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RESEARCH

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The Social Representations of Patients' Relatives in Intensive Care Units: The Implications to Self-Caring

Representações Sociais de Familiares de Pacientes em Unidades de Terapia Intensiva: Implicações no Cuidado de Si

Representaciones Sociales de Familiares de Pacientes en Unidades de Terapia Intensiva: Implicaciones en el Cuidado de Si

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ABSTRACT

Objective: The study's goal has been to both analyze and describe the meanings associated with care and intensive care unit, and its implications for self-caring by relatives of patients hospitalized in the intensive care unit. **Methods:** It is a descriptive research with qualitative approach, and also with theoretical-conceptual support of the Social Representations Theory, which was performed with 40 family members of patients hospitalized at an intensive care unit over the period from November 11th to 29th, 2014. **Results:** The testimonials were synthesized in the three following thematic units: "Intensive Care Unit: Death versus Care", "Changes in Self-Caring: The relatives of patients hospitalized in an intensive care unit" and "Care: Act of love". **Conclusion:** Through this research, it was possible to describe the social representations of the relatives of patients hospitalized in the intensive care unit with regards to both the care and the intensive care unit, and its implications for self-caring as well.

Descriptors: Care, Intensive Care, Nursing, Social Psychology.

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RESUMO

Objetivo: Analisar e descrever os significados associadas ao cuidado e a unidade de terapia intensiva, e suas implicações para o cuidado de si por familiares de pacientes internados na unidade de terapia intensiva. **Métodos:** Pesquisa do tipo descritiva, qualitativa, com suporte teórico-conceitual da Teoria das Representações Sociais, realizada com 40 familiares de pacientes internados na unidade de terapia intensiva, no período de 11 a 29 de novembro de 2014. **Resultados:** Os depoimentos foram sintetizados em três unidades temáticas. Assim denominadas: "Unidade de Terapia Intensiva: Morte versus Cuidado", "Mudanças no Cuidado de Si: familiares de pacientes internados na unidade de terapia intensiva" e "Cuidado: Ato de amor". **Conclusão:** Por meio desta pesquisa, foi possível descrever as representações sociais dos familiares de pacientes internados na unidade de terapia intensiva sobre o cuidado e a unidade de terapia intensiva, e as suas implicações para o cuidado de si.

Descritores: Cuidado, Cuidados Intensivos, Enfermagem, Psicologia Social.

RESUMEN

Objetivo: Analizar y describir los significados asociados al cuidado y la unidad de terapia intensiva, y sus implicaciones para el cuidado de sí por familiares de pacientes internados en la unidad de terapia intensiva. **Métodