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The support of social network in homecare[a]

O apoio da rede social no cuidado domiciliar

El apoyo de la red social en el cuidado domiciliario

Ingrid Meireles Gomes[1]
Maria Ribeiro Lacerda[2]
Jéssica Alline Pereira Rodrigues[1]
Tatiana Braga de Camargo[1]
Débora Cristina Paes Zatoni[1]
Verônica Silva Nascimento[1]

1. Universidade Federal do Paraná (UFPR).
Curitiba, Paraná, Brazil.
2. Universidade Federal de Santa Maria.
Santa Maria, Porto Alegre, Brazil.

ABSTRACT

Objective: Interpret the experience of support from the social network for people involved in homecare. **Methods:** It is a theory based on data, with 12 participating patients in homecare, members of primary and secondary social networks; conducted in the area of a Family Health Strategy Health Unit of a metropolitan city in Southern Brazil. We used semi-structured interviews for data collection and data analysis was with the Glaser method. **Results:** We staged four categories that describe the phenomenon under study "to identify the sources of support in homecare; "featuring the social networks that provide support in homecare", "it is understood as part of the social network that provides support for homecare" and "realizing changes arising from homecare". **Conclusions:** Highlighting importance of social networks in homecare, the nurse as significant social support, use of electronic resources as a source of support and need for participation.

Keywords: Home nursing; Social networking; Social support.

RESUMO

Objetivo: Interpretar a vivência do apoio da rede social pelas pessoas envolvidas no cuidado domiciliar. **Métodos:** Trata-se de uma teoria fundamentada nos dados, com 12 participantes, pacientes em cuidado domiciliar, membros de redes sociais primárias e secundárias; realizada na área de uma Unidade de Saúde Estratégia de Saúde da Família de um município metropolitano do Sul do Brasil. Utilizou-se de entrevistas semiestruturadas para coleta de dados e análise de dados foi segundo Glaser. **Resultados:** Elencaram-se quatro categorias que descrevem o fenômeno em estudo "identificando as fontes de apoio no cuidado domiciliar", "caracterizando as redes sociais que fornecem apoio no cuidado domiciliar", "compreendendo-se como parte da rede social que fornece apoio no cuidado domiciliar" e "percebendo mudanças decorrentes do cuidado domiciliar". **Conclusões:** Destaque para relevância das redes sociais no cuidado domiciliar, o enfermeiro como apoio social significante, uso de recursos eletrônicos como fonte de apoio e necessidade de participação da população.

Palavras-chave: Assistência Domiciliar; Rede Social; Apoio Social.

RESUMEN

Objetivo: Comprender la experiencia de las personas implicadas en el cuidado domiciliario en relación al apoyo de la red social en dichos cuidados. **Métodos:** Se trata de una teoría fundamentada, con 12 pacientes, personas en cuidados domiciliarios, miembros de redes sociales primarias y secundarias, llevado a cabo en el área de una Unidad de Salud Estrategia Salud de la Familia de una ciudad metropolitana en el sur de Brasil. Se utilizó entrevistas semi estructuradas para la recopilación de datos, y análisis de los datos fue segundo Glaser. **Resultados:** Se enumeraron cuatro categorías que describen el fenómeno objeto del estudio "identificando las fuentes de apoyo en el cuidado domiciliario", "caracterizando las redes sociales que ofrecen apoyo en el cuidado domiciliario", "viéndose como parte de la red social que proporciona el apoyo en el cuidado domiciliario" y "percibiendo cambios derivados del cuidado domiciliario". **Conclusiones:** Se destaca la relevancia de las redes sociales en el cuidado domiciliario, el enfermero como apoyo social relevante, el uso de los recursos electrónicos como fuente de apoyo y la necesidad de participación de la población.

Palabras clave: Atención Domiciliaria de Salud; Red Social; Apoyo Social.

INTRODUCTION

Aspects like changing demographic and epidemiological population profiles, with expanding chronic diseases and elderly persons, failure of the system of reference and counter reference, resulting in hypertrophy of hospital emergencies, growing demand for better quality care, increasing comfort and privacy at home, and even lower costs and hospital overload[1-3], show that the current social homecare (HC) panorama emerges as an integrator choice between the basic network of health care and the hospital network. This enables greater visibility and complementarity in health care network as a whole.

