

Support networks in home care for premature newborns: an experience report**Redes de apoio no cuidado domiciliar ao recém-nascido prematuro: um relato de experiência****Redes de apoyo de atención domiciliar para el recién nacido prematuro: un informe de experiencia****Received: 24/10/2019****Approved: 01/07/2020****Published: 11/08/2020****Lígia Aparecida da Silva¹****Marcela Soares Dias²****Fernanda Maranhão Santos³****Diene Monique Carlos⁴**

This is an account of the experience of a case as the mother of a premature newborn. It aimed to report the experience of home visits in the context of Primary Health Care, emphasizing the importance of support networks in the care of premature newborns. Held in a city in the interior of the state of São Paulo in the first half of 2018, it used the Minimum Map of Social Personal Network. Home visits made it possible to strengthen the bond in the mother-child binomial and identify a weakened personal social network, also indicating two emerging problems: family in social isolation and little individual empowerment. It is perceived a medium network, not very dense, homogeneous, with a predominance of absent and/or broken social bonds. The results denote the importance of home visits for continuity of hospital-home care, reflecting on the relevance of support networks for families of premature newborns.

Descriptors: Infant, Premature; Social support; Humanization of assistance; Nursing.

Este é um relato de experiência de um caso como de mãe de um neonato prematuro e teve como objetivo relatar a experiência da visita domiciliar no âmbito da Atenção Primária à Saúde, ressaltando a importância das redes de apoio no cuidado ao recém-nascido prematuro. Realizado em uma cidade do interior do Estado de São Paulo no primeiro semestre de 2018, usou o Mapa Mínimo da Rede Pessoal Social. As visitas domiciliares possibilitaram fortalecimento do vínculo no binômio mãe-filho e identificação de uma rede pessoal social fragilizada, indicando também dois problemas emergentes: família em isolamento social e pouco empoderamento individual. Percebe-se uma rede média, pouco densa, homogênea, com predominância de vínculos sociais ausentes e/ou rompidos. Os resultados denotam a importância da visita domiciliar para a continuidade do cuidado hospital-domicílio, trazendo à reflexão a relevância das redes de apoio às famílias de recém-nascidos prematuros.

Descritores: Recém-nascido prematuro; Apoio social; Humanização da assistência; Enfermagem.

Este es un informe de experiencia de un caso de una madre de un recién nacido prematuro y tiene por objeto informar sobre la experiencia de la visita a domicilio en el ámbito de la Atención Primaria de la Salud, destacando la importancia de las redes de apoyo en la atención del recién nacido prematuro. Realizado en una ciudad del interior del Estado de São Paulo en el primer semestre de 2018, utilizó el Mapa Mínimo de la Red Personal Social. Las visitas a domicilio permitieron fortalecer el vínculo en el binomio madre-hijo e identificar una red personal social debilitada, lo que también indica dos problemas emergentes: la familia en aislamiento social y el escaso empoderamiento individual. Se percibe una red media, poco densa, homogénea, con predominio de lazos sociales ausentes y/o rotos. Los resultados muestran la importancia de las visitas a domicilio para la continuidad de la atención hospital-domicilio, lo que pone de manifiesto la pertinencia de las redes de apoyo a las familias de los recién nacidos prematuros.

Descriptores: Recien nacido prematuro; Apoyo social; Humanización de la atención; Enfermería

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INTRODUCTION

The neonatal component (0 to 27 days) has historically represented the greatest contribution to infant mortality¹, especially death occurred in the first 24 hours². One of the elements that make up this scenario is preterm births, that is, those that occur at a gestational age of less than 38 weeks. Of the total number of births that took place in Brazil in 2016, 11.11% were of children born with gestational age less than 37 weeks³. Among factors that contribute to preterm birth are placental and amniotic fluid impairments, maternal infections, maternal age (adolescents) and primiparity (condition of primiparous, first delivery)³.

