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FAMILY-CENTERED CARE IN THE PERSPECTIVE OF NURSES FROM AN ADULT HOSPITALIZATION UNIT

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ABSTRACT
The study aimed to identify the perception of nurses that work at adult hospitalization units on Family-Centered Care. A descriptive, exploratory research, with qualitative approach, with nurses that work at a private institution in northern Paraná. Data collection occurred in January 2015, through interviews conducted during educational activities. The reports were treated following the assumptions of content analysis, thematic mode. After analysis, two categories emerged: "Nurses' perception on family participation in the care" and "Considerations about Family-Centered Care". Nurses were not willing to accept the family's collaboration, in addition to lacking knowledge in relation to the theme studied in the research. Despite stressing out the family's importance, its effective participation is still very limited.

Keywords: Family. Care. Nursing.

INTRODUCTION

Healthcare has several care models, such as evidence-based practice model and patient-centered care model. In the need for a differentiated approach, the Family-Centered Care (FCC) emerges, characterized as a philosophy to unite the care provided by the multidisciplinary team, giving voice to the patient and his/her family[1].

In this approach, the family participates in the care planning, realizing its own adversities, and identifying possible resolutions. This form of care subsidizes the patient's autonomy, recognizing the family as an inherent unit in the child's life[1,2].

The rise of the FCC is due to the perception that the family is a key element within the care and that social isolation is a strong risk factor, especially for children, seniors and people with chronic diseases. At the beginning, the FCC approach was applied only in the pediatric context, encouraging children's participation in the care to their health. With its use in the care to adults and seniors, FCC started to be advocated in other social contexts[1].

The main assumptions of the FCC are: dignity and respect (health professionals listen and respect choices, perspectives, values and beliefs of the patient and family); shared information (professionals communicate and share information on the patient and his/her therapy completely and impartially, that is, professionals do not omit data and adopt a neutral stance in the light of the provided information); participation (patients and families are encouraged and supported to participate in the decision-making and care); and collaboration (patients and families are included and regarded as the institution's support, assisting in the development, implementation and evaluation of policies and programs in professional education and in the care provision)[3].

The family is very important during hospitalization, especially when it is long and associated with situations of difficult diagnosis and exhausting therapeutic process. The family accompanies and is responsible for the patient care, in addition to providing emotional and financial support[4].

Including the family or companion in the care assists in the implementation of strategies and development of nursing actions together, seeking not only the training of this person to care for his/her loved one, but also the formation of partnerships. In this way, the family feels welcomed by the team

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itself even though the hospital routine is different from that experienced at home[5].

Thus, considering the importance of the family in the hospital context, the need for formation of partnerships between family and health professionals, and the scarcity of studies addressing the theme related to family inclusion in the care to the adult patient during hospitalization, we justify this investigative proposal, aiming at unveiling the perception of nurses on FCC at adult hospitalization unit.

METHODOLOGY

Exploratory, descriptive study, of qualitative approach, carried out with nurses that work at adult hospitalization units of a private institution located in a municipality in Northern Paraná. The institution was chosen intentionally, because it attends patients with different levels of complexity, also poviding an Intensive Care Unit (ICU). Moreover, it has broad and flexible visiting hours and is in favour of companions independent of patients' age group, since most hospitals only allow companion for patients under 18 or for those above 60 years.

The institution had 24 nurses distributed among the following units: ICU, surgical hospitalization, maternity, emergency room and surgical center. The study excluded those who were on vacation or on leave during the data collection period, which occurred in January 2015. The number of subjects was not determined a priori, because it is a qualitative research, thus the number of participants was kept open, eliminating a prior establishment.

At first, there was a previous contact with the institution's coordination for the study authorization. The initial approach to professionals was held personally in their work units, not interrupting the service dynamics, scheduling the best time for presentation of objective and formal acceptance to participate in the study, and, as a result, the beginning of the survey.

A pre-test was performed by implementing a semi-structured questionnaire about the topic (FCC), applied in the visiting room of each unit or in another location that provided privacy, which addressed issues related to the family inclusion and participation during hospitalization, and about the professional's prior knowledge on the theoretical framework of the FCC.

Later, there were two educational interventions, one per week, about the studid framework, in order to empower professionals, identify gaps, promote FCC, address questions and provide a space for learning and discovery of new possibilities of social assistance. The meetings were previously scheduled according to availability of the institution, held in the conference room of the hospital, with consent of the nursing coordination and operational management. The best time for the professionals was chosen, independent of the work shift, thus the educational intervention was performed more than once on the same day, in order to meet the demands of all participants.