The HC involves scheduled and ongoing activities related to prevention, promotion, treatment and health rehabilitation[4] and the care with death, varying depending on the context in which it operates. Thus, we see that, in this context, we seek to overcome the idea of treating the disease, striving for maintaining health. To this end, it is necessary to understand that the subject does not exist on itself but is part of a social network influencing and being influenced by illness situations. The change of the place of provision of health services alone may not be able to break with the hegemonic curative model, but the HC has a transforming character that enhances the reflection on the concepts of human being, on health and disease, as well as the recognition of individuals and multiple relationships to achieve care[2].

As to the understanding of the HC as a viable alternative for building a more comprehensive care philosophy, it is believed that, even when considered as an interface between basic unit and hospital network[3], it must reflect that until now it is an attempt to accomplish this interface. We should consider that there are still some difficulties in achieving the expectations assigned to it as a public health policy.

This is care provided by an interdisciplinary team to patient-family binomial at home, considering physical, psychological, historical, socio-economic, cultural and spiritual factors. It comprises, therefore, also the social network that the subject is part of and what might be done to achieve a better quality of life.

In this way, social networks represent the relational textures that the subject establishes and the characteristics if those social networks5 interfering, influencing and being influenced by individual behavior. The functional aspect of these networks and the resources used effectively represent social support[5].

Social networks can be characterized by structural aspects as size, density, composition, dispersion and variety; in their roles as social companionship, emotional support, cognitive guidance, social regulation, material aid and services and access to new contacts. They also attribute links, such as the predominant function, multidimensionality, reciprocity, intensity, frequency of contacts and history[6]. They can be further divided into primary or secondary social networks. The primaries, those with reciprocity and trust bonds, are kinship relations, friendship and/or neighborhood. The secondary may be formal and/or informal, the third sector, market or mixed[7].

We do not intend here to deepen the discussion on social networks, recognizing that limits are not restricted to existing or absent social support, but this is just one of the aspects linked to the concept of social networking. In this study, we sought to meet this aspect, the support from these social networks.

Social support offered by social networks presents a wide range of benefits related to physical, mental, psychological, social and emotional aspects. However, health professionals do not always use knowledge about available networks as tools to enhance the health of individuals. It is believed to be part of the health professional working on the HC to recognize this peculiarity of care and use their health benefits on behalf of individuals and society.

This is a necessary challenge to overcome the biological model, a further step to understand the human complexity. This way, you can prevent networks with collaborative role in treatment as well as prevention and health promotion, of being abandoned by society due to ignorance.

Given the above it was proposed to conduct a research, leading to a dissertation entitled "The experience of support from the social network for people involved in homecare", which aimed to interpret the meaning of the experience of the support network social the people involved in HC and build a theoretical model that this experience configures.

The objectives proposed for the research in question, the construction of the theoretical model on that experience, can be found in the published article[8]. We propose here to present data resulting from the first objective. This study has as objective to interpret the experience of support from the social network for people involved in the HC, from the emerging categories in the above theoretical model.

METHODS

This was a qualitative study using the method called "Grounded Theory (GT)" or Grounded Theory, widely used in recent years in nursing[9]. It combines technical and systematic procedures for examining the capacity to develop theories grounded in experienced social reality, in this way uniting the depth of qualitative interpretative traditions quantitative logic and rigor[9,10].

According to the method, participants are selected in sample groups (SG) until they reach theoretical saturation, and data collection and concurrent analysis are responsible for guiding the selection of the next participants and either or not the creation of new SGs. They amounted to twelve interviews, but eleven participants; since there were two interviews with the first participant of the first SG, a possibility validated by the use of GT.

Participants comprised three SGs: composing the first group, we envisioned that the subjects were more likely to report experiencing the phenomenon, so we opted for the patients who were in homecare. The selection criteria were to be adults or elderly, who were on HC for more than six months served by the

health facility of Family Health Strategy (FHS) reference for this study, with responsible caregivers and they could communicate orally; those who did not fit in any of these criteria were not considered. The subjects were addressed following the home visits schedule of health facility of FHS; this group amounted to four participants. The second SG was composed of members of the primary social networks cited by participants in the first SG, with neighborly relationship, parentage and/or friendship, amounting to three participants. The third SG included members of the secondary networks cited in the previous two groups and the third group itself, who completed four participants, a nurse, a doctor, a physiotherapist and a representative of the Municipality Health Department.