Services and professionals must organize themselves to care for the premature baby and their family, essentially in the transition from hospital-home care. Studies have indicated that care is still directed only to mothers, who express the importance of social support for this^{4,5}, many families are not oriented for this care during hospitalization^{4,6}, do not receive guidance on formal networks that will follow up of premature infants after hospital discharge^{7,8}, and there is a recommendation to insert the family member in the nursing plan for the discharge of premature infants⁵.

Thus, it is essential to invest in Primary Health Care (PHC), with guaranteed home visits to premature infants, since it is in this context - the home - that health care occurs. The social support network built by families is relevant to this care. Social networks are specific resources for social support and the exchange of social support is the main basis for the development and maintenance of social relationships⁹.

The types of social support stand out: emotional; informative and instrumental. *Emotional* support concerns the feeling of belonging, esteem or appreciation; displays of affection and love. *Informational* support is the provision of facts or advice that can help a person solve problems. *Instrumental* support consists of offering or supplementing material assistance for questions or practical problems¹⁰. From the analysis of social networks, social support brings a nuance of the specificity of social relations, and, consequently, of its effects on individual well-being and health⁹.

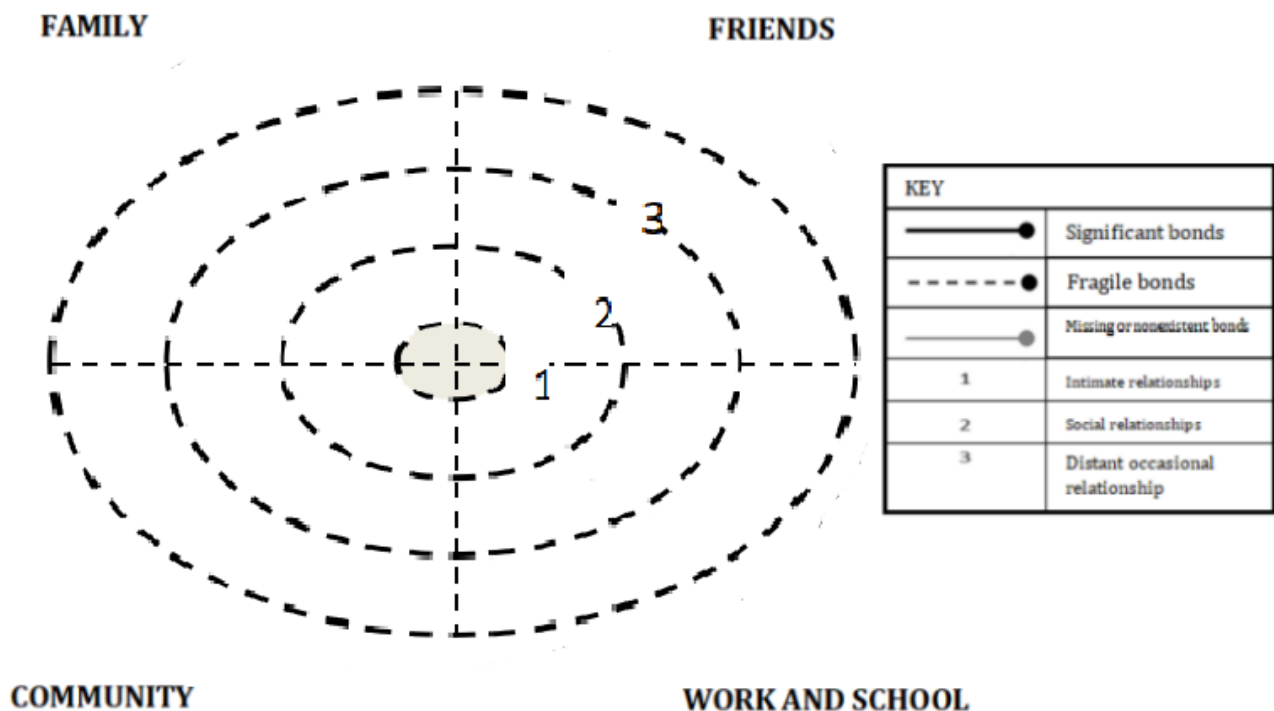
This article brings the need to look at social support networks of families of premature newborns, during home visits to monitor the transition from hospital-home care. Thus, this study aims to report the experience of home visits within the scope of Primary Health Care, emphasizing the importance of support networks in the care of premature newborns.

