networks by Lia Sanicola. According to this author, social networks can be divided into two major categories: primary and secondary networks, which differ by the types of interactions that occur between the individuals<sup>(2)</sup>.

Primary networks are made up of family members, relatives, friends and neighbors, and secondary networks are divided into the categories of formal, informal, third sector, market or mixed, depending on the type of interaction. The formal secondary network is the set of state-run institutions that form the social welfare system for the population. The informal secondary network is an offshoot of the primary network, constituted by informal mutual help groups. Secondary networks from the third sector are those formed by civil society organizations that provide services, but not for profit. Market secondary networks are related to for-profit economic activities, and their existence is linked to money and profit. Finally, mixed secondary networks are those that mix different types of interaction, i.e., although they provide services that ensure a right, services are paid for<sup>(2)</sup>.

The site of the present study was a pediatric inpatient unit in a public hospital that specializes in pediatrics and is a reference for clinical and surgical diagnoses, located in the city of Rio de Janeiro, which hospitalizes children from the ages of 1 month to 12 years. The children come from the state of Rio de Janeiro, or other Brazilian states.

The study participants were ten mothers, who accompanied their hospitalized child and voluntarily agreed to participate in the study. The inclusion criteria were: caregivers who stayed full-time with their child, had been at least one week in the hospital, and did not have any difficulties/limitations in communicating. The exclusion criteria were: occasional caregivers for the child, caregivers under 18 years old, and caregivers of children in a critical/unstable clinical state at the time of the data collection.

The data was collected from February to December 2015. For selecting the participants, the on-duty nurse was consulted to indicate which caregivers remained with their child full-time during the week. Based on this information, they were randomly asked if they were interested in participating in the study.

The interviews, which were individual, were conducted using a form to characterize the participants and a semi-structured script to build a network map. They were recorded and then transcribed by the researcher. The anonymity of the interviewees was ensured, who were identified according to their kinship with the hospitalized child. The others cited in the network were identified according to the kinship or social relationship with the interviewee. There were no further interviews after theoretical saturation, since there were no new elements from the narratives of the participants.

The relational networks of the mothers/caregivers were analyzed through the creation of a map of their social network to determine its size and how bonds were established between the different types

of networks present. The analysis of the social networks required knowledge of their structure with respect to size – the number of people present, since size indicates whether a network is small (up to nine people), medium (from ten to 30) or large (more than 30 members), and also enables examining the types of bonds established among the members cited<sup>(2)</sup>.

To create the social network, it was necessary to use symbols in the form of geometric figures (representing the types of social networks) and graphic markings (indicating the type of bonds)<sup>(2)</sup>, as shown in Figure 1.

Types of Networks		Types of Bonds
Primary network –	$\bigcirc$	Strong -
Formal secondary network –		Normal -
Market secondary network-	$\triangle$	Weak -
Third sector secondary network -		Broken -
Mixed secondary network-		Conflictive -

Figure 1 – Representation of the types of networks and bonds. Rio de Janeiro, RJ, Brazil, 2016

This study was assessed by the Research Ethics Committee of the proposing and co-participating institution, being approved as per Opinion No. 938.786/2015.

#### RESULTS

The results were obtained through profiles of interviewees. As for the characterization of the ten interviewees, there were nine mothers and one great-grandmother (legal guardian). The age range was from 18 to 58 years. With respect to the location of residence, five lived in the city of Rio de Janeiro, four lived in other cities in the state, and one was from Africa, who at the time of the data collection was living temporarily in the city of Rio de Janeiro for her child's health treatment.

In terms of marital status, eight lived with a partner and two were married. The number of sons and daughters ranged from one to six. In relation to education: two had completed elementary school, three had not completed elementary school, three had completed high school, one had not completed high school, and one had graduated from university.

