



Social Networking Family of Caregivers during Hospitalization of Children*

As Redes Sociais dos Familiares Acompanhantes durante Internação Hospitalar de Crianças
Las Redes Sociales de los Familiares acompañantes durante la hospitalización de los niños

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ABSTRACT

Objective: To identify and analyze the significant networks of family, social and hospital support described by the family caregivers of hospitalized children 5-12 years during the hospital stay. **Method:** Descriptive study, exploratory and qualitative study conducted with 20 caregivers of children hospitalized in a hospital in a city in southern Brazil, through semi-structured interviews and significant social networks maps, tailored to the hospital setting. **Results:** Data analysis showed that the most active social network was comprised of families through emotional support, material aid and services. Relations with hospital health care team and the hospital context were cited as providing support to the caregivers of the hospitalized child. **Conclusion:** The identification of social networks in the child's hospitalization course enables equip professionals working in the institution aiming at better targeting of actions and care for the family and hospitalized children.

DESCRIPTORS

Social Networking; Caregivers; Child Hospitalized.

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INTRODUCTION

Social networks are important resources in health care and can be understood as groups of complex relationships established among members of family, schools, health and social assistance organizations, among others⁽¹⁾.

When receiving medical care, children need to count on the help of adults that are privileged interlocutors mediating the whole relationship/communication established between children and the team. The families often deal with immediate issues of children's medical problems, such as pain and suffering, the side effects of administered drugs, and various medical guidelines⁽²⁾.

Consistent predictors of family wellbeing during the experience of being with a sick child include family flexibility, the ability to balance the disease demands and the other family needs and responsibilities, clear family boundaries, effective communication, positive responsibilities, active coping, encouragement of individuals' development within the family, and integration in a network of social support⁽²⁾.

It is important to emphasize the difference between the terms *social network* and *social support* since these are interconnected concepts that hold some differences. The *social network* has been conceptualized as an objective evaluation of the size and frequency of contact with friends, relatives and spouse, in its structural or quantitative aspect. The *social support*, on its turn, has been described as a subjective perception of the quality of support evaluated by the individual⁽³⁻⁵⁾.

The personal social network is the sum of all people that an individual perceives as significant in a relational universe sustained by aspects of culture, sub-culture, history, politics, economy, religion, environment, existence or lack of public services, and regional, national or continental characteristics⁽⁶⁻⁷⁾.

The type of interpersonal exchange between the members of a network defines its functions, characterized as follows: *social companionship* (carrying out joint activities or staying together in critical situations such as illness and somebody's death); *emotional support* (reactions of empathy, encouragement and support); *cognitive guide* (relationships that promote role models, personal or social information and clarification of expectations); *social regulation* (relationships that promote conflict resolution, neutralize behavioral deviations and recall responsibilities); *material or services assistance* (specific professional assistance, such as health services); *access to new contacts* (openness to other relationships that show bonding potential)⁽⁶⁾.

The composition of significant social networks can be determined and evaluated in terms of its structural characteristics (size, density, composition, dispersion, homogeneity/heterogeneity and type of functions) and attributes of the bond (predominant function, multidimensionality, reciprocity, intensity/commitment, frequency of contacts, history)⁽⁶⁾.

The above aspects were taken into consideration to justify the study purpose, which was to identify and analyze the significant family, social and hospital support networks described by the family caregivers of hospitalized children aged 5-12 years during the hospitalization period.

METHOD

This is descriptive and exploratory study of qualitative approach. It sought to describe, characterize and relate the peculiarities, expressions and activities of the family caregivers in their temporal and local contexts⁽⁸⁾.

The study participants were 20 family caregivers of children aged 5-12 years hospitalized in medical and surgical clinics of a pediatric hospital located in the southern region of Brazil, which is part of the Brazilian Unified Health System (SUS). The inclusion criteria were: a) being the child caregiver during the hospitalization period (minimum of three days); and b) not having debilitation caused by acute/chronic illness (physical or mental) that could interfere with data collection. The recurrence of information indicated data saturation, showing no need for further changes in the number of participants.

