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# The network social support experience of people involved in home care\*

A VIVÊNCIA DO APOIO DA REDE SOCIAL PELAS PESSOAS ENVOLVIDAS NO CUIDADO DOMICILIÁRIO

LA VIVENCIA DEL APOYO DE LA RED SOCIAL POR LAS PERSONAS EN CUIDADO DOMICILIARIO

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#### **ABSTRACT**

Objective: To build a theoretical model to configure the network social support experience of people involved in home care. Method: A quantitative approach research, utilizing the Grounded Theory method. The simultaneous data collection and analysis allowed the interpretation of the phenomenon meaning The network social support of people involved in home care. **Results**: The population passive posture in building their well-being was highlighted. The need of a shared responsibility between the involved parts, population and State is recognized. Conclusion: It is suggested for nurses to be stimulated to amplify home care to attend the demands of caregivers; and to elaborate new studies with different populations, to validate or complement the proposed theoretical model.

# **DESCRIPTORS**

Homebound persons Home Care Services Social support Caregivers Home health nursing

#### **RESUMO**

Objetivo: Construir um modelo teórico que configure a vivência do apoio da rede social pelas pessoas envolvidas no cuidado domiciliário. Método: Pesquisa de abordagem qualitativa, com a utilização do método Teoria Fundamentada nos Dados. A coleta e análise concomitante dos dados viabilizou a interpretação do significado do fenômeno A vivência do apoio da rede social pelas pessoas envolvidas no cuidado domiciliário. Resultados: Destacou-se a postura passiva da população na construção de seu bem-estar. Reconhece-se que deve existir uma responsabilização compartilhada entre as partes envolvidas, população e Estado. Conclusão: Sugere-se que os enfermeiros sejam estimulados a ampliar o cuidado que realizam no domicílio para atender demandas dos cuidadores; e que novos estudos sejam elaborados com populações diferentes, a fim de validar ou complementar o modelo teórico proposto.

# **DESCRITORES**

Pacientes domiciliares Serviços de Cuidados Domiciliares Apoio social Cuidadores Enfermagem domiciliária

#### RESUMEN

Objetivo: Construir un modelo teórico que configure la vivencia del apoyo de la red social por las personas en cuidado domiciliario. Método: Estudio de abordaje cualitativa, con la utilización del método Teoría Fundamentada en los Datos. La recopilación y el análisis concomitante de los datos hizo viable la interpretación del significado del fenómeno La vivencia del apoyo de la red social por las personas implicadas en el cuidado domiciliario. Resultados: Se destacó la postura pasiva de la población en la construcción de su bienestar. Reconociendo que debe existir una responsabilidad compartida entre las partes implicadas, población y Estado. Conclusión: Se sugiere que los enfermeros sean estimulados a ampliar el cuidado que realizan en el domicilio para atender las demandas de los cuidadores; y que sean elaborados nuevos estudios con distintas poblaciones, con el fin de validar o complementar el modelo teórico propuesto.

# **DESCRIPTORES**

Personas impossibilitadas Servicios de Atención de Salud a Domicilio Apoyo social Cuidadores Cuidados de enfermería en el hogar

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# INTRODUCTION

The health work has been developed to overcome the curative care model, and for this reason, it has been directed to the integrality of care and primary health care. Home care is a favorable practice for this change when it articulates preventive, promotion, curative, assistance and education actions<sup>(1)</sup>. It is worthy to consider the home care as a viable option of health care considering the increase in longevity and chronic illness existing in the society and the financial restrictions in health, as it propitiate the frequency reduction and the costs of hospitalizations<sup>(2)</sup>.

Home care involve different categories, as care, hospitalization and home visit, each one with its own characteristics<sup>(3)</sup>. It requires knowledge of its peculiarities from health professionals: home context, individual, family, caregiver, interdisciplinary team and network social support.

This way, the comprehension of involved people in health care (HC) is perceived as important for its concretion either by its individual or collective role. In this context, it is believed to exist a real social network influence in HC, considering it as a group of individuals interacting and allowing to build and rebuild an individual identity constantly time and space<sup>(4)</sup>.

HC represents a situation in which the social network is highlighted, being formal or informal, primary or secondary. With the arrival of an ill family member, life is of those involved in the context is modified, causing physical, emotional, organizational, personal and collective adaptations<sup>(5)</sup>. Those adaptations can be relieved or even resolved when there is effective network social support.