Regarding the medical diagnoses of the children, most were suffering from chronic diseases, such as: Arnold Chiari Malformation (2) (types 1 and 2); Diagnostic investigation (2) (suspected cystic fibrosis); cerebral palsy (1); chronic non-progressive encephalopathy (1); West syndrome (1); Chronic pulmonary histoplasmosis (1); Meningoencephalitis (1); and Biliary atresia (1). The length of time the children were in the hospital ranged from seven days to eight months.

It is important to note that it was the first hospitalization for four of the children who were there for a diagnostic investigation (2), whereas two children had been born and were sent straight to the hospital - study context - one with Arnold Chiari Malformation (type 1) and the other with biliary atresia. The other six children had been hospitalized in the past, with frequencies varying from two to 14 times.

The social network maps, obtained during the interviews, provided a view of the relational context

within which the mothers/caregivers of the hospitalized children were inserted. Figure 2 presents a map with a summary of the social network of the ten participants, illustrating the primary and secondary networks, with the main members cited and the respective bonds established during the period of hospitalization.

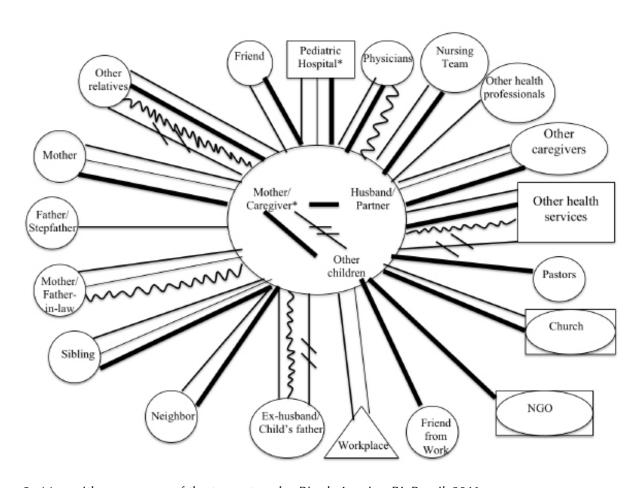


Figure 2 - Map with a summary of the ten networks. Rio de Janeiro, RJ, Brazil, 2016

The creation of the map with the summary considered all the social relations from the individual maps for each mother/caregiver, taking into account that the primary and secondary networks were composed of family members with the same kinship, as well as other people and institutions. However, in reference to the bonds established, they were: normal, strong, conflictive and broken. For this reason, there is more than one type of graphic marking in the figure above.

It was noted that out of the ten social network maps, nine were medium-sized (10 to 30 members), varying from 15 to 25 members. Only one social network map was large (more than 30 members), with 32 members, according to the theoretical-methodological framework used<sup>(2)</sup>.

The primary networks of the mothers/caregivers of children in the hospital for the first time, although considered medium-sized, had a larger number of members than the primary networks of mothers/caregivers whose children had been readmitted and hospitalized for a longer length of time, i.e., they had a more restricted primary network, but with strengthened bonds. The social networks for first-time hospitalizations can be characterized as large.

Also in reference to primary networks, the ten mothers/caregivers interviewed established strong bonds with their partners/husbands and children, and six of them established strong bonds with their mothers (relative), whereas one had a normal bond and the other, a conflictive one. Two participants did not cite their mothers, since they were deceased. They reported having normal bonds with other family members referred to here as relatives, such as aunts: strong bonds with six aunts, normal bonds with six, and a conflictive bond with one. Of the eight female cousins cited, there were strong bonds

with half of them and normal bonds with the other half. In relation to in-laws (seven mothers-in-law and two fathers-in-law), there were normal bonds with six, conflictive bonds with two and a weak bond with one.

Last, 11 friends were cited, where there were normal bonds with six, strong bonds with five, and one caregiver was also considered a friend with whom strong bonds were established. Two mothers cited neighbors, one with normal bonds and one with strong bonds.