METHOD

This is a case study experience report, understood as an investigation “of a contemporary phenomenon (the aforementioned “case”) in its context in the real world, especially when boundaries between phenomenon and context may not be clearly evident”¹¹.

The case study was guided by the construction of a Minimum Map of the Social Personal Network proposed by Sluzki¹². The participant was the mother of a premature newborn, accompanied by nursing students during two home visits, during the first semester of 2018.

Such a map is constituted by a drawing represented by a circle with four main quadrants: family, friendship, school/work, and community relations (religion, sport, cinema, theater, clubs, squares, among others). In addition to these, there is a quadrant that covers the relationship with health and social assistance services. The quadrants are permeated by two other circles, which indicate intimacy and intensity of relationships, as shown in Figure 1.

Figure 1. Minimal Map Model of the Social Personal Network¹², São Paulo, 2018.

In addition to representing the nature of social networks, these maps allow an understanding of how relationships are established. They are delineated through lines with different colors or lines, which graphically represent links between families and people/institutions, and can be of three types: significant, fragile and broken or nonexistent¹².

At the end of the qualification of the links, the map of the social network will be analyzed with the perspective of the relationships inscribed on it, according to the following criteria that Sluzki¹² calls as structural characteristics of the network:

- Amplitude: it relates to the number of people present, and allows to see if a network is small, medium or large;
- Density: refers to the quality of the bonds observed, both at the personal and institutional level, with regard to the line of the traces;
- Intensity: refers to the exchanges made - material, affective or informative;
- Dispersion: allows reflection on affective and/or geographical distance, and reveals degrees of intimacy;
- Frequency: shows the systematicity with which the link is established;
- Duration: denotes the time of knowledge among people in the network;
- Distribution/composition: refers to the number of people or institutions present in each quadrant. There are resources and gaps in the network;
- Homogeneous or heterogeneous: the characteristics of members and institutions are evaluated, with the aim of verifying diversity and similarities that make up the network. For example, a homogeneous network can be considered closed and fragile because it does not allow dialogues with different singularities, personal and institutional, that build social life.

In addition to these characteristics, the network's functions are recognized, that is, the potential and advantages for the implication of a more articulated and committed society, strengthening community work guided by supportive partnerships¹². Such functions are constituted by: social companionship, emotional support, cognitive and advice guide, social regulation and control, material help and services, and access to new contacts. The latter refers to involvement with cooperative and supportive networks, which makes it possible to build

new personal, collective and institutional bonds, expanding the subjects' personal social network.