The HC can be recognized as a potential for greater approximation of professionals with the community<sup>(5)</sup>, allowing better use of available social resources and the community resolute potential. Thus, the knowledge of social networks with a collaborative role for health of individuals is believed to enable the health professional to promote a more comprehensive care, based in the needs and everyday realities, propitiating autonomy to subjects<sup>(6-8)</sup>.

The identified importance of the network social support for HC and the perceived lack of studies considering a joint vision of different involved people in HC about networks<sup>(9)</sup>, this investigation was proposed to search the answer for the question what is the meaning of the network social support experience of people involved in home care? The objective is to build a theoretical model that configures the network social support experience of people involved in home care.

#### **METHOD**

This is a qualitative approach research that utilized the Grounded Theory (GT), a method to elaborate theories and theoretical models based in data from social reality, systematically collected and analyzed<sup>(10)</sup>.

The study context was the territory limits of a Health Basic Unit with the Family Health Strategy teams (USESF) of a metropolitan region from Curitiba. The data collection was from January to June of 2012, through semistructured interviews, scheduled with the participants in a convenient place and date during a home visit done with the USESF team. The study was presented to participants and it was the moment where they would give their consent to participate voluntarily.

In agreement with the method, the subjects were listed from the necessity coming from the data: at the end, they composed three sample groups (SG). The first was composed by four patients in home care (following the criteria of being over 6 months in HC, to have a familiar responsible caregiver, to be an adult or elderly and to be able to communicate verbally), totalizing five interviews, two were with the first subject. The second SG was composed by three members of primary social networks, selected for being cited by the subjects or patients from the first group as relevant in the HC, and the three interviews were conducted. At last, the third HC was composed by three members of secondary social networks, indicated by the first and second SGs, ending in three more interviews. Thus, the involved subjects in HC in this study, in accordance with their own data, included patients, family members, friends/neighbors and health professionals.

The data analysis followed the glasserian model of codification, composed by two phases – the substantive and the theoretical; being the first subdivided in two moments – the open and selective codification. In the last phase was the theoretical codification, the theoretical code opted in the present study was denominated interactive family<sup>(11)</sup>.

This code proposes interactions within the data built by mutual effect relationships, reciprocity, mutual trajectory, interdependency, effects interaction and covariance<sup>(11)</sup>. Mutual effect is when there is non-standardized relationships within the variables; reciprocity deals with interactions with reciprocal exchanges; mutual trajectory happens when the alterations happen concomitantly; effects interaction points the existence of a sequence relationship; and the covariance presents a linear relationship within the variables.

This study followed the resolution 196/96; it was approved by the Ethics in Research Committee, under the registration CEP/SD 1198.123.11.08. After verbally accepting to voluntarily participate in the research, the subjects signed the Free and Informed Consent Term. The confidentiality and possibility to withdraw without justification was guaranteed, as well as the absence of material, physical or emotional onus.

#### **RESULTS**

The data pointed to elaboration of four categories: Identifying the social support in home care; Characterizing the social networks that provide support in home care; Understanding it as part of the social network that

provides support in home care; and Perceiving changes coming from health care. From the existing interactions between those categories, through the theoretical code denominated as interactive family, a central category was built, described as the following statement: Experiencing the social network support from people involved in home care that presents the studied phenomenon, identified as The experience of the social network support from people involved in the home care.

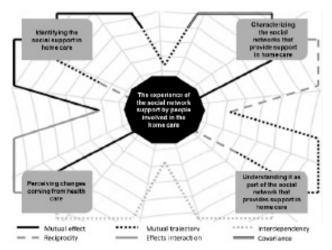
In the category *Identifying the social support in home* care the composition of perceived support sources in the experience of HC was apprehended, including primary social networks, mainly composed by the family, neighbors and friends; the secondary social networks were specially identified as USESF, but also by physiotherapy clinic linked to the Unified Health System (SUS) and the Church; and the use of electronic resources as source of social support and as a tool to obtain support. In this category the existing support sources, underutilized or known by the community also emerge, as those coming from the Social Action Secretary and the Health Secretary. Still, the perceived reasons for the difficulty in obtaining social assistance, specified by justifications for support restriction by primary networks and by experienced problems in the search for formal support.

Characterizing the social networks that provide support in home care, is the category in which the characterization of such networks by social support functions is comprehended, identified as material and services help, social company, emotional support, cognitive guidance and advices and access to new contacts. Other network aspects that integrate the size and multidimensionality of social networks are the frequency of contacts, the connection and compromise within members, at last, the main necessity and the perceived absence of social support.