Fifteen mothers, three fathers, a paternal grandfather and a sister participated in the study. The average number of days accompanying the child was around 4.3 days. Regarding sociodemographic data, the average age was 29.4 years, and 17 participants were married or in a common-law marriage. With regard to educational level, most participants had completed elementary school. Regarding professional occupation, four caregivers were unemployed and the others worked in general domestic services, beauty and personal care services, education, sales, clothes making, agriculture, driving, mechanic and administrative services. The average monthly income ranged from 1 to 3 Brazilian minimum wages.

Data collection occurred through a semi-structured interview and a Network Map tailored to the hospital context, including: a) relationships within the hospital context; b) relationships with other services outside the hospital; and c) relationships with the hospital health staff, replacing the community relationships that were contemplated in the relationships developed outside the hospital context. In this study, the Network Map was used to complement the interview, since this is one of its possibilities as a research tool in qualitative studies⁽⁹⁾.

After presentation of the study and its objectives, were collected the signatures of the Informed Consent form. The completion of interviews and elaboration of the Network Map occurred individually, lasting 60 minutes on average, in a reserved place inside the hospital. All interviews and the Network Map elaboration were audio-recorded and transcribed for the subsequent data analysis.

The names of participants were omitted, keeping only the degree of kinship in relationships with family, and terms such as Friend and Neighbor. The male gender was used for all individuals cited in the *relationships within the hospital context* and *relationships with the hospital health staff* to preserve the anonymity of participants. Similarly, all mentioned medical specialties were standardized in the single term 'Doctor', and the nursing functions were grouped in the 'Nurse' terminology.

The Network Map data were analyzed considering the structures related to size (number of people in the

network), composition/distribution (total proportion of members located in each quadrant and circle) and the network functions. The gathering of information obtained through the Network Map of each participant (illustrated on Figure 1) enabled the construction of a General Network Map with the group vision of all participants, showing the similarities, differences and trends of the network in each quadrant.

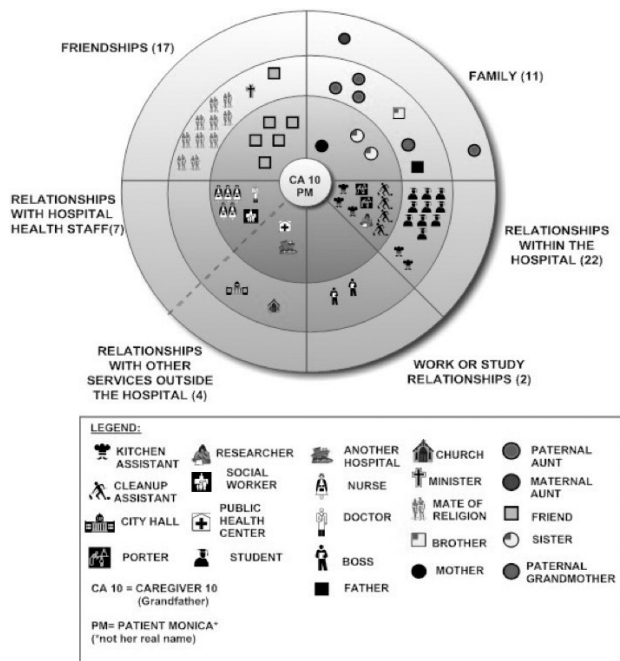


Figure 1 - Network map of the family caregiver with distribution of people in subnetworks

The networks in the map quadrants formed the following subcategories: *family relationships*; *friendship relationships*; *relationships with the hospital health staff*; *relationships with other services outside the hospital*; *work and study relationships*; and *relationships within the hospital context*. Such subcategories were articulated with the analysis elements related to the network attributes (size, density, composition, dispersion, homogeneity/heterogeneity, functions and bonds) according to the perception of the family caregivers.

The present study was approved by the Ethics Committee in Research of the Universidade Federal de Santa Catarina under number 009/08 - FR - 176955. All names of participants have been changed to ensure their confidentiality.

