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INTEGRATIVE REVIEW ARTICLE

BEING A FAMILIAR CAREGIVER IN THE HOME SPACE: INTEGRATIVE REVIEW SER FAMILIAR CUIDADOR NO ESPAÇO DOMICILIAR: REVISÃO INTEGRATIVA SER UN FAMILIAR CUIDADOR EN EL ESPACIO DEL HOGAR: REVISIÓN INTEGRADORA

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ABSTRACT

Objective: analyzing the national scientific literature about the practice of home and hospital care developed by the familiar caregiver. **Method:** an integrative review with a view to answering the question << *How familiar caregivers develop home care with no specific training for this?* >> held in the database Lilacs and the virtual library SciELO. There were used the descriptors family [and] social support [and] nurses. National articles with availability of the free and full text were included, from 2002 to 2012. **Results:** for the familiar caregiver's social network is formed by family, friends, coworkers, for support to overcome difficulties, and the nursing staff in regarding guidelines for care. **Conclusion:** there was a predominance of the level of evidence six, demonstrating the need for scientific productions with greater methodological rigor, in order to incorporate the new findings to nursing practice. **Descriptors:** Family; Social Support; Nursing.

RESUMO

Objetivo: analisar a literatura científica nacional sobre a prática de cuidado domiciliar e hospitalar desenvolvida pelo familiar cuidador. **Método:** revisão integrativa com vistas a responder a questão << *De que forma os familiares cuidadores desenvolvem cuidado domiciliar sem formação específica para isso?* >> realizada na base de dados Lilacs e na biblioteca virtual SciELO. Foram utilizados os descritores família [and] apoio social [and] enfermagem. Foram inclusos artigos nacionais com disponibilidade do texto completo e gratuito, de 2002 a 2012. **Resultados:** para o familiar cuidador a rede social é formada pela família, amigos, colegas de trabalho, pois dão suporte para superar dificuldades, e a equipe de enfermagem no que tange as orientações para o cuidado. **Conclusão:** houve o predomínio do nível de evidência seis o que denota a necessidade de produções científicas com maior rigor metodológico, a fim de incorporar os novos achados à prática de enfermagem. **Descritores:** Família; Apoio Social; Enfermagem.

RESUMEN

Objetivo: analizar la literatura científica nacional en la práctica de la atención domiciliar y hospitalaria desarrollada por el familiar cuidador. **Método:** revisión integradora con el fin de responder a la pregunta << *¿Cómo los cuidadores familiares desarrollan cuidados en el hogar, sin formación específica para esto?* >> celebrada en la base de datos Lilacs y en la biblioteca virtual SciELO. Se utilizaron los descriptores familia [y] el apoyo social [y] enfermería. Fueron incluidos artículos nacionales con disponibilidad del texto completo y libre, de 2002 a 2012. **Resultados:** para el familiar cuidador la red social está formada por familiares, amigos, compañeros de trabajo, por el apoyo para superar las dificultades, y el personal de enfermería en sobre directrices para la atención. **Conclusión:** se observó un predominio de los seis niveles de la evidencia que demuestra la necesidad de que las producciones científicas con mayor rigor metodológico con el fin de incorporar los nuevos hallazgos a la práctica de enfermería. **Descriptores:** Familia; Apoyo Social; Enfermería.

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INTRODUCTION

When a family member is sick, it is in the family where is centered the source of care, mainly in cases where treatment is prolonged. In this context, emerges the familiar caregiver, who helps the sick relative partially or completely, in the difficulties and / or disabilities to perform the basic activities of life.¹

The family is a dynamic unit, with a particular identity, constituted by people united by ties of blood, affectivity, who perceive themselves as family, living for a time building a life story. Family members have, create and transmit beliefs, values, knowledge and health practices, have rights and responsibilities, developing an own structure and organization.¹⁻²

The caregiver is defined as any adult member of the family or community. Someone who is able, and has the main function of home care of someone who, by reason of age or physical or mental condition, either partially or totally unable to care for themselves, or for a specified final time.²