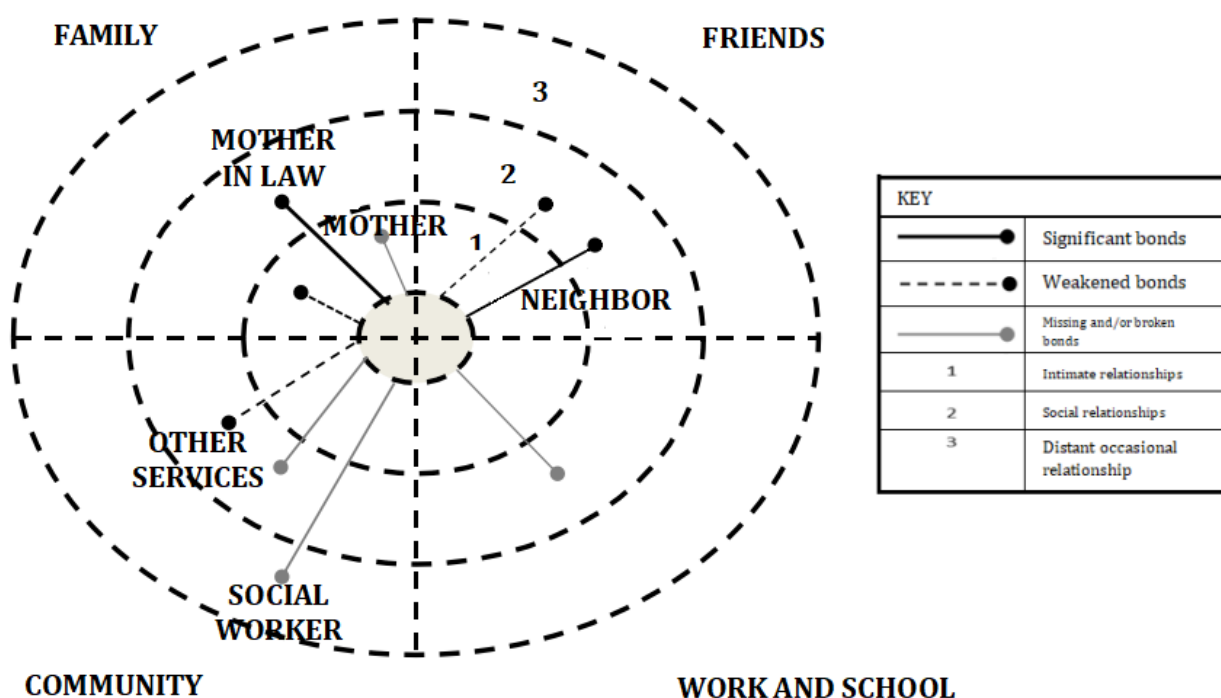
The bonds can also be analyzed according to their attributes, such as (i) the predominant functions; (ii) multidimensionality, which refers to the number of functions that each component of the network performs; (iii) reciprocity; and (iv) the historical character¹².

RESULTS

The analysis and description of the Minimum Map built allowed to verify two emerging problems: family in social isolation and little individual empowerment. It was a medium network, not very dense, homogeneous, with a predominance of social ties and with missing and/or broken ties.

When looking at the quadrants in Figure 2, it appears that, in the family, the bond was missing and/or broken with the mother (intimate relationship); weakened bond with the partner (intimate relationship); significant bond with the mother-in-law (intimate relationship). In this quadrant, little emotional support was identified by the partner and instrumental/emotional support by the mother-in-law, since in addition to affective relationships, she offered financial and material help to the premature baby's family.

Figure 2. Minimum Map of the Social Personal Network (adapted¹²).



In relation to friends, the bond was weakened with a neighbor (social relationship), who, despite being close, did not maintain frequency in the relationship; and weakened with other neighbors (social relationship), because there were situations in which they disregarded the possibility of the premature infant's survival, and talked about this issue with the mother, leaving her very distressed (according to her report).

At work and school/study, the bonds were absent, since the parents were unemployed and had no prospect of seeking studies. In the community, the bond is weakened with the Health Services (social relations); absent and/or broken with other services (social relations); and missing with Social Assistance.

In relation to the health service, the mother reported that the PHC unit suggested that there was no need for the premature infant to be monitored by the service in the territory, since

he was already monitoring by a specialized service. The mother also reported the absence of support from the social assistance service, despite economic vulnerability.

Home visits made it possible to empower the bond between the mother-child binomial and allowed the identification of a fragile personal social network. When talking about the care provided to the premature newborn, there was a significant bond between mother and child, good hygiene conditions, adequate growth/development, infant vaccination and pediatric urgencies/emergencies related to the infant. However, there was little concern with the youngest child (1 year and 2 months), causing discomfort on the part of the students, since the child was insecure and with periods of regressive behavior in relation to the mother's interaction with the baby, raising questions about the cognitive and socioemotional development of the firstborn.

The mother brought difficulties in caring for the premature baby, showing concerns about simple actions, such as administration of oral medication. She was not instructed on basic maneuvers to deal with choking, even after hospitalization of the premature infant due to aspiration and consequent cardiorespiratory arrest.

The mother reported on the need for exclusive dedication to the premature newborn, arguing about her ability to perform proper feeding and hygiene care. Therefore, such care for the newborn is exclusive to her and the care related to the first child is performed by her partner, the children's father. In relation to personal interactions with the partner, there were no moments for perceptions, since he was home, but he refused to participate in the meetings.