When their children became ill and were hospitalized, all the mothers/caregivers in the study, regardless of the number of hospitalizations and length of hospitalization of the child, mentioned being able to count on the following members from their primary networks: husband/partner and other children, with strong bonds. The other members cited in primary networks in which normal bonds prevailed were: father/stepfather, uncles, mothers- and fathers-in-law, cousins, and friends. However, it was noted that the type of bond established in the primary networks of mothers/caregivers varied according to their needs.

In relation to secondary networks, all the mothers/caregivers mentioned the health institutions (formal secondary network) involved in the treatment and follow-up of the child, as well as churches, nongovernmental organizations (NGO) (third sector secondary networks), and workplace (market secondary network). The members of the secondary networks included: caregivers of other hospitalized children and health professionals, pastors and, lastly, co-workers.

With respect to the formal secondary network, all the interviewees especially mentioned the hospital – the site of the study; two participants reported strong bonds, one reported a weak bond and the rest were normal bonds. However, seven participants also cited other hospitals: in four of them, where the diagnoses had been performed and referrals were made to the hospital of the study, the bonds were classified as strong. It should be noted that these were where the children had been born and hospitals where they had stayed for more than three months doing clinical treatment. The bonds in two hospitals, located outside the city of Rio de Janeiro, were broken, because physicians were not available.

In the health institutions cited, the importance of the following categories of professionals was also noteworthy: nursing staff, physicians, an occupational therapist, physical therapist, psychologist, social workers and an administrative technician, as well as other mothers/caregivers.

Among the nursing team members cited, there were eight nurses and 11 nursing technicians. In reference to establishing bonds, strong bonds were mentioned with only one nurse, whereas the bonds were normal with the rest of the nursing team. However, they were said to be attentive, kind and available to provide care.

Fifteen physicians were mentioned: eight with normal bonds, six with strong bonds, and one with a conflictive bond. The bonds with the other health team professionals, which were five in total – an occupational therapist, physical therapist, psychologist and two social workers – were normal. There was also another professional with the position of an administrative technician with whom the bond was normal. Thirteen mothers of other hospitalized children were also cited: the bonds with nine of them were normal, three were strong, and one was weak.

In terms of third sector secondary networks, four mothers cited the church: three with strong bonds and one with normal bonds. The foreign participant mentioned an NGO, with which the bond was strong. As for members of the church, one mother/caregiver reported having strong bonds with two pastors who were considered friends; four friends were also cited who were members of the congregation, with normal bonds.

In relation to the market secondary network, three mothers/caregivers noted their husbands' workplace, with normal bonds; two cited the workplace, with weak bonds, due to uncertainty about returning to the job at the end of the maternity leave. However, these two women claimed to have established strong bonds with co-workers.

It can be seen that the mothers/caregivers established diversified secondary social networks. No participant cited the mixed and informal secondary network. It also stood out that the primary and secondary healthcare networks were not cited by the participants; i.e., the tertiary healthcare network

was sought the most, due to the specialties, technologies and resolution of problems considered chronic, according to the physicians' diagnoses of the children. Most cited the hospital, the setting of the study, with normal bonds; there were also strong bonds with other health institutions, primarily those where the child was born and the initial clinical diagnosis was performed.

In terms of the bonds with health professionals, it is relevant to note that stronger bonds were reported with professionals who gave the child and mother greater care and attention. Few mothers cited the workplace as a social network, since most of them were not formally employed.

## DISCUSSION

The average size of most of the networks coincided with the findings of a study conducted with families of hospitalized children, where most of the maps were medium-sized (15), i.e., formed by 10 to 30 members<sup>(2)</sup>. In stressful events, such as the hospitalization of a child, the existence of a social network with various members can be much safer than having just one relationship. Furthermore, members offer different types of support and help alleviate the stress of difficult situations<sup>(8)</sup>.

It should be noted that no one establishes a relationship with just one person. What determines the support received by mothers/caregivers may be related not to the number of people who are part of their social network, but to the types of bonds established, and which needs are met.