Two meetings were held, which were recorded with digital recorder and lasted approximately 40 minutes. During the meetings, the nurses participated in lectures and extra activities, where they were encouraged to remember and share with the group in the next meetings moments when the FCC could have been applied, or if they eventually acted against the philosophy proposed by the framework, to reflect and contribute to discussions on their health care context. They were considered extra activities because nurses were requested to think about those moments out of the meetings, when they were at another environment, work or not.

Of the 16 nurses initially approached, only eight finnished the process. In the first and second interventions, 10 and eight nurses participated, respectively, of all the shifts of the institution. The reasons that led them to leave the research were time outage, even proposing that the intervention would be held at the best time for them, and some refused to participate without claiming a reason. The post test, and last step of the process, was applied only to the nurses who participated in the three stages (pre test, educational activity with lecture and extra activity, and post test), totaling eight participants.

The post-test was conducted in the form of interview, consisting of issues relating to the FCC in order to analyze the activities carried out previously and help identifying gaps. Data were analyzed using content analysis, Bardn's thematic mode[7].

The analysis consists of three phases: data analysis, material exploration and formation of categories and treatment of the categories obtained and interpretation. In the pre-analysis, the first contact with the material was performed, when raw data for the formulation of the initial ideas are organized, with fluctuating readings, separating the

information according to the major rules proposed by the author: completeness, representativeness, homogeneity and relevance. In phase two, the exploration of the material and formation of categories, data are classified, highlighting with different colors similar parts of the text, and, later, similar phrases are grouped into initial thematic categories, which would be discussed with other authors of the area. In the third and final phase, treatment of the categories obtained and interpretation, after selecting the most significant and representative categories to the objectives of the study, they are inferred and compared to other relevant authors[7].

In order to preserve the anonymity and confidentiality of the information, participants have been identified with the letter I for 'interview' and with arabic numerals, according to the interview sequence.

The Research Ethics Committee of the State University of Maringá approved the study, opinion 892,447 of 12/01/14, CAAE: 38194414.0.0000.0099. All participants signed the informed consent term (ICF), in two-way. All the ethical precepts of Resolution 466/2012 of the National Health Council were respected.

RESULTS AND DISCUSSION

Data were analyzed according to the pre-and post-test interviews of eight nurses that participated in all stages of data collection, resulting in 16 interviews analyzed. In order to achieve the objective of this study, the analyses were performed individually, comparing before and after the interventionist actions.

After analyzing the data, the following categories emerged: Nurses' perception on family participation in the care and Considerations about Family-Centered Care.

"**Nurses' perception on family participation in the care**" identified that, initially, five nurses believed that, in some ways, family does not collaborate significantly in patient care.

> Since it is a sector where patients are very dependent, the family is not prepared to assist the patient when they are at this stage. Bedridden patient, with diet, that does not eat anymore, needs an entire hospital aid [...] they do not know how to deal with the patient so they call all the time, they are not prepared [...] the person does not know and ends up leaving, get scared and leaves only for the nursing. (I1)

> The family participation sometimes is also a factor that hinders, because of their acceptance of nursing care, accepting standards, they think their way is right and not our way. (I7)

The fact that nurses use terms like 'right and wrong' signaled the relationship based on hierarchy and in the absence of ties. Nurses state that the family is not prepared to assist in the care, that they are not qualified; however, if we think about the nurse's teacher role, he/she should be the facilitator of this process.

For the FCC to happen fully, the nursing staff should be more open to the family, for a complete assistance[8]. This study found that nurses generally see the family problems or deficits and do not recognize it as an additional resource in the care.

When asked about the reason for the family little participation in care, the subjects reported that the collaboration and interaction depends on the family profile, which may be plausible in the hospital environment, due to changes in these people's lives with the hospitalization. In this context, the family's wishes are permeated by fear and insecurity.

Some families go through this period of hospitalization and enter naturally in the FCC. On the other hand, some prefer not to provide care for fear of the unknown or due to lack of information. In this sense, the nursing professional is responsible for guiding and explaining in detail the importance of family participation in this context, aiming at the improvement of the patient, in addition to allowing the hospital environment to become more like home.

To this end, professionals need to understand the real meaning of hospitalization in the other's perspective and what implications are brought to families' life and routine, so that they can propose strategies that include reception and minimize difficulties arising at the moment[9].

Professionals should encourage the continuity of natural connection that exists between most patients and their families as a form of support network[1]. The support network is set in the family context and the nurse needs to understand the person that will perform care and that will be willing to receive and discuss guidelines on the care provided to his/her loved one. In addition, the network may also be characterized as an interaction between a group of people that establish bonds of friendship and information, contributing to the mutual well being[10].