RESULTS

In this study, we adopted the average number of 16-30 people in the networks, hence, the small size was up to 15 members, and the large size was more than 30 people. This is because the Network Map was adapted to the hospital environment, including the quadrant subdivisions of *relationships with people of the health staff* and *relationships with people of the hospital context*, expanding the number of individuals who could be mentioned by participants in their

networks. Thus, in terms of size, the general map indicated 14-63 as the number of people mentioned in the networks of participants, with three networks of small size, nine networks of medium size, and eight networks of large size.

Regarding the composition and distribution of the proportion of network members in each quadrant and circle, the greatest number of mentioned people (187 in total) was observed in the quadrant of *family relationships*; the highest frequency of people was located in the circle of greater intimacy relationship (83 in total), in relationships with the least degree of commitment (61 in total) and in occasional relationships (43 in total). The quadrant of *relationships with other services outside the hospital* had the lowest number of people mentioned (33 in total); the most intimate relationships with 19 citations, merged with the relationships with the least degree of commitment, cited 12 times, and the occasional relationships, cited two times. The data set also indicated that in the attribute of *function of network members*, the emotional support was the predominant type of exchange between people, and observed in all quadrants. The material and services assistance was also observed in the social relationships of participants in almost all quadrants.

The *density* attribute represents the connection between the cited members in levels of greater or lesser intimacy. It indicated that the subsystems of family, neighborhood and church had the closest relationships with each other and therefore, with a high level of density. The reports also showed the easiness with which the participants access the members cited in their networks, demonstrating a low degree of *dispersion*.

The caregivers' social networks also showed homogeneity, since there was a higher frequency of female members cited in the family and friendship relationships. In addition, the aspects generating potential tensions among the subnetworks were not identified, indicating the absence of significant differences in the cultural and socioeconomic aspects between the cited members and companions.

SUBCATEGORY OF FAMILY RELATIONSHIPS

This subcategory included the significant people in the family context. Among those most frequently mentioned in relationships of greater proximity and intimacy, the father came in first place with 16 citations, followed by the maternal grandmother, maternal aunt and paternal aunt. The perceived functions were of emotional support and material assistance, understood as a specific type of collaboration since these were the people with whom the caregivers could count on.

SUBCATEGORY OF FRIENDSHIP RELATIONSHIPS

The significant people most cited by the family caregivers during hospitalization within the social context of friendship were Male friends and Female friends, mentioned 16 times, followed by Male neighbors and Female neighbors (11 citations), in a higher degree of proximity through functions of emotional support and material assistance in the care of children and with household chores:

So I'm here, but kinda like: on tenterhooks, thinking about there [at home], but don't wanna leave him [child] here [at the hospital] alone, no way [...] then there's my neighbor that [...] today my washing machine arrived and she [the neighbor] offered herself: 'look, I'm gonna do the laundry for you' [...] 'cause I got nobody to do it, I really don't (Geraldo's caregiver).

Note that four family caregivers have mentioned people who attend the same church and were classified as 'Brothers' (religious brothers), and were also indicated with greater proximity and function of emotional support through prayers for the child's health recovery:

Friends from church [...] close, really close friends united in prayer, praying. So many! [laughs] and it helps a lot, you know? I feel it helps [...] twelve brothers came one day, and 13 brothers came on the other day (Pedro's caregiver).

SUBCATEGORY OF RELATIONSHIPS WITH THE HOSPITAL HEALTH STAFF

Among the significant people of the hospital health staff, the most mentioned by all participants were the nurses, with 20 citations, in a higher degree of proximity, indicated as 'caring people', 'loving' and 'willing to serve', when requested. The perceived functions were emotional support and services assistance, characterized by the specific collaboration based on the physical assistance provided in child care, such as feeding, hygiene, checking of vital signs, performance of exams and medication administration. The social worker was mentioned seven times with the function of emotional support and services assistance.