The role of people as part of the social network is presented in the category *Understanding it as part of the social network that provides support in home care* containing the meanings of being a participant in the HC social network, as the feelings and motivations from those subjects in this context of care; the patient position of needing support in his condition of being cared as social support of third parties or as searching for an available support; and the importance of the social network support for the caregivers, for the patients and family and also to the own network.

The category *Perceiving changes coming from health care* exposes the peculiarities coming with the need for care or for being cared at home; changes for the patient, as the emotional and operational changes and in the social relationships; and also changes for those who act as the source of social support for the patient, involving personal modifications and variations in the support given over time in the HC.

Those four categories describing the phenomenon have a straight relationship with the central category, as the relationships are not formed by themselves; they are connected parts from a central concept described as *Experiencing the social network support from people involved in home care*, which can be perceived in the theoretical model proposal explaining the phenomenon *The experience of the social network support by people involved in the home care* (Figure 1).



**Figure 1-** Theoretical model of the phenomenon *The experience* of the social network support of people involved in the home care.

The given amplitude of interactions within the data should be considered, not being possible to draw them in a theoretical model by uni and bidirectional lines exclusively. Thus, behind the model drawing a net was inserted, symbolizing the existing multiple interactions in the studied phenomenon. Besides that, the existence of different types of lines connecting the categories can be observed, demonstrating the possibility of more than one type of interaction within the same data, simultaneously or not.

As perceived in the theoretical model, the proposed categories *Identifying the social support in home care* and *Characterizing the social networks that provide support in home care* establish three different types of relationships; of mutual trajectory, mutual effect and covariance. Simultaneously, recognizing the composition of the social network of the subject in HC, the description of this network characteristics are distinguished, exposing the mutual trajectory relationship.

The consequence of the alterations in the network characteristics generated in the identification of its members indicates the existence of mutual effect. This situation can be exemplified as follows: when there is an increase of commitment within the members of a specific social network with the person needing HC, an alteration can happen in the type of network that this member will represent, a neighbor can become a friend or even start to develop new supporting functions. The same can happen with members of any identified networks. As it is perceived in the following speech about the social network created or modified from the need of home care:

More were the people who appeared after, that ended up getting closer to me and becoming my friends (Interview 3).

Waw, the neighbor woman now is a mother; she does everything (Interview 2).

The opposite can also happen, that is, members of a network that had affective connections before can restrain the contact or even be excluded of the social relationship circle, decreasing the subject' network. This way, the existence of a covariance relationship is perceived within the two categories mentioned above, as the alteration in one of them interfere linearly on the other.

The following speeches presents this situation, the first when talking about the longer time in the partner' trips, who is a truck driver, and started to come less home after the HC was initiated; and the second by the distance of the brother.

Now he travelled on the first of on December 31<sup>th</sup> and hasn't come until now (more than two months after) (Interview 1).

There is one (brother) who came twice to see me and hasn't anymore. If he calls, it is for one of my sisters and does not ask about me (Interview 2).

The relationship between the categories *Characterizing* the social networks that provide support in home care and *Understanding it as part of the social network that provides* support in home care is a mutual trajectory. In the measure, which the network characteristics are known, the role for those involved in the HC can be understood.

Another relationship linking those categories is the reciprocity. The subject perception about his role in the social network is modified by the network characteristics, and this new perception can alter diverse types of characteristics. For example, the existence of higher support availability with access function to new contacts or cognitive and advice guidance, in a way to transmit information about the available social networks, including by the electronic resources, the higher search for available support or even the importance amplification of having a wide and affective social network as consequence. Consequently, this can increase the connection size, or the frequency of the social network contacts of the subject in HC.

(...) Then the health agent goes there, sees the patient's condition and comes. (...) when the agent is really active, the patients are benefited, because we move with the team to make something to help (Interview 11).

In the popular pharmacy has, because we buy there. I hear here on the radio them talking about this government program (Interview 5).

Within the categories *Understanding it as part of the* social network that provides support in home care and Perceiving changes coming from health care there is an interdependence relationship. Because only when one is aware of your role as a social network in HC is when he perceives

which changes this fact will result for different people involved and for the HC itself. Similarly, to comprehend one-self in this process, necessarily one has to perceive how his change his life, the social relationships and the support.

The neighbors say: - Neighbor lady, I haven't seen you lately. Then I say: - But I'm dealing there, the woman is in bed, but I did not abandon you (Interview 7).

Identifying the social support in home care and Perceiving changes coming from health care are categories that establish sequential relationship, that is, effects interaction; as the patient perceive changes in his life as consequence of the HC, with the dependence increase, consequently the lack of support from the social network is perceived. Another sequence is established when there is perception by the social network members of the patient' autonomy and, consequently, less need of support from this network.