To facilitate understanding of the data, the participants received over codenames stating of which SG they took part and an interview number. The participants of the first SG were identified as patient, the second SG as a member of the primary social network, and the third secondary social network.

The study followed the Resolution No. 466/2012 and was approved by the Research Ethical Committee, under the registration No. SD1198.123.11.08. Data were collected after signing the informed consent, recording a semi-structured interview, modified by each new collection, as presupposes the method of GT. Occurred between January and August 2012, within the coverage area of a health facility of FHS at the municipality in the metropolitan region of Curitiba, southern Brazil.

Data analysis followed the model proposed by Glaser, described in two steps: the substantive coding, divided into open and selective coding and the theoretical coding. The coding is a systematic process in which the researcher parses the data and reassembles them to combine conceptually with the theory or theoretical model that explains the reality under study[10,11].

RESULTS

The encoding of the data that enabled the development of the theoretical model called "The experience of support from the social network for people involved in homecare," was described by four categories discussed here: "identifying the sources of support in homecare", "featuring the social networks that provide support in homecare", "understanding part of the social network that provides support in homecare" and "realizing changes arising from homecare".

Identifying the sources of support for homecare

In relation to primary social networking approach to family relationships, neighborhood and friendship, identified as having more intimacy. In this context, the family is the primary social network identified as the main support for those in HC, citing in particular siblings and spouses.

The increased amount of females in care is perceived, especially in anticipation of social support arising out of the children. The lack of support is more acceptable when it comes to male children. When there are only sons, others are motivated to engage in the HC:

> *Then I started to help and do things for her there, help, because the boys are only male children she has. "[...]" Poor thing, she is alone, has only male child (Member of the primary network - 7)*

> *Sometimes we have to be joining the family "[...]" to take better care of the patient, because, as the family needs more help... especially when you have only men, no women to help in the care... (Member of the secondary network - 11).*

Although the family is highly valued in this environment of care, also complaints of lack of support from its members stand out. Among the problems mentioned are those emphasizing the application for financial reward, inappropriate achievement care and fights between family members as the responsibilities of the HC:

> *Now he and the other sisters are not talking. They fought because they went to the beach in January, and he found that they had to look after me, and they did not care. Then he felt bad and fought with them. Now they do not speak for guilt of having to take care of me (Patient - 2).*

Neighbors are also mentioned in the various sample groups, and there is usually a specific neighbor with which it strengthens the social relationship after the HC, the others do not offer significant support. When mentioning friends, this is associated with this nearest neighbor, and friends without neighborly relations are little referred to.

Secondary social networks included a health unit of FSH, church and physiotherapy clinic. Professionals who stand out as social support in the speech of members of the secondary social networks are the community health workers, while for patients and primary social networks are nurses and doctors:

> *My relationship is more with the nurse, because I know her about seven years or so. (Patient 3).*

The health unit of FSH shows up as the main secondary social network, and its value is highlighted, although problems related to this support network are cited: the lack of population on the operation and the different categories and functions of health professionals, the shortage of human and material resources, and poor working conditions.

Recognizes the difficulty of receiving support at home, participants say, when they were not restricted to the home,

they obtained more care at health unit of FSH; since they had the possibility of getting to the unit. It is noticed that the service behavior is still rooted in the UBS model:

> *Before, when I could walk, I went to the unit. Once a week I would, but now I cannot. Only occasionally, when they come to check my blood pressure [...] except that my blood pressure is uncontrolled, [...] so I had to have weekly monitoring (Patient - 5).*

In the city where this study took place, the city public outsources physiotherapy, service is relatively quick and has easy access; it is believed that this is the reason why, in addition to health unit of FSH, physical therapy support is the only one mentioned as a social network with professional service character.