The doctor was cited 16 times in the services assistance function, but from the perspective of collaboration or support based on medical knowledge. In other words, as an expert who performs well the functions of diagnosis, treatment, clarification and guidance to the family about the child's clinical condition. However, the doctor was not mentioned by four family caregivers, which is a fact to be considered. It may indicate communication and relationship difficulties, because some family caregivers reported the behavior of some medical professionals as 'brief contact', 'not very close' and 'poorly affectionate', as illustrated by the following excerpt:

I think the doctors are always so serious. It's like, I think they put their professionalism in the first place. They should be a bit more like the nurses [...] 'cause the nurses pass a lot of confidence to children, are always joking, get here laughing [...] and the doctors get here serious, it seems they make them afraid [children] (Pedro's caregiver).

SUBCATEGORY OF RELATIONSHIPS WITH OTHER SERVICES OUTSIDE THE HOSPITAL

Among the people mentioned by the participants, professionals from the Basic Health Unit (doctors and nurses) were those with the highest frequency in a relationship of

greater proximity (cited 12 times). These professionals were characterized by the function of services assistance and access to new contacts. In the view of participants, these professionals are responsible for children's first care, making referrals to the hospital so they can receive the most appropriate care to their needs.

The Minister (10 citations) and "Religious Brothers" (10 citations) were also perceived in relationships of greater proximity and mentioned by half of the family caregivers in this subnetwork of relationships. They were also mentioned by some participants in the friendship network, as seen previously. The relationship with a mate of religion was perceived as a source of stimulation through the function of emotional support based on religious beliefs and as cognitive and advice guidance.

SUBCATEGORY OF WORK AND STUDY RELATIONSHIPS

The significant people in the work or study context most cited by the family caregivers were the Boss and Teacher, mentioned seven times, and Coworkers, cited four times. These people were mentioned in a bond relationship of 'frequent interactors'⁽⁶⁾.

SUBCATEGORY OF RELATIONSHIPS WITHIN THE HOSPITAL CONTEXT

This subcategory was composed by significant people in the hospital context (hospital employees who were not part of the health team). Among the most cited people were Kitchen assistants and the Porter, with 14 citations, referred as being in a relationship of proximity, and whose functions were perceived as material and services assistance, as well as emotional support. The Cleaning assistants were also perceived as being part of these same functions, and mentioned nine times in a relationship of greater proximity. All family caregivers have mentioned significant people in this subnetwork of relationships, making it the third network of relationships with larger distribution. The citation of the Porter revealed that the caregivers felt 'welcomed' and 'properly informed about the hospital norms'. In their speeches, they signaled aspects such as 'kindness' and the 'respectful and polite attitude' of this worker of the institution.

The Kitchen assistant had very good references from the family caregivers, and was characterized as a collaborator in 'a good mood' and 'friendly'. In this hospital, the kitchen assistant was in contact with the study participants at least five times a day when bringing the patients' meals, and perhaps this has allowed a greater proximity with children and their caregivers, who described them as professionals who 'made jokes', 'talked' and 'encouraged the kids' in relation to food:

Then he [Kitchen assistant] tries to please and says: 'You [child] have to eat, otherwise you'll end up weak [...] tell me what you fancy'. Sometimes he [Kitchen assistant] says: 'this [food chosen by the child] we haven't got, but I can get you that' [...] A very nice guy" (Caregiver Luis)

The 'kindness' and 'attention' offered, and the 'willingness to serve' were also mentioned by the study participants when referring to the cleaning assistants. From the caregivers' perspective, these professionals showed the aforementioned characteristics through 'questions about the children's state of health' and 'conversations' with the caregivers:

People from the laundry, the cleaners, right? They always treat us so kindly, don't they? There's even a colleague who's worked with me [name], he used to come here every day, he asked what did he [...] which disease he had [child]. He came here, he was concerned about it, you know?" (Caregiver Duarte).

DISCUSSION

The presence of the Mother as the Child caregiver during hospitalization was a lot more frequent than that of other family members. This fact is in agreement with studies that have demonstrated the predominance of the mother's presence at events like this, related to the female ability to devote herself to children in moments they need attention, meeting their demands of hygiene, food and comfort, in addition to the contact that allows manifesting the feeling of unity between them both⁽¹⁰⁻¹¹⁾.