Domiciliary care already has its concept based on the possibilities to motivate changes in quality of attention to people's health¹. Domiciliary care is a health care strategy, which aims to emphasize the autonomy of the ill subject, as well as providing greater family participation in care.^{3,4} However, one must know the health status of families, life contexts and available resources that contribute to the practice of home care. Seeking to promote the ability of the caregiver to be able to perform home care, with the help of health professionals who have technical and scientific knowledge; and, especially, having sensitivity and technical-scientific capacity to set goals for home care.³

Assume the responsibility of being the main familiar caregiver of a dependent home care patient causes many psychological, physical and social changes of caregivers. Note also that often the family caregiver has no adequate support to experience this situation.⁵ Thus, the social support network, which includes friends, family and people who live with the patient are affected, because of the changes the disease causes. Added to this, there has still, lack of recreational opportunities, inability to work outside the home, denial of social and personal life. Studies reveal that the primary caregiver's social network consists of relatives and friends, but that many caregivers do not receive or have few people to compare with

the number of people who thought count within their social network.⁶⁻⁷

It is known the importance of the social network to improve the quality of life, cure and / or recovery of patients with chronic disease in which the positive effect could be confirmed in cases where diseases require prolonged therapeutic actions in this way the solid, effective and reliable social network fosters behavior health monitoring.⁸⁻¹⁰

Families have been recognized as providers of care to the relative with chronic disease, as well as mediating the exercise of this role as important in the social network members. Therefore, it is necessary to know the health of families, the life contexts and available resources that contribute to the practice of comprehensive health care to the familiar caregiver.¹¹ Thus, the familiar caregiver provides the emotional support and care essential to maintaining lives of family members with chronic diseases, making it essential for the survival and protection.

Facing the exposed, we question << **How familiar caregivers develop home care with no specific training for this?** >> to search for an answer to this question this study aims to:

- Analyzing the national scientific literature on the practice of home and hospital care developed by the familiar caregiver.

METHOD

This is an integrative review; a method that allows the synthesis of several published studies, enabling general conclusions about a particular subject.¹²

For this study, six phases were developed: 1) formulation and identification of the theme; 2) data collection, inclusion and exclusion of studies; 3) definition of the information to be extracted from selected studies; 4) review of the studies included in the integrative review; 5) interpretation of results, and 6) presentation of results.

1) Formulation and identification of the theme: In this phase, we performed an initial search in bibliographic databases for knowledge of the material already published about the subject. At the end of this phase came to defining the research question: How can nurses assist family caregivers who develop home care without specific training?

2) Data collection, inclusion and exclusion of studies: in this step the literature survey was conducted on the databasis of Latin American Literature and Caribbean Health Sciences (LILACS) and digital library Scientific Electronic Library Online

(SciELO), with the following descriptors: "family" [and] "social support" [and] "nursing".

There were constituted as inclusion criteria: publications Timeline (2002-2012); articles to make available the full text in Portuguese language and free. The exclusion criteria, in turn, were articles that did not make available the free and full online access, dissertations, theses, monographs and books.

From a total of 2778 articles found in LILACS database, after refinement with the descriptors, there were only two articles of these, one was excluded because it does not fit the theme and the other for not providing the full text.

In digital library SCIELO 1909 articles were found after refinement with the descriptors, remaining 11 articles, of which, six articles were excluded because the criteria used for selection, leaving five articles that formed material for analysis.

3) Definition of information to be extracted from selected studies: In this phase, the selected data were evaluated for their quality and respect to the research problem. For this we used a form of extraction of information contained in the articles, the information was transcribed manually and carefully, after reading the articles. Author, title of the production, year of publication, database or digital library, journal, level of evidence, methodology and summary of results: In phase extraction of information for the form, the following information was transcribed, confirming the

sample with a total of four articles for analysis.

4) Data analysis: after manual transcription to the form, the information was entered into a summary table (Figure 1) with the following information: code, journal, title, method, level of evidence, year and summary of results. To identify the levels of evidence used are the seven levels of evidence of Melnyk and Fineout-Overholt.¹⁴ A thorough reading, the form of extraction and summary table provided sustenance for the two categories that emerged in this study, they are: the social network of familiar caregivers and guidance of familiar caregivers.

5) Presentation of data: this stage of the discussion topics were presented, demonstrating its preparation together with impressions and reflections of authors from extensive reading.