What she used to do now I do, almost everything in the beginning. When it is only us at home, is hard. (Interview 8).

Now I stopped a little because she is better and her kids gained more practice in the job. So now I've stopped a little. But when she was bad, I saw that she was really not good, I ran, left everything here (Interview 7).

Those categories also have a mutual effect relationship, as the alteration of one category by the other will not always be unidirectional. There are situations where there are no standards within them. Although the influence of one category on the other is perceived, it is not possible to measure how this influence will happen. For example, in a HC situation the patient can perceive to receive more support from the closer people. Thus, the creation of expectations that the same will happen with other social networks in which this individual is part of can happen, but the no intensification of pre-existing situations ends up generating unhappiness or disappointment, leading the patient to have negative feelings.

They (sisters) help financially, in the tasks, in everything. (...) He (brother) used to come always, for me to cook for them. As my son says: - The uncle is selfish, mom; if you are fine he will come back. Then I'll say: - Now it's not needed, right?! (Interview 2).

The mutual trajectory and reciprocity are the relationships developed by the categories *Identifying the social support in home care* and *Understanding it as part of the social network that provides support in home care.* The identification of networks that are part of a social network of a subject in HC allows the comprehension of oneself as part of it; at the same time that recognizing one's role inside this network allows a critical vision, therefore perceiving reciprocity.

There are many things that I (familiar caregiver) learned with her (patient) while teaching, now in the way she is. If not, there was no way. Until today, there is no way to say that I am not depending on her (Interview 8).

The mutual trajectory is related with the search for new available sources. As the search for new contacts for social support broadens the existing sources of assistance that are underused, starts to be utilized. This still happens when perceiving that the comprehension of the support importance for the involved people in the NC is in accordance to the recognized support.

The social networks are certainly important in all aspects. I think there are people surviving through this. (...) They (other social networks) are work collaborators, right? If someone does a service and collaborate with what I do, ends up helping me too (Interview 10).

There are still, the relationship between the categories *Characterizing the social networks that provide support in home care* and *Perceiving changes coming from health care* with a mutual effect. This relationship can be perceived by the alterations that the network and support characteristics provoke in the patient as well as in other people involved in the HC. Alternatively, in opposition, by the way those changes from the HC interfere in the support characteristic.

From the type of function from the received support, the patient will perceive higher or lower significant alterations in relation to be in HC; the same happens with the variation on the size of the network and its functionality. In counterpart, the changes passed by the subjects in HC alter those characteristics in an unpredictable manner. People who perceive their social relationships as reduced can develop strict social networks, but intense and high density, causing positive emotional changes and facility to adapt. However, this may not happen and this size reduction in the network can result in a support with little types of function and consequently negative changes.

I even started to think one day that I was depressed, with fear. Because I think this is not possible! I wanted to talk to someone, right? Never, it is hard to have. It is that I have been always active (Interview 5).

Other people involved in HC are also affected by the described mutual effect relationship. One chance in the offered support over HC time alters different characteristics, as the size, the connection or simply the type of support function. On the other hand, the characteristics of social assistance cause personal changes in caregivers, for example, reducing or amplifying their personal social network.

# **DISCUSSION**

Regarding the category *Identifying the social support in home care* the national literature corroborate<sup>(12-14)</sup> the present study findings, that the social network composition is mainly formed by family members and neighbors in the primary networks and by USESF professionals in the secondary networks. Studies that investigated<sup>(12-14)</sup> different contexts and health care subjects pointed to the importance of

the social networks for health; this way, it is believed those subjects as well as the patients should be part of the action plan of health professionals. It is necessary to think about it, in special when dealing with HC, an environment where those subjects, more than an option in care, should be seen as subjects, who also need assistance by being modified by the reality that they help to change.

In opposition, international studies points to friends as the most significant social network, even more than family member, propitiating improve in the social isolation and decrease of the possibility to develop depression, even when the family role is highlighted in the social network<sup>(15-16)</sup>.

The recognition of the USESF as social network that supports subjects in HC allow the possibility to create bounds of trust between users and professionals, besides the establishment of favorable relationships within the social network support and the families, contributing to the subjects' health<sup>(17)</sup>.

Different authors<sup>(14;17-19)</sup> approach the use of electronic resources (radio, television and telephone) as source of support, but as an incipient way. Those resources are weighted as valid as social support for subjects if utilized in an adequate way<sup>(17)</sup>; and this use can represent significant assistance, especially for the patient's families<sup>(18)</sup>.