The church is also referred to as secondary social network, in two different contexts, more like individual support from members who are part of it, as friends or neighbors on HC, and less as the religious institution in itself. That is, when participants mention support from the church, in fact they point to the support of people they know from church, individually, by ties of friendship, not by the church as an institution. Thus, the support mentioned in relation to the church has characteristics of primary and not secondary support.

> *No business of no church. The church helps a lot, you have the right part of it too, but actually is a brotherhood, [...] we talk about the help the church, but help is so to say, those who help are known there. (Member of the primary network - 8).*

The utterings of the participants pointed out that, in addition to the expected or obtained direct support by people, the use of electronic resources such as the telephone, radio and television, emerge as sources of support. They facilitate access to support. Of these, the main feature is that the phone is considered relevant tool for anyone who is on HC, for enabling contact with the outside. Radio and television, as well as social company, are resources that provide spiritual support, facilitating access to masses and services.

We ponder in this category about the problems that the population suffer in attempts to gain support of secondary formal networks: excessive existing bureaucratic obstacles in order to gain formal support available and the inconstancy of the formal support provided. Factors that can support a formal fear of losing this support, with consequent feeling of powerlessness and insecurity and the feeling of being humiliated to seek formal support.

Participants report that, in HC, the population eventually assume responsibilities they consider fit to formal government sources of support, such as health care, drug spending high cost and medical care given specialty, as well as long-material resources duration for care at home:

> *And there were times they sent to bandage and I showered, and was with unprotected injury waiting until they show up. They did not appear or when they came they had no material. Patient 3.*

Featuring the social networks that provide support for homecare

Among the functions of social support mentioned, the emphasis is given to the social company type, referenced and highlighted the three SG, you can see that just to have company and not feel isolated from the social world outside the home can have a significant value for patient:

> *Because sometimes you need more of a friend than someone who will do anything for you. Even just help me, hear me, to be available whenever I need. I do not have, so the few that appear is very precious (Patient - 3).*

About the type of support with material aid and services, it is noted that it involves a wide range of items, which are accentuated health care, locomotion, with household chores and personal care.

Health care, carried out mainly by the family, followed by professionals health facility of FHS, include from stimuli engines for rehabilitation, specific diet to specific procedures, such as dressings. Likewise, the care of household chores are assigned to the family.

Personal care is rarely mentioned in the uttering of the participants, which demonstrates the idea that the person on HC is often seen only as patient as a sick body, not as a human being, which has complex needs, outweigh the physical. This concept is followed through even in the account of the patients themselves, who cite health care at the expense of personal. Other types of social support were also cited, but with less evidence, such as emotional support, cognitive guidance and advice and access to new contacts.

Regarding the size of the social network offering support in the HC, note that it is small, ie, few people are part of the social network that offers support to HC these patients. This information is in line with participants' satisfaction with their network because, although some participants point to the need for more members in the network, when asked directly about their satisfaction with the existing social network, often say they are satisfied.

The density between the different sources of support mentioned can be identified as low, almost nonexistent is the connection and mutual support between members of different sources:

> *No, it was never tried. Funny, social functions separated from health when should be together. You have no interaction between these services. (Member of the secondary network - 12).*

No, on the care of professionals in clinics [physiotherapy] we do not have any return. (Member of the secondary network - 11).

One can recognize that the primary social networks are multidimensional, while the secondary are not. The frequency of contacts within the network is cited in a diversified manner, immediate family and one neighbor with significant role appear as high frequency contacts, while the general vicinity and familiar with different types of kinship show up as low frequency contacts; other social networks are not mentioned in relation to the frequency.

Being understood as part of the social network that provides support for homecare

When participants attribute personal meanings to be part of the social network that provides support in the HC, there are feelings, positive and negative, as well as motivations. Feelings are mixed for the different participants involved in this experience; however, it is noteworthy that this ambiguity is striking in the speech of those who are part of formal secondary social networks. Satisfaction and frustration coexist simultaneously, especially through the perception of the effectiveness of the work on the HC:

When we get things, you have that family support; we have a pleasure, of course! When we see it all will work like a charm. Now when the family does not answer, not taking care of itself, [...] we get a little frustrated. So we suffer a little (Member of the secondary network - 11).

Among the positive feelings stand up satisfaction and happy to help him feel important to someone and receive affection for its support. The negative feelings point to the overload of responsibilities, fear of upsetting more than help, insecurity, helplessness and suffering by considering the patient's condition on HC as negative.