6) Presentation of results: phase in which is expressed all knowledge acquired after the research where it is possible to demonstrate the importance of support from nurses for family caregivers. The themes that emerged were divided into two categories: 'Social Network of the familiar caregivers', and "Orientation of caregivers and their families."

Next, get introduced to Figure 1 with the synthesis of the productions analyzed in this study.

Code	Journal	Title	Method	Evidence Level	Year	Summary of Results
I	Revista Brasileira de Enfermagem, Brasília (DF)	Social support to the family of the patient with cancer: identifying pathways and directions	Literature review	-	2010	Network and social support are features that nurses can offer to families
II	Revista Texto e Contexto- Enfermagem, Florianópolis (SC)	Social network links and supporters of the families of children with cancer	Descriptive research, semi-structured interview	6	2010	The family seeks to organize to deal with the disease causing strengthening of family links and the network of support. Religiosity is used to support the cancer
III	Revista Brasileira de Enfermagem, Brasília (DF)	Social network of family support for children admitted to a pediatric intensive care unit	Descriptive study with a qualitative approach	6	2010	Working with families must be permeated by the attention the peculiarities that surround the family context and its relations, which ratifies the importance of more global role of nursing
IV	Revista da Escola de Enfermagem da USP, São Paulo (SP)	Influence of social support on quality of life of family caregivers of people with addiction	Descriptive and transversal study	6	2011	Evidence of the influence of network of social support on quality of life and burden of family caregivers
V	Texto e Contexto Enfermagem, Florianópolis (SC)	The social support for cancer patient's family in poverty	Qualitative study, interviews	6	2012	The study highlights the need for nursing interventions for the real need of the families of patients with cancer in situation of social vulnerability

Figure 1. Summary table with the scientific productions analyzed.

RESULTS

The results will be presented from the two categories those emerged from this study: "Social Network of familiar caregivers", and "Orientation of familiar caregivers and their families." The first, being based on strategies to supporting the nursing team for these caregivers, both of them in the emotional and instrumental aspect and daily support. And the second category identifying the main guidance provided to family caregivers, targeting not only the disease but also the family structure.

♦ Social network of familiar caregivers

Social networking is defined as the sum of relationships that an individual understands how important it is in his life. This is a social circle consisting of bonds of affinity, forming a kind of fabric that links the people.¹³ A social network can foster the ability to confront the social and health problems of the individual, through social support. Social support includes the process of social ties and bonds of solidarity that involves the exchange relations which involve reciprocal obligations and may contribute to the health of the people, through the companionship, emotional support, through advice, material aid, among others.¹⁵⁻¹⁶

The social network has an important role in the support given to these subjects, relating the emotional, instrumental and daily strategies, encompassing aspects such as support in the home, friends, family, employment and emotional structure.¹⁶ In strategy, the focus is to support coping with the disease and new health conditions of the individual patient, which the family caregiver faces to thus be able to provide better care to their familiar.¹⁷ Once the emotional structure of the family caregiver is shaken, social support is essential for the family to be able to face stressful situations without affecting their mental health.¹⁷ Note also the presence of instrumental support, which is based on the financial support, division of responsibilities and provision of information. This financial support was received most often from relatives and friends, to aid maintain treatment when done in the family residence and also to help basic expenses.¹⁷

The division of responsibilities is important not to be a caregiver burden, so it does not set aside your everyday life, to care for the children, spouse and home. And the health care team is essential in providing information, that you will feel better prepared, it is possible to encourage the caregiver and not physically wear out,

because every act of attention that professional offers you is a stimulus for more effective care.^{8,18-19} Addition to these supports, psychosocial, spiritual, informational, emotional and physical are also offered, all of which are essential to wear both an emotional caregiver as the family structure does not occur.^{8,18-19}

It is important that the family and the social group of the individual have information about the disease and its impact on everyday life. So that they can foster the ability to confront the social and health problems of others, through the companionship, emotional support, advice, material aid, among others. Its positive effect can be restated to refer to cases in which diseases require prolonged treatments, finding themselves in this way, the relationships between people fosters behavior health monitoring.^{8,18-19}

♦ Orientation of the familiar caregiver and his family

The guidance given by the health care team to familiar caregivers is essential for greater safety of care for the sick family, thus avoiding unnecessary hospitalizations.¹⁵⁻¹⁶ It is noteworthy that some studies indicate that the caregiver is generally not seen as a person who needs clarification and more accurate information about the disease and treatment requires that the patient, being therefore necessary to devise strategies for guidance for this family because of the lack of information in addition to affecting care is a major complaint of family caregivers.¹⁵⁻¹⁶

The caregiver often requires written information when the professional is not present, a practice that contributes to enabling familiar caregivers coping with difficult situations. Moreover, whenever possible it is important that the health professional is available to solve the doubts of the caregiver, and refer you to the appropriate professional when necessary.²¹

Nursing is a source of support for family carers in this way, it is necessary to recognize who is the social network where the caregiver is inserted in order to link it to the care of nursing care provided to the subject sickened.^{19,15}

By knowing the support networks of family caregivers, nurses, creates subsidies to mediate situations arising from the illness and / or therapeutic program of the sick individual. Thus, nursing conducts a more humanized care to these families together.²¹

DISCUSSION

A social network can be defined as a group of people with whom the contact is

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maintained, some form of social bonding, relationships or situations that provide instrumental and emotional support for the person. Support resources that flow through bonds. Have social support is a reciprocal process regarding any information or assistance offered by people or groups that there is habitual contact, involves the exchange relations that can contribute to the health of the people, through the companionship, emotional support, of advice, material aid.²⁰⁻²¹

There is more of a social support network, and each one is facing a kind of necessity that the caregiver needs to be able to give support to deal with the emotional and physical stress that family suffers, especially during hospitalization, which is when they are away from their routine, leaving his life in the background.¹⁷

The main support network of familiar caregivers is the closest relatives, followed by support from friends, neighbors and coworkers. This network is essential to overcome the difficulties.¹⁷ The disease can also weaken the bonds established, therefore it is considered extremely important that nurses and other health professionals act as supporters. Thus, this bond may be used, thus to enhance the orientation to family caregivers and their families.¹⁹

Family caregivers need to receive emotional support from family and especially the health care team, as this will give the support and guidance they need to cuidar.o that will result in greater emotional basis for coping with the disease.¹⁷

The orientation of nursing professionals is essential, not only at the time of hospitalization, but primarily in home care where caregivers are vulnerable without professional assistance, requiring further information on the development of care.²⁰⁻²¹

But the difficulties are not only care, but also in relation to financial difficulty, because in most cases the caregiver needs to leave the job to be able to give attention to the family, or even to purchase drugs. For these reasons this support health professionals causes them to have the freedom to vent and feel welcomed and encouraged to face the difficulties linked to the disease.¹⁰

FINAL REMARKS

From this study, it was verified the predominance of articles published in nursing journals of the State of Santa Catarina and the Federal District. The year 2010 deserves mention for having the highest number of publications on the subject. Regarding data

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collection, the study revealed that the interview is the most widely used method, as well as research with qualitative approach.

The articles analyzed in this integrative review revealed the predominance of evidence level six, which denotes that the research does not depict strong evidence on the subject, with respect to evidence-based practice.

The publications analyzed showed no just thinking about home care focusing only on the patient, it must enter the family that develops such care in the home space, strengthening the links, and recognizing the prior knowledge of these families.

The social network and support are keys to the family, otherwise familiar caregivers become overwhelmed by the daily care. In this context, it becomes imperative that the nursing staff to create strategies to support these families both emotionally and instrumental aspect in order to strengthen the bonds between nurses and familiar caregivers.

Furthermore, guiding families to practice caution is essential, since these often are unprepared to care at home. Family members need to respect the guidelines their understanding and cultural aspects, recognizing the potential for family care.

This study showed the gap in knowledge production, on understanding the real needs of family caregivers to develop care in the home environment. Recommend new studies about the understanding of the real needs of families those play the primary role of caregiver of a patient with chronic disease, strengthening the domestic scenery. We emphasize the need for studies with greater methodological rigor in order to incorporate higher level of evidence and combine it with the findings of this new research in nursing practice.

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