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Caregiver's perception about learning for home care

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ABSTRACT. The objective was to know the perception of the caregiver about the learning needs of care to be performed at home. This is an exploratory descriptive research, with a qualitative approach. Data collection occurred through a semi-structured interview, from August to October 2014, with six caregivers of patients hospitalized in a medium-sized hospital in the municipality of Santa Maria, Rio Grande do Sul State. The data were analyzed by the content analysis method, identifying two categories: The caregiver's perception about the learning needs; The attendance of the caregiver's learning needs. The study showed that the learning based on empirical, instinctive and observational methodologies, without the participation of the nurse in the process. There is need to improve this learning. The participation of the nurse as an educator in the planning, organization and development of the educational action stands out, since he/she is part of the care; however, the caregivers did not visualize this professional.

Keywords: nurse, caregivers, nursing education, residence.

Percepção do cuidador acerca da aprendizagem para o cuidado domiciliar

RESUMO. Objetivou-se conhecer a percepção do cuidador acerca das necessidades de aprendizagem de cuidados a serem realizados no domicílio. Trata-se de uma pesquisa descritiva exploratória com abordagem qualitativa. A coleta de dados foi realizada por meio de entrevista semiestruturada, de agosto a outubro de 2014 com seis cuidadores de usuários internados em um hospital de médio porte no município de Santa Maria/RS. Os dados foram analisados pelo método da análise de conteúdo, identificando-se duas categorias: a percepção do cuidador acerca das necessidades de aprendizagem; o atendimento das necessidades de aprendizagem do cuidador. Constatou-se que a aprendizagem foi baseada em metodologias empíricas, instintivas e observacionais, sem a participação do enfermeiro no processo. Evidenciou-se a necessidade de aprimorar esse aprendizado. Enfatiza-se a participação do enfermeiro, enquanto educador, no planejamento, organização e desenvolvimento da ação educativa, pois faz parte do cuidado, entretanto, esse profissional não foi visualizado pelos cuidadores.

Palavras-chave: enfermeiro, cuidadores, educação em enfermagem, domicílio.

Introduction

In the last decades, the Brazilian population has undergone a process of demographic and epidemiological transition. These data are confirmed by the fall in fertility, increased longevity, accelerated aging of the population, as well as the increase in chronic diseases Instituto Brasileiro de Geografia e Estatística [IBGE] (2010), which has been the main cause of morbidity and mortality in Brazil (Veras, 2011).

Chronic diseases were considered aggravating factor of age, but it is now known that these diseases affect the young and middle-aged population as well. Chronic conditions, besides being associated with the elderly, are also linked to life habits, such as sedentary lifestyle, smoking, unbalanced diet, genetic predisposition, among others (Veras, 2011). Chronic diseases can bring associated serious consequences such as functional disability, emotional imbalance and permanent dependence on care.

The adversities in the daily life of the family facing the process of illness, treatment, rehabilitation and social reintegration of one of its members, generate sudden changes, of the most different forms, that must focus on the fulfillment of the care needs, requiring, many times, a permanent caregiver to provide care for the illness.

For Braz and Ciosak (2009), caregiver is responsible for the execution of the most different actions that will benefit the well-being of the person who depends on care, providing the maintenance of basic needs and improving his/her quality of life as a member of a group of individuals mostly linked by emotional ties.

Amendola, Oliveira and Alvarenga (2008), identify family caregivers as lay caregivers. Marcon, Lopes, Antunes, Fernandes, Waidman (2006) and Souza, Pacheco, Martins, Barra and Nascimento (2006), consider as the primary caregiver the family member who dedicates more time to caring for the family member who needs care. This is characterized as being the one who assumes responsibility for the care of some family member, without any type of payment.

For the caregiver, facing a situation of illness of a relative or someone close to him/her is already difficult, especially when this illness accompanies sequels that make the user dependent on constant care. These changes become even more painful when the caregiver, with little or no knowledge, needs to take care of someone who lacks specific/peculiar care.