People seen as sources of support, either on his particular action or as an institution, recognize the value of support they offer and claim that part of the social network that supports the HC becomes the reference for others who need support, thus augmenting the supporting social network:

After I started taking care of her [patient on HC], a lot of people asking for help come for advice. There were women coming to ask us if we always are praying together. Yeah... I help, again and people coming to ask always. I'm always in the middle of them (Member of the primary network - 6).

It is stated that the existence of social networks that provide support in the HC facilitates this practice and that the existence of a network can be very important for other, complementing each other. For, patients the value of social support is also recognized,

there is this appreciation in relation to their physical and emotional improvements, increased survival and solving personal and social problems. The influence for the family is poorly reflected, pegged mainly to the possibility of improvement in the patient.

Motivations to be part of the HC in the subject's social network are varied, highlighting the kindness, moral obligation and proximity of the person HC, still being presented as reasons: empathy for the ill person, the existence of strong prior link to the HC need, professional obligation, and patience and family ties. It refers to the provision of support to each other as a characteristic form of personality:

But that's equal to them [team of FHS] "[...]" Staff is so, most want to help patients for themselves (Member of the secondary network - 11).

The guy who is in the patient's situation, also assumes the role of a source of support within their social network, especially for one who lives in the same household and who went on to take responsibility for the patient. But there are also cases in which the patient remains in a co-dependent relationship with another:

So we had a patient who visited us at home and the son was an alcoholic. She wanted to take care of that child, and it was she who needed care, the situation was cyclic (Member of the secondary network - 11).

This category covers up even the role of participants in search of support available. It is noticed that the participants complain of lack of support, without in return demand, these same individuals, forms of support available, even if they have access to information on how to obtain the necessary help. Maintaining a passive attitude toward the support that you can enjoy:

Have spoken for us to have a place where they come pick her up at home, take her along, it is until noon. But it did not follow. And then that's it then, is remains with has has has [...] Then do the same another said, offering home no one comes (Member of the primary network - 8).

Noticing changes resulting from homecare

This category covers changes for both the patient on HC, as for him who is supporting this patient. For patients we perceived changes can be understood as social changes, such as the strengthening or decrease in bonds, and to a single participant, also the beginning of new relations; personnel changes. With respect to the modification of feelings these patients, we saw especially the flow of negative feelings and, finally, operational changes in the daily lives of these participants. About the restrictions at home, the increase in spending on health and greater dependency on others:

I will not, the church is near "[...]" but I will not, because now I depend on driving to go. (Patient - 4)

I think the money I could invest in better food, or something else, it has to be all going with the medicine. (Patient - 5).

For one that is social support HC in patients also are personal changes such as the decrease in the frequency of contacts with their own social network, changes in routine, need for knowledge of new tasks, other care for them:

What she did touched for me to do just about everything in the beginning. I had to learn. (Member of the primary network - 8).

I stay here at home, but my thinking is there. It is there at her house, does the tart [patient on CD] okay? Is he all right there? So you get the worried mind there and cannot do anything for her (Member of the primary network - 7).

DISCUSSION

We consider the question of intricate females to take care to refer to the condition of women in the role of natural caregivers; the vision of the necessary availability of the woman starts with public managers[12]. This study ratifies this situation and demonstrates that in secondary social networks the presence of a woman is expected to perform care. This needs to be rethought, since there is not always a female available for this function, and when that occurs, it disqualifies men to assume this responsibility and is the situation is considered a home without a caregiver, a situation that prevents the proper conduct of the professional HC. Thus reinforcing the social characteristics of sexual discrimination.

Studies show the main health professionals cited as a source of support, as this research shows doctors and community health workers;[13-15] in a study[15] the nurse is appointed and yet it weighs about the real role, as the remarkable confusion of the population as to professional roles within nursing. It is noteworthy, in this research, the significant role of social support provision properly nurses as participants cited the names of professionals, which allowed the researchers to have science that specifically speak of female nurses.