In relation to the importance of family participation, all nurses commented that, as the family is automatically inserted in the hospital environment, this adaptation process is crucial to improving family-health team interaction. According to these individuals, only the family understands the patient's actual pain.

The stories show that the more gifted of popular knowledge, or common census, and, in some cases, scientific knowledge acquired informally, the greater the family's attempt to participate in the comprehensive care of the patient.

> Oh, I like when the family is present, because they have this vision of the patient before hospitalization, they come to talk to me about what is normal and what is not and this helps us see what we can do. For example, a restless patient, what we can do. (I3)

> Family participation is very important, because they help in the patient's recovery. We can observe when they come out of the ICU, because when they get here, they become what they are at home. They become calmer, accept better the procedures that will be carried out, when the family is with them. They bring people the patient likes and that are with them, the food the patient likes, the pillow the patient was using at home, everything the patient has at home, so that the hospital environment becomes more like home environment. (I2)

Nurses understand that family members or caregivers are the most suitable for completion of care since they know their real needs and characteristics, especially when patients are unable to verbalize them.

Although the speeches show that presence, the effective participation of the family is still very limited because few professionals see it as a real coparticipant of care. Bringing the family to decision-making and to shared information is still something far from the experienced reality.

When performing the care planning, the nurse needs to pay special attention to the guidelines passed to patients and their families. Witnessing the care provided by nurses to the patient calms the family down, because it realizes that the team provides care in a competent, compassionate and dignified way[11].

In this context, the nursing aims at a family member that actually follows the patient. On the other hand, professionals do not interact with the family and do not share decision-making, generating conflicts in this process. Sometimes, the subjects of this research choose companions that do not question and feel annoyed with distressed and insecure family members.

> I think it is good sometimes, but I do not think we can include the family in all the patient's processes [...] Providing the family information on the patient's diagnosis, those things we can do, but involving the family in the decision [...] I think it is difficult to involve the family in these things. (I6)

Regarding the difficulties dealing with the family, some reported the family fragility to accept the patient's diagnosis, which could lead to a setback for nurses, who feel obliged to provide some time for clarification. There were also reports of the lack of patience of the family, who do not understand that they have other patients, in addition to its.

> They have difficulties accepting the diagnosis, the patient's prognosis, let's say, patient's prognosis is closed, the family is fully aware, but, by the time the patient is evolving to death, they completely change their mind... they get desparate, even though they were aware. I think they lack a little of patience, because we have several patients [...] and they want us to be there promptly, it is difficult when you have many family members. (I1)

> We have some families that do not understand the diagnosis, do not understand why the patient has to be hospitalized, sometimes they do not want to understand and then it gets worse because we explain, go and do, and when we get to the room, they arre doing things that harm the assistance. We have many troubles when the family does not cooperate or when the family argue with their doctor and then they start to act differently from the doctor and they are jeopardizing the patient's assistance. (I2)

The lines reflect the cure culture that focus on disease and pharmacological treatment and not on the human being as a whole. Considering the family as the unit of care seems to be something apart for nurses[8], since they act according to protocols and do not see the care shared with the family as a strong ally[11].

In the second category, entitled **"Considerations about Family-Centered Care"**, six respondents reported not having any knowledge about the reference, stressing that the discussion on FCC is still scarce in the adult context.

> I have never heard of family-centered care [...] (I2)

> [...] I have already heard the term, but I have never read anything about it, I do not know if it is some kind of study, something, I am not aware of [...] (i5)

In the post-test, we identified that some nurses showed awareness of the subject and believe in transformations, but others exhibited extreme realism and do not believe that the intervention has had beneficial effects.

> [...] my perspective is that I have improved in relation to communication and about the introduction of the family in the care of the patient and not only in what I thought because you can improve it. I have improved a bit, but I can improve more [...] (I5)

> [...] there is the hard side, some families are difficult, sometimes we lack employees, we have many things to do, the person often charges too much and, whether or not, it delays our service [...] (I2)

Some individuals also reported little or no change in their conduct after the educational action due to lack of time and little encouragement of their boss. A nurse told that staff shortages and the presence of “difficult” relatives slowed his service, thus hindering the FCC applicability.

> Some families are difficult, sometimes we lack employees, we have many things to do, the person often charges too much and, whether or not, it delays our service. (I2)

> For us, I think it is not going to change anything, because if the management and the team are not aware of it, we will not solve anything. (I1)

Although aware that the FCC means a breakthrough in nursing care and a range of good practices(8), time-related limitations, human resources deficiency, excess work and compliance with rules and routines are common factors that prevent professionals from practicing the FCC, as signaled in the lines.

The daily encouragment of the family by the health team in relation to the care provision to the loved one is important, always supporting and collaborating with the well being of the patient to develop links between family and team(11).

We highlight the speech of a research subject that mentioned already providing guidelines for the family, but their lack of interest is the main factor that prevents implementing FCC:

> We already did this, we do not do it when the family does not want it, when you see they do not want it [...] when you call and they are not willing, but we teach them if they are willing. (I4)

The FCC is not yet seen as fundamental to the holistic nursing practice because the team is subject to routine and duties that need to be completed(8). As revealed in this research, working with families was not one of the fundamental principles for professionals and many of them have not incorporated the family involvement in the care context.

FINAL CONSIDERATIONS

Although most subjects demonstrate understanding in relation to the importance of family involvement and how FCC helps in the patient’s recovery, the reality is still far from what is recommended. The interventions were beneficial, however, for changes to be effective and with long-term implications, a process of intense training with support from bosses and the institution is necessary.

A limitation was the non-adherence of all nurses that attended the pre test in all the research stages, because it began with 16 participants and, in the end, there were only eight. Unfortunately, it was not possible to justify exactly what reasons led to the withdrawal, since the researchers were available for completion of study in all shifts.

Future studies are necessary to understand the family participation during hospitalization in adult life. Legally, not all institutions allow the companion’s permanence, but the FCC suggests, among others, the family inclusion in the patient’s preparation, because, that way, even if the family is not present during all the day, at some point, it needs to be trained and ready to receive its loved one in the family environment, especially in cases of dependency.

This study occurred in a particular reality and context, thus, we believe that the results cannot be generalized to other scenarios. However, our intention was to raise the look to the adult clientele since the FCC is best discussed in the pediatric context.

Another point is that, even after the educational intervention, most professionals kept their conduct in relation to family matter. This is not a weakness of the study, however, it shows that many other studies will be necessary to change this care reality, and reinforces the need to include the theme still in the graduation for nurses to start their professional life more attentive and open to the family matter.

The main objective of the FCC assumptions is the humanization of health care, with a focus on the whole family and not only on the individual patient. In this regard, since the nurse is the professional that

stays most of the time with the patient, he/she has great development potential in order to achieve partnerships with families. Nevertheless, this process should be started even in graduation for adequate and prior awareness and proximity to the theme and its later applicability.

CUIDADO CENTRADO NA FAMÍLIA NA PERSPECTIVA DE ENFERMEIROS DE UMA UNIDADE DE INTERNAÇÃO ADULTO

RESUMO

: O estudo teve como objetivo identificar a percepção de enfermeiros que atuam em unidades de internação adulto, sobre Cuidado Centrado na Família. Realizou-se uma pesquisa descritiva exploratória, de abordagem qualitativa com enfermeiros que atuam em uma instituição privada do norte do Paraná. A coleta de dados ocorreu em janeiro de 2015, por meio de entrevistas realizadas durante atividades educativas. Os relatos foram tratados seguindo os pressupostos da análise de conteúdo, modalidade temática. Após análise, identificaram-se duas categorias: "Percepção dos enfermeiros sobre a participação familiar no cuidado" e "Considerações acerca do cuidado centrado na família". Percebeu-se resistência à colaboração da família por parte dos enfermeiros e a escassez de conhecimento destes em relação ao referencial estudado na pesquisa. Apesar de ressaltarem a importância da família, notou-se que sua participação efetiva ainda é bastante limitada.

Palavras-chave: Família,. Cuidado. Enfermagem.

CUIDADO CENTRADO EN LA FAMILIA EN LA PERSPECTIVA DE ENFERMEROS DE UNA UNIDAD DE HOSPITALIZACIÓN ADULTO

RESUMEN

El estudio tuvo como objetivo identificar la percepción de enfermeros que actúan en unidades de hospitalización adulto, sobre Cuidado Centrado en la Familia. Se realizó una investigación descriptiva exploratoria, de enfoque cualitativo con enfermeros que actúan en una institución privada del norte de Paraná. La recolección de datos ocurrió en enero de 2015, por medio de entrevistas realizadas durante actividades educativas. Los relatos fueron tratados siguiendo las suposiciones del análisis de contenido, modalidad temática. Tras el análisis, fueron identificadas dos categorías: "Percepción de los enfermeros sobre la participación familiar en el cuidado" y "Consideraciones acerca del cuidado centrado en la familia". Se percibió resistencia a la colaboración de la familia por parte de los enfermeros y la escasez de conocimiento de estos con relación al referencial estudiado en la investigación. A pesar de resaltar la importancia de la familia, se notó que su participación efectiva aún es bastante limitada.

Palabras clave: Familia. Cuidado. Enfermería.

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