In this sense, nurses bring in the essence of their work the care that involves health education, through the educational practice regulated by Decree 94.406/87 Art.08 (Brasil, 1986). This educational competence intends to, among other purposes, qualify family caregivers to face the vicissitudes of home care, thus providing technical and emotional support and contributing to the improvement of the quality of life of both.

When developing the educational practice, the nurse, as an educator, needs to consider two important aspects involved in this process: teaching/learning; the educator and the learner, who, in the present study, is identified in the figure of the caregiver. These are interdependent and generators of a continuous, dialogic and transformative cycle so that behavioral changes of the educator, user and caretaker triad can be achieved (Bastable, 2010).

In this sense, it is important that the nurse/educator, during the hospitalization of the user and not only in the pre-discharge, carry out the diagnosis of the learning needs of the care to be performed at home according to the doubts and wishes of the caregiver/aprentice. It is necessary to consider this function with empathy, ethics and social commitment, and to base on the clinical, spiritual, social, psychological and cognitive conditions of the family member.

Thus, educating to provide care needs to consider the dignity, autonomy and search for ways to interweave the educator's and aprentice's knowledge, to enable teaching/learning without impositions and hypocrisies, creating authentic and liberating forms (Freire, 2011), with the caregiver.

The nurse, in order to operationalize health education to the caregiver, needs to get rid of value judgments, the pride that supports vertical and linear knowledge (Freire, 2011), because it is important to consider the beliefs, values and empiricism of the one who learns to care and, thus, promote health.

In this way, the family member assumes the condition of being an ally of nursing/health in improving the well-being and promoting the safety of the one under his/her responsibility. Therefore, the research question emerges: What is the perception of the caregiver about the learning needs of the care to be performed at home?

The objective is to know and analyze the perception of the caregiver about the learning needs of the care to be performed at home.

Material and methods

This is an exploratory, descriptive research, with a qualitative approach (Minayo, 2014). The study participants were six caregivers of patients hospitalized in a medical clinic unit of a medium-sized hospital in the municipality of Santa Maria-RS.

The study included the caregivers of users hospitalized for a minimum period of thirty days, with partial or total mobility restricted to the bed that needed constant care at home. Caregivers who had technical training in the health area were excluded from the study.

This study is linked to the research project entitled 'The Impact of the Companion/Familiar Presence'. Data collection began shortly after the approval of the project by the Research Ethics Committee of the Franciscano University Center under number 30552314.0.0000.5306 and authorization of the services integrated to this study, being carried out from August to October 2014. The study complied with the ethical criteria established by Resolution 466/2012 of the National Health Council (Brasil, 2012). Semi-structured interviews were conducted using a script, previously tested, containing guiding questions that addressed the theme, namely: what do you know about the care to be performed with your relative at home? Explain. Do you feel ready to take care of your family member when he leaves the hospital? Why? Describe the care to be taken at your home. How will you perform this described care? How did you learn this care? Who gave you this information? Would you have something more to say about your experience?

Data collection occurred through a semi-structured interview, from August to October 2014. According to the availability of the caregivers, time and place were scheduled at the institution, and the data were recorded, transcribed and later returned to the participants to validate the search information.

The data were analyzed and interpreted by the content analysis technique, in the thematic analysis modality, which consists of the discovery of the sense nuclei that make up a communication, where the presence or frequency means something for the analyzed analytical object. In this way, the pre-analysis was carried out, followed by the exploration of the material and the treatment of the obtained results and interpretation (Minayo, 2014).

In order to guarantee the anonymity of the participants, the acronym C (initial caretaker letter) followed by an ordinal Arabic number was assigned according to the sequence of interviews: C1; C2; C3; etc.

Results and discussion

From the analysis of the interviews, two categories emerged: The caregiver's perception about learning needs: improving the quality of home care; The attendance of the caregiver's learning needs: a development in the quality of nursing / health care.