Regarding the types of support function mentioned in the present study in the category *Characterizing the social networks that provide support in home care*, there is no consensus in the literature about the main types. One possible reason can be the subject's variability in each study about social networks that provides support. However, this might not be the only reason, considering that in different studies<sup>(12,20)</sup> with elderly as subjects, it was also possible to note the disparity in the types of function of the cited support.

Thus, cultural, economic, geographical, educational, within other factors can influence this characterization<sup>(15)</sup>. However, in the present study, the analysis of those factors was not conducted; a reason to suggest new similar studies, but with populations with different characteristics, to verify the presented phenomenon and rectify or complement the proposed theoretical model.

The motivations to be social support in HC presented in the category *Understanding it as part of the social network that provides support in home care* are frequently discussed in the literature<sup>(20-25)</sup>. The obligation can be perceived as a motivation, people give support because of an obedience condition to norms and social values<sup>(20-25)</sup>. There are also positive motivations, as love, affection, devotion or acknowledgement<sup>(21-23)</sup>. Independently of the motivation, especially for that person who assume more caring load at home, the generation of overload is recognized<sup>(21,26)</sup>.

In relation to the caregiver' feelings, a variation due to the life context of each subject is noted<sup>(25,27)</sup> but it is possible

to note an ambiguity of involved feelings; pleasure and satisfaction happen simultaneously to impotence, impatience and insecurity<sup>(25,27)</sup>. In this study, this ambiguity is perceived beyond the members of the informal social networks, afflicting specially members of secondary networks, as the health professionals. This happen because those subjects, besides acting in the HC, they suffer interference by the caring they provide.

The small search for social support demonstrated a passivity of the population in the search for ways to promote wellbeing. The participation of people in the search for available social resources is believed to influence directly the reach of supports<sup>(28)</sup>. Similarly to this study, authors<sup>(29)</sup> observed the population deficit in searching for assistance, identifying within the reasons for it, the illness stigma, problems with alcoholism and tobacco, but ended recognizing the difficulty to understand the reason for the small search.

About the category *Perceiving changes coming from health care* it is important to consider the changes from the need of HC affects the entire social network. However, the primary influence is highlighted more specifically, the responsible caregiver<sup>(21,23,30)</sup>. This influence is related to diverse factors and reaches varied dimensions of the caregiver life, which gives exposure to physical, emotional, personal and social risks<sup>(21,23,26-27)</sup>. Thus, the caregiver can have the sensation of lacking autonomy upon his life and prioritize the care for the other in detriment of himself<sup>(21,23,30)</sup>.

In this context, it becomes imperious that nurses direct their sight to caregivers, understanding them as subjects that specially in HC, need support<sup>(26)</sup>. Those professionals need to recognize the home complexity as caring environment and the influences brought to the lives of all involved people.

Social networks are believed to be able to minimize the difficulties of those caregivers and even stop the physical and mental illness of being support in HC<sup>(26)</sup>, besides the representation of those as a factor of influence for the satisfaction of needs from the home cared patients<sup>(16)</sup>. Thus, nurses are expected to recognize the influence and possibilities that social networks support can offer to perform HC and for the reach and maintenance of patients health and from other involved people.

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## CONCLUSION

The presented findings reinforce the understanding of social networks as potential for HC, as attending the necessity of support for subjects involved in this context. With the theoretical model construction, it was possible to recognize how the relationships happen within the social network that gives support to HC and consequently, it is expected to give instruments for nurses to act in this care environment, using the social network support as facilitator.

More research is suggested in the same topic, with similar methodology, in regions with diverse population characteristics, to complement or rectify the proposed theoretical model. It is also considered that with the proposal it would be viable to verify the direct influence of factors that characterize the population, as geographical, economic, educational, within others, in the experience of social network support of those involved in HC.

The reflection about how the citizen conscience is being built is needed. In most diverse situations, people seek too little the options of available support in the society, presenting a passive posture in front of found barriers. It is perceived that populations wait for solution of their health and social problems to be solved by formal bodies, without committing to solve them.

The responsibility for the population needs should be shared. The government and formal bodies cannot be relieved from their responsibility of existing social needs. However, each one, individually and collectively should have a citizen conscience and adequate attitudes to reach their rights.

At last, it is important to note especially in HC, the caregiver should be understood and attended as subject of nursing actions, considering this environment presenting more than one work object for nurses, due to alterations coming from HC, which affect different involved people in the home context. This way, it is recommended for this professional to be stimulated to amplify the care given at home, trying to understand the nuances of this environment, guiding the ones involved to activate their social network, to participate in support groups and to find material resources and social company to support them.

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