However, the fact of the mother not always accompanying the child during hospitalization draws attention. Often, there are situations when the mother figure is replaced by older sisters, grandmothers, aunts, fathers or grandfathers⁽¹²⁾. This aspect became evident in this study, given the presence of five family caregivers with different degrees of kinship with the hospitalized child (parents, grandfather and sister). This phenomenon can be observed in some family arrangements in which the model of the breadwinner father no longer responds to the only reality, and mother's work is the main source of income, resulting in the selection of other people to accompany the child during hospitalization.

Before the illness of a child, the search for support of relatives such as grandparents gives reassurance to the mother staying at the hospital with the child, for knowing that her other children are under the care of a close relative⁽¹³⁾. This kind of support subsidizes the family caregiver in his/her daily needs and brings more security and confidence, allowing an exclusive dedication to the care of the hospitalized child. The relatives of hospitalized children organize themselves during the hospitalization period, assuming the functions of house cleaning and care with other children, sharing the visits and assisting financially⁽¹⁴⁾.

Neighbors and friends are often present with the families of hospitalized children by helping them with organizing and living this experience in a less traumatic way through emotional support and assistance with household chores and the care for other children⁽¹⁴⁾. This ability to share represents a reciprocal bond between people by promoting support for social causes involving families. Such aspects are characterized as a 'solidarity network', the interpersonal relationships linked by strong bonds with neigh-

bors, friends and people at work, mentioned as individuals who play an important role during the hospitalization of a child and provide help in various ways⁽¹⁵⁾.

The religious congregations, especially the evangelical, have become a source of support in the resolution of crisis. When there is a disease, the 'prayer chains' are common, in which people sharing the same faith unite and form bonds. The shared faith represents a form of support and comfort that favors the construction of invisible and strong support networks⁽¹⁶⁾. In this case, the emotional function is based on religious beliefs, and in addition to this function, there is the cognitive guide function, providing advice and guidance.

Studies on the negative factors of hospital care reported by parents of children during hospitalization have shown that the limited contact and impersonal attitude of doctors do not encourage the family to seek interaction⁽¹⁷⁻¹⁸⁾. On the other hand, the caregivers who mentioned doctors in relationships of greater proximity have emphasized the 'professional competence' and 'attention provided' to the patient and caregiver through 'clarifying information and guidelines' that included the child's participation.

In the health team, the nurses stand out as the professionals with more contact with patients and their caregivers. This is explained by their procedures and guidelines performed daily, and for staying longer in the nursing stations of hospitals, where access to patients and caregivers is more frequent than the contact with doctors. Moreover, in this study, the professionals referred by the term 'nurse' were more numerous than the other health staff members.

The disease situation affects the networks due to the reduced opportunity for social contacts and decrease of the reciprocity and gratification received⁽⁶⁾. However, the presence of a disease may also lead to new networks such as those formed in social and health services, because they often acquire a central character, given their instrumental attributes and emotional support capacity. These data corroborate the findings on the perception of parents in relation to the health professionals' support during the hospitalization of children, evidenced by the willingness to help in the care of the child and family, sensitive listening, comprehension in face of the fears and doubts, and assistance with material needs⁽¹⁴⁾.

The citations of Boss were related to the material assistance function, perceived as 'attention' and 'solidarity' offered to the caregivers, who could take time off work to stay with the child in the hospital. The Teacher was mentioned through the functions of services assistance and emotional support, and pointed as a person 'interested in the child's health problem', 'reassuring' the family about the possibility of recovery of school subjects as soon as the child could return to the academic activities.

For participants, the interest of workers in the hospital context (porters, kitchen assistants, cleaning assistants) was perceived positively as a necessity with high degree of importance. Given their socioeconomic and cultural conditions, some families identify with these professionals, who normally keep a greater interpersonal contact with patients

and caregivers, and present a less formal behavior and simpler language, or perhaps closer to the reality of families that feel weak in face of all the technical apparatus of the hospital.