The caregiver's perception about learning needs: improving the quality of home care.

The perception of the caregiver, during the patient's hospitalization in a medical clinic about the care to be performed at home, involves attending to basic human needs, including food and hygiene. They also emphasized specific care, such as checking systemic blood pressure, pharmacological treatment, pressure ulcer prevention, and those promoting improved mobility.

> [...]when she sttoped walking, we started to treat her, to perform the care, change, turn sides around, and feed her in the mouth, medicate her at the right time, all the care you have with someone in bed, get the pressure device, and check it almost every day [...] (C1).

> [...] I had to give a lukewaem and thicker meal... so he would not choke, we gave him enough fruit, we took care to keep him hydrated ... (C2).

> [...] she wakes up and I go there to clean her up, I clean her body up, perform the oral hygiene, step by step with liquid soap [...] (C3).

The data show that caregivers know about the care that should be performed at home and perform them, albeit empirically. Data from a study carried out with 29 caregivers of patients with chronic diseases in the city of Apucarana, Paraná, showed that the activities of movement, hygiene care and patient exchanges are among the main difficulties mentioned (Tsukamoto et al., 2010). The participants C1, C2 and C3 of the present research did not mention these difficulties. Moreover, Tsukamoto et al. (2010) pointed out that a large number of caregivers mentioned not knowing about the importance of preventing chronic diseases such as pressure ulcers. This data is in contrast to the C1 report of this study, since he exposes the need to alternate the patient's decubitus position, demonstrating that he knows about the importance of moving from decubitus of the individual receiving the care to prevent possible injuries.

According to Perlini and Faro (2005), a study carried out with 35 caregivers reported several negative consequences that may affect the health of the user and the caregiver when he or she does not present an adequate preparation to provide care. Among these losses, there are the repeated hospitalizations, as well as physical and emotional exhaustion of the caregiver. These data are similar to the findings of this research, because participant C1 reports checking blood pressure almost every day. However, he does not specify the results or the reason for this procedure; inadequate checking may have negative consequences for the user. This participant also reports alternating the patient's position, but does not mention the use of any technique, such as the moving sheet, in order to preserve her own health and provide a better comfort to the user, a desirable comfort.

Corroborating this finding, Oliveira, Boaretto, Vieira and Tavares (2014), in a study carried out with caregivers, affirm that the learning and the execution of the care would be facilitated with orientations pertinent to each need, allowing the correct execution of the care and softening the physical and emotional overload that caregivers are submitted to.

The caregiver plays an important role in promoting, preventing, maintaining and recovering the health of the family member at home. On the other hand, the care given by the home caregiver, in most cases, for being an empirical care, can bring undesirable consequences to the health of the one who receives care, and even for him / herself. Therefore, although the caregiver / learner provides care with affection and zeal, the nurse/educator needs to carry out a survey of the caregiver's learning needs in order to try and address the most different doubts that may exist regarding the promotion of health education (Martins, Nascimento, Erdmann & Belaver, 2012).

In addition to solving doubts, the nurse, along with the health team, should seek to develop with the caregiver, during the period of hospitalization of the user, a qualification of singular care, that is, the care that meets the real needs of the individual. The

correct execution of the bath, the alternation of decubitus, the care with wounds, thus improving care and reducing the physical overload of the caregivers at home (Pedreira & Oliveira, 2012).

The caregivers mentioned that they knew about the accuracy of the home environment adjustment, regarding the use of furniture and utensils that facilitate care, such as: hospital bed, wheelchairs and bath, protection bars. They also mentioned the need for economic resizing in the sustainability and quality of life of the family and home nucleus and the importance of solidarity support by other family members.

> [...] we bought the chair, the comadre inox, I adapted the bathroom, my nephew made a drain and the chair enters, because she could not get into the bathroom box, he also put an iron bar on the wall of the bed for her to hold and a safety guard in bed so she will not fall [...] (C3).
>
> [...] we got a hospital bed, a wheelchair and a bath chair [...] (C4).
>
> [...] my brother buys all the medicines for her because she earns a minimum wage, she can barely eat, so she cannot buy medicine [...] (C5).

The speeches (C3 and C4) demonstrate that caregivers are aware of the need for some tools to provide care, perform the home environment readjustment, and purchase equipment to facilitate this care. Another speech (C5) shows that there are financial difficulties to maintain care with the relative and that the income of the user is insufficient to meet these needs. At the same time, ithe reports show manifestations of solidarity by other relatives.

According to research by Marques and Freitas, (2009), which sought to identify aspects in the implementation of home care in Porto Alegre, Rio Grande do Sul State, there is a mobilization by the family in order to reorganize the physical spaces and facilitate care. They also list the capacity of creativity of the caregivers who use certain improvisations to improve the care provided at home. These findings coincide with the statements of the participants C3 and C4 of this research that reported the environmental adaptations and mobilizations of other family members in this reorganization. Nardi, Santos, Oliveira and Sawada (2012), in a study carried out with 19 caregivers in Jandaia do Sul, Paraná State, showed that the caregivers pointed the inadequacy of the physical environment as a difficulty, as it undermines the performance of the home caregiver. The speeches of C3 and C4 did not show explicitly the inadequacies of the environment as difficulties, but showed that they performed adjustments with the purpose of facilitating their performance and guaranteeing better care. Thus, it can be deduced that the caregivers of the present study also felt these difficulties and sought to solve them by making the necessary environmental adjustments. The adaptations demand from the family creativity, solidarity and, above all, human feeling towards their relative that will receive the care. In addition, there is the financial factor, with the cost of the expenses inherent to the conformations and that, certainly, will not always be easy to solve.

According to Costa and Castro (2014), data from a study carried out in Minas Gerais State, with 11 caregivers, oppose the findings of this construct because it highlighted the lack of support for caregivers by other relatives, as well as lack of solidarity. The same research also listed the lack of financial support, evidencing an overload for the caregiver due to this set of factors. This data is opposed to the staement of C5 that reports receiving financial support from a member of the family and C3 who points out solidarity help from another relative. However, a study by Oliveira et al. (2014), in the west of Paraná with 13 caregivers, identified that the participants' low family income affect the care of the dependent relative, since the costs of caring for a person at home are quite high. This data corroborates the speech of participant C5 of the present research, because as described, there is a need for another family member to assume part of the financial burden.

The development of effective care at home is linked to several factors, including an environment that provides safe care, because the lack of certain equipment can cause falls and accidents, worsening the health condition of the user and hindering the work of the caregiver and, on the other hand, there is the cost caused by all of this. In this sense, health actions should consider the environments where the human being is inserted, the interactions and relationships constituted throughout life (Zamberlan, Medeiros, Svaldi, & Siqueira, 2013). Thus, the nurse educator needs to develop in his/her educational practice the sensitivity to perceive and identify the caregiver's learning needs, as well as to know the family context in which care is inserted Silveira et al. (2012), since all these factors influence the promotion, prevention and recovery of health. In this way, nurses, with their educative action, may be able to provide the necessary knowledge to heal the fragilities found, to allow positive and effective results to improve the quality of life of the caregiver and the one who receives the care.

As the speeches show (C2 and C3), the participants in the study knew leisure as a wellness condition of the individual receiving care at home, considering entertainment as a complement for improving the quality of life.

> [...] we never leave him alone. While one is going to do the service, the other is near him, talking. He also likes watching television, listening to the radio, so sometimes we leave him watching TV or listening to the radio [...] (C2.)

> [...] she likes radio, I have a little radio that I call at night for to listen to, so I can rest a little [...] (C3).

The speeches report that caregivers care about the well-being of their family members who are under their care and use television and radio to provide a distraction.

A survey conducted by Brondani, Beuter, Alvim, Szareski e Rocha (2010) in Rio Grande do Sul, with 15 caregivers, found similar data because it showed the use of television and radio devices as a demonstration of sensitivity and affection of caregivers to their relatives under their care. This data resembles the reports of C2 and C3 that use the same means as a leisure alternative for their care-dependent relatives. This concern evidences the sensitive to the family member, as they are concerned not only with physical/biological needs, but also, in a broader context, seeking to address psychological, social and emotional needs through resources they deem appropriate.

Disabling diseases can lead to the need for daily care, and this zeal, most of the time, is attributed to a family member, and, thus, the caregiver needs attention, since the work of spending the entire time, many times, to the patient, entails a physical and emotional overload for the caregiver (Baptista et al., 2012).

In addition, the caregiver often does not have the necessary training to carry out those activities imposed to him/her. In this sense, the nurse integrating the nursing / health team needs to consider the unpreparedness and lack of specific knowledge of the caregiver (Silveira et al., 2012). This sensitivity of perceiving and considering these difficulties allows guaranteeing effective and decisive care for the well-being of the caregiver and the person under his / her care.

Therefore, health education must understand the learning needs of the caregiver/learner according to his / her culture, knowledge, and even perceive in the silence the absences of the knowledge necessary to carry out home care to the patient under his / her care. The nurse cannot neglect the educative action and needs to be attentive to the simpler evidences perceived by the caregiver, Bastable (2010) in order to construct a relation based on a transformative teaching / learning.

The attendance of the caregiver's learning needs: a development in the quality of nursing/health care.

Meeting the learning needs of the caregiver is a turning point in the quality of nursing care, since the participants learned to care through observation, intuition and their life experiences. Moreover, there was a concern with health education of the individual under their care at home, because the participants did not feel prepared or qualified to meet the needs of their relatives.

> [...] I mean, until now, we have learned by ourselves [...] (C5).

> [...] the nurses came to me and I said, if you need help just tell me, I do not know, but I can help, so I kept watching a nurse taking a diaper, she put it down and used another diaper to bag the penis, That already helps a lot [...] (C4).

> [...] At first, it was difficult, but whe we keep doing it everyday, we get to learn, things are clearing up, we keep watching the nurses doing it and then it gets easier, but currently I do not feel prepared [...] (C1).

> [...] I think we lack courage, we have to help, we will not leave the person without care, but I do not feel prepared [...] (C4).

In the speeches, the caregivers considered that they perceive their need for learning. However, they express that they learned the care to be carried out at home by means of the repetition of the actions performed by the nursing team in the hospital routine and pointed out that they do not feel prepared to perform care at home. Participants C1 and C5 claim to have learned to perform the by themselves. Garcia et al. (2011) found similar data in a survey carried out with 11 caregivers in Santa Maria, Rio Grande do Sul State, in which they reported learning to perform the care to the patient, in most of the time, in an isolated way.

Similarly, participants in the present C1 and C4 reported having learned care through the observation of professionals in the hospital setting. These data are similar to those of Silva et al. (2012), in a research developed in the city of Belo Horizonte with 17 caregivers, in which some participants mentioned having learned to handle bladder and nasoenteric catheters by observing the professionals in the hospital environment. In this sense, Oliveira et al. (2014) point out in the reports of the participants of their study that the health professionals' orientations are important for the

caregiver and that they would promote the learning and the effectiveness of the care, since they would know how to do it correctly, but they reported not receiving sufficient information to provide care at home.

The learning needs of the caregiver/learner for home care can be solved during the hospitalization process, as this would facilitate the care to be performed at home. This understanding bias emphasizes the role of the nurse/educator as a participatory and collaborative subject in the teaching/learning process.