The lack of mention of nurses as an important social support in other studies lacks reflection, especially when we note that in studies that reflect on the role of this professional, this relationship is predominant[16-18]. It has been a paradox between what is expected from this work and what it has represented effectively in the community. This research, however, shows that the nurses from the population itself speak and can demonstrate that there might be a connection between the expected and effected by this professional in the practice in the FHS. It is noteworthy that necessary new research could confirm this hypothesis.

The understanding of electronic resources as a source of social support deserves to be deepened, especially the constant development of new technologies and the increasing ease of using them as communication tools. Although it proposes to use these resources as a possible expansion of the support available, including family members,[18] It considers that, to be effective as social support, these resources need to be used appropriately[13].

Regarding the type of support material aid and it is noted in the literature services,[15] corroborating the findings of this research, the predominance of practical activities for the benefit of the patient. This shows that even home is a distinct care environment, enabling targeted actions for completeness and uniqueness of the human being,[1] in face of the practical activities of caring for the body, the concern with subjectivity and even taking care of themselves are often forgotten.

The awakening of new feelings as a result of the HC is common, whether positive or not, deal with them as best you can is important to practice HC evolve. Both patients and members of the network, who also have modified feelings, must understand this. With a predominance of mixed feelings, meanings of care assigned to each caregiver vary with the context of life,[19] and you can still see that caregivers perceive the HC as an opportunity for learning, growth and personal fulfillment[20].

It reflects on the ambiguity of feelings on the HC, usually associated to this experience the informal caregiver, especially to family[19]. In this research, by contrast, this ambiguity stood out among members of secondary networks, health professionals, as well as the family also influence and are influenced by the HC they provide.

A responsibility sometimes attributed exclusively to healthcare professionals or institutions they represent, it is to offer formal support. However, it depends not only on the health care team responsible for getting support using the network. This responsibility must be shared, it is up to the patient and/or family/caregiver to seek sources of support available that takes notice. While recognizing that the facility that participants have to make contact with the available resources influence the scope of existing support[18].

You can see a passive attitude of those on HC. It is expected that the source of support come to the home, without, however, show interest in getting it. Here there is an issue of accountability, people complaining, should play a joint action with the complaining macrostructure.

Although in this study the importance of social support for the family has been described by the influence it brings to the patient and only indirectly to the family; it is important to consider that social networks have great importance for family and caregivers[18,20].

Therefore, you can see that, although it is known that the HC also influences family life, there is the perception of the participants that the support of the social network is able to minimize the difficulties of these participants and even prevent physical or mental illness arising of care at home. Social

networks, such as support groups for family members or even to assist in the procurement of materials, acting as a social company, not only for the patient, among others, could enhance the practice of HC as enable the maintenance of caregiver health also assisting in preparing them to care.

CONCLUSIONS

We believe that this research has enabled the understanding of the experience of the support of the social network for people involved in the HC, allowing to glimpse its nuances, difficulties, facilities and needs, especially for presenting the differential include the different actors involved in the experience study, and not only patients. Thus, it is expected to contribute to equip nurses to take advantage of the possibilities that the recognition and use of social networks can offer to the HC.

Although we know that the social network not always has a positive impact on the lives of individuals and concretely represents social support, the importance of social networks for the health of people standing out in this research is the positive factor associated with the presence of a network capable of encouraging the scope of welfare, maintenance and recovery of health; or also by the negative influences of deficient networks. This is reflected in a special way on the HC, in which patient and caregiver are even more restricted to home, limiting social interactions.

It is worth mentioning the importance of understanding the use of electronic resources as a source of social support and influence of networks also for caregivers. Aspects suggested to be addressed in further studies. We argue about the need for nurses to violate and take actions directed care to the caregiver, especially at home, in order to minimize physical illness, mental and emotional this.

The recognition of nurses as an important social support is another aspect that merits further development in order to ratify the rapprochement between the expected and the realized by this professional in the FHS, highlighted in this research.

Finally, there is the need for political participation and civic awareness also professional and formal institutions, but especially the population, which keeps an uncritical and passive attitude towards your needs. Lack the population to recognize their role in the construction of citizenship, more to know about their rights, look for them actively.

Living in society is more than a cluster of private lives, means a whole that surrounds each individual in a tangle of relationships, even indirectly, echo one another. It is necessary to think of the good for the community.

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