CONCLUSION

The present study aimed to identify and analyze the significant networks of family, social and hospital support from the perspective of family caregivers of children during their hospitalization period. In this sense, during children's hospitalization, it was observed that the significant social networks were characterized as medium-sized networks. The family relationships were the most cited in a greater level of intimacy when compared to other relationship networks of the participants.

The predominant functions of the networks were emotional support, material and services assistance through a high density level, and more intimate relationships with each other resulting from the mobilization caused by the hospitalization experience. The networks were configured homogeneously through a more frequent indication of female members in family and friendship relationships, as well as absence of significant differences of cultural and socioeconomic characteristics among participants and the people mentioned in the subnetworks.

The most active network of relationships was the family, especially represented by the Parents, Grandmothers and Aunts, who performed functions of emotional support

and material assistance, providing the necessary security for the caregiver's permanence in the hospital and the continuity of care at home and with the family during the child's hospitalization.

The relationships with the hospital health staff and within the hospital context represented the other networks with highest number of citations, highlighting that the number of cited people was basically the same. This indicates that both health professionals (doctors, nurses, social assistants) and the institution workers (kitchen assistants, cleaning assistants, porters) were mentioned as significant people and able to provide support to the hospitalized child's caregiver. However, the kitchen assistants and porters stand out as those mentioned in a relationship of greater proximity than the relationship with doctors. This shows that even though the family caregivers recognize the competence and ability of medical professionals for the treatment and care of the patient, they are still not perceived as people who provide emotional support.

Data from this study allowed the 'discovery' of employees working in the hospital, but who remain invisible in most cases. However, their presence and support to family caregivers are particularly evident. Thus, the recognition of the quality of this support needs to be considered by managers of hospitals, providing a better targeting of actions and care for the family and for hospitalized children.

RESUMO

Objetivo: identificar e analisar as redes significativas de suporte familiar, social e hospitalar descritas pelos familiares acompanhantes de crianças hospitalizadas de 5 a 12 anos, durante o período de internação. **Método:** Estudo descritivo, exploratório e de cunho qualitativo realizado com 20 acompanhantes de crianças hospitalizadas em uma unidade hospitalar em uma cidade do Sul do Brasil, por meio de entrevistas semiestruturadas e dos Mapas de Redes sociais significativas, adaptado para o contexto hospitalar. **Resultados:** A análise dos dados demonstrou que a rede social mais atuante foi composta por familiares, através de apoio emocional, ajuda material e de serviços. As relações com a equipe de saúde do hospital e com o contexto hospitalar foram citadas como capazes de fornecer apoio ao acompanhante da criança internada. **Conclusão:** a identificação das redes sociais no curso da hospitalização da criança possibilita instrumentalizar os profissionais que atuam na instituição objetivando um melhor direcionamento de ações e cuidados destinados à família e a criança hospitalizada.

DESCRIPTORIOS

Rede Social; Cuidadores; Criança Hospitalizada.

RESUMEN

Objetivo: Identificar y analizar las redes sociales significativas de la familia, el apoyo social y del hospital descrito por los miembros de la familia que se acompañan de los niños hospitalizados con 5-12 años durante la estancia hospitalaria. **Método:** Estudio descriptivo, exploratorio y estudio cualitativo, realizado con 20 acompañantes de niños hospitalizados en un hospital en una ciudad en el sur de Brasil, a través de entrevistas semi-estructuradas y mapas de las redes sociales significativas, adaptadas al entorno hospitalario. **Resultados:** El análisis de datos mostró que la red social más activa se compone de familias a través de apoyo emocional, ayuda material y servicios. Relaciones con equipo de atención médica hospitalaria y el contexto hospitalario fueron citados como la prestación de apoyo a la acompañante del niño hospitalizado. **Conclusión:** La identificación de las redes sociales en curso de la hospitalización del niño permite dotar a los profesionales que trabajan en la institución con el objetivo de una mejor focalización de las acciones y el cuidado de la familia y de los niños hospitalizados.

DESCRIPTORIOS

Red Social, Cuidadores, Niño Hospitalizado.

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