Generally, the social network of family members/caregivers during the hospitalization of a child are comprised of the most significant people, including: partner/husband, followed by mother, because these are the people that caregivers can count on<sup>(15-16)</sup>. The primary social networks of caregivers of hospitalized children are composed of family members and friends, through whom they receive emotional support, material help and services<sup>(14,17)</sup>.

The first relational experiences of a person occur within the family, which is the first and most important nexus in networks, because it is constant over the course of time, stretching from birth until death. The family is a central reference point that always reemerges, for good or for bad, as a resource or as a hindrance<sup>(2)</sup>.

Friends are combined with family members in primary networks. Friends provide emotional closeness, which endures regardless of physical distance. They are able to share the other person's joy and sadness, can loyally keep a secret, know when to stand back and when to draw close to give appropriate advice<sup>(2)</sup>. In this regard, it is understandable that mothers/caregivers establish strong bonds with other caregivers since they share the same feelings and concerns in relation to their hospitalized children.

Besides the support received from the family, friends and neighbors also provide support, in the sense of helping the mothers get organized and taking on domestic chores and caring for the other children<sup>(15,18)</sup>. The neighborhood network may also be called on or not. Neighbors are often a valuable resource that is interpreted and mobilized in different circumstances<sup>(2)</sup>.

Secondary networks are primarily characterized by relationships that are not chosen, due to the fact they are institutional<sup>(2)</sup>. Health professionals are linked to mothers/caregivers through situations and contexts related to the treatment and health care given to the child<sup>(15,19-20)</sup>. Nurses are the professionals that have the greatest contact with the child and his/her caregivers, followed by medical teams<sup>(15)</sup>.

Health institutions constitute the social welfare system in which exchange of rights takes place, and this exchange should be complementary to the primary network, assisting it to become autonomous, but it should not be the main source of support in a social network<sup>(2)</sup>. Many support networks are formed within hospitals, as family members start sharing the same environment and the experiences and suffering related to the health-disease process. Together, they seek to preserve their human dignity<sup>(5)</sup>.

Secondary networks from the third sector are comprised of nonprofit organizations where there is an exchange of solidarity and constitution of rights. They are alternatives to the state, as in the case of churches<sup>(2)</sup>. These networks are considered essential, since they ensure supply of the mothers'/

caregivers' material needs, such as basic food baskets and clothing, as well as emotional support, through giving words of spiritual comfort, motivation, encouragement and hope, among others<sup>(7,21)</sup>.

Religious congregations, more specifically the evangelical ones, have become a source of support and help for resolving problems. They are characterized by interaction with pastors and church members, where all share the same faith, are connected together through it, and where friendships may form. Relationships with fellow congregants are perceived as a source of encouragement through emotional support based on religious beliefs, in addition to providing cognitive guidance and advice (14-15).

The market secondary network is an organization that belongs to the economic sphere, such as a professional activity or job. It should be pointed out that this type of network does not create links, except in relation to what is exchanged. The author argues that co-workers are another type of neighbor, which is different from relationships with friends, who are chosen and where there is deep affection (2).

The limitation of the present study was the site of the study which primarily hospitalizes children suffering from chronic diseases. This prevented learning about the social networks of children hospitalized for acute causes or short-term treatments. Therefore, the findings of the study cannot be generalized.

# CONCLUSION

The study shows that the construction of social networks by mothers/caregivers is diversified and that the strongest bonds were found in primary networks, represented by the nuclear family (husband/partner and children) and mothers (relatives). The situation of extended and frequent hospitalizations of children affects the dynamics of social networks in that, over the course of hospital stays, the members that form the primary network decrease, but the bonds are strengthened.

The secondary network consisted primarily of tertiary health institutions, church and workplace. Among the members of this secondary network, the main ones are nursing and medical teams, pastors and co-workers.

It can be concluded that primary and secondary healthcare networks were not considered by the study participants, since the children did not receive care in any of these locations. In summary, it is important that hospital institutions and their health professionals create links with the primary and secondary healthcare networks for follow-up on the child after discharge from the hospital.

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