It is observed the apprehension and anguish of the mother regarding the transfer of care to the newborn to another person, since, in her thinking, only she is able to dedicate herself with caution. However, with regard to the transfer of care to the first child, she is relieved and calm.

Regarding assistance for the care of the newborn, there was a report that the mother-in-law (mother of her partner) and a neighbor offer support, as a result of the fragility in the parturient's relationship with the mother, due to family disagreements. The bond with other family members was not mentioned and is weakened with the neighbors, since there is little contact. The mother reported intentions to reconnect with family and friends.

Regarding study and work, there was a perception that both mother and father were not empowered to seek better living conditions, given that the family's financial support comes from donations from family members and acquaintances, due to unemployment.

With regard to the community, the social vulnerability in which the family finds itself is perceived, both by the lack of leisure and the lack of assistance, since the only services linked to them are related to PHC due to the children's routine consultations. for follow-up (child growth/development and vaccination).

DISCUSSION

The findings of this study revealed the isolation of the family in the care network, especially of the mother. When people in this network position themselves negatively and/or little affectionately with families, they can reinforce the parents' fear, insecurity and anxiety for adaptation and home care as indicated by the literature^{13,14}.

The absence or fragility in relations with support services, which welcome the newborn's family and help them, generally deals with aspects present in the mother's experience of technology-dependent children^{15,16}.

Such results corroborate studies in the area - in the care of children and adolescents who are victims of domestic violence¹⁷; and in the care of technology-dependent children, with specific efforts from the intersectoral network and fragmentation of care through a wide, but dispersed network¹⁵.

The mother reinforced difficulties in basic care and survival with her son. Such aspects are similar to a study that identified failures in communication between mother and health

team during hospitalization and after discharge; it is quite common for these newborns to have special health needs, which the family will need to manage⁶. Parents need to be part of the hospital discharge process, which must be started at least two weeks before it occurs and/or when the newborn has thermal stability, oral feeding and cardiorespiratory feeding^{5,19}. A study revealed that this abrupt transition from the hospital to home was understood as “careless”, generating greater adaptation stress²⁰.

Some recommendations for the transition of care for newborns at risk are important, such as: construction of nursing diagnoses that prioritize aspects involved in care⁸; instrument or protocol that considers continuity of care^{13,20}; referral to APS¹³.

In this study, maternal overload in the care of premature children was evident; this result corroborates research that sought to analyze the support network for caregivers of children with special needs, which showed the focus on the female gender related to the care of these children^{15,21} and, mothers of children with these needs present great burden, taking the burden of care all for themselves, pointing it out with such density due to it being survival care and “*supernatural*”^{22,23}.

In this family, there is a need to create and re-signify bonds with friends and family, since there is no effective and lasting emotional support. These aspects are in line with investigations that show the importance, but the absence of an effective social support network for mothers of premature babies^{5,19}.

Another emerging issue in the study was the lack of family empowerment to seek opportunities for study and work. This aspect was evidenced in research that sought to know the context of care for families involved in violence against children and adolescents; family and community empowerment is still a challenge¹⁸. Therefore, the essentiality of assistance programs for families in situations of socioeconomic vulnerability is identified, aiming to empower them and guarantee the rights to health, education, work and culture provided for by Law by the Brazilian Federal Constitution of 1988.

CONCLUSION

Considering what was said above, the present study allows us to conclude that the home visits executed proved to be an effective tool for comprehensive and individualized assistance to families of premature newborns.

Home visit is a form of care that allows for the recognition of family context, targeting support networks and directing interventions in a specific way for the moment experienced by each family, especially the newborn child.

The main limitation of the study is related to being an experience report of two visits, which, despite this, points to a reality that needs intervention. This limitation, at the same time, can be overcome by contributions to future research with other methodological designs.

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CONTRIBUTIONS

Diene Monique Carlos collaborated in the conception, outlining, analysis and interpretation of data and review. **Lígia Aparecida da Silva** contributed to the conception, outlining, analysis and interpretation of data and writing. **Marcela Soares Dias** and **Fernanda Maranhão Santos** participated in the analysis and interpretation of data and writing.

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