The educational practice developed by nurses for home caregivers is also relevant in the social setting, since it reduces the iatrogenic risks that may occur due to lack of knowledge, attenuates the patient's readmissions, contribute to the improvement of the quality of life, in addition to mitigating the nosocomial infections due to the long and repeated hospitalizations, allows exchanging information and acquiring knowledge during the learning process, besides reducing the hospital expenses (Silva et al., 2012).

All these justifications lead to the understanding that the nurse's educative action with the caregiver during the patient's hospitalization brings considerable benefits and, therefore, the nurse needs to assume it with social and ethical responsibility, since it is an inherent legal part of the care, the essence of his/her profession.

In relation to this meaning, the nurse/educator must consider that the caregiver is an individual endowed with longings, feelings, beliefs and values, and when using the strategy of the educative action, during the period of hospitalization of the individual who receives the care, may be able to value the caregiver's performance and to allow developing effective care for their family members and themselves (Brondani et al., 2010).

In this sense, the nurse needs to recognize the needs of the caregiver/learner, taking into account the singularity of each one, the context where he/she lives and considering that he/she is an important person in the teaching-learning process (Silveira et al., 2012).

When questioned about who had advised about information regarding care, the participants did not refer the nursing/health team as subjects of the learning process. They highlighted other professionals who were unrelated to the period of hospital stay.

> [...] the health agent goes there to perform the monthly visitation, so she guides us on how to perform it, hot o handle it, bath, everything [...] (C2).

> [...] Only now, in this winter, a person started to go to our house, a health agent who is supporting us, they go there to teach things to us [...] (C5).

The speeches of the participants show that they learned to develop the care through the guidance of the health agents during home visits. The manifestations of C2 and C5 indicate that they receive information passed on by the health agents, not referring, at any moment, to the nurse and/or nursing team during the period of hospitalization. Biolo and Portela (2010) pointed out similar data in a survey carried out in Passo Fundo, Rio Grande do Sul State with ten caregivers. The authors found that some participants reported receiving care guidelines regarding what they should carry out, from physicians, professionals of the Family Health Program, information from other relatives who experienced similar situations or from self-discovery according to their daily needs. However, data from this research are in contrast to the study by Garcia et al. (2011), where the caregivers reported receiving guidance from the nursing team regarding the chronicity presented by the patient during the hospital stay.

The role of the nursing professional is the care that encompasses not only technical procedures, but also health education, health research and management. In the mid-nineteenth century, nursing began to be recognized as an autonomous discipline and, since then, it has been evolving as a science. The art of educating, legally bound to this profession, allows considering the nurse an educator, being his / her learners not only the nursing team, but also the users, their relatives and caregivers (Bastable, 2010).

Finally, sharing information, orientations and experiences are forms/methods used in the learning process that foster the dialogue of knowledge as a possibility to achieve results that meet the needs of the care to be carried out in the domicile, encompassing the learner's affective, cognitive, spiritual and psychomotor (Bastable, 2010).

Therefore, the learning process currently advocated does not present the nurse/educator as a mere transmitter of information, but focuses on the learning of the caregiver/learner who needs to participate actively in this process. In this sense, the nurse/educator is seen as a facilitator, which makes the educator and the learner accomplices in the educational process, enabling decision-making about what it is necessary to share for effective learning (Bastable, 2010). However, it is necessary for the nurse educator to attend and be present in the educative function and, thus, achieve visibility of this function with the home caregiver, exercising the learning actions.

Conclusion

When knowing and analyzing the caregiver's perception about the care learning needs to be carried out at home, although the caregivers/learners performed home care, the forms of learning based on empirical, instinctive and observational methodologies. In this context, it is evident the need for an intervention that improves this learning, which must be contemplated by the nurse as educator.

The nurse, along with the nursing team, needs to develop a health education plan for the caregiver during the hospitalization period. This plan needs to be developed in a gradual, continuous and procedural way, in the hospital environment, extending from the first day of hospitalization to discharge, qualifying the caregiver/learner and, thus, ensuring continuity of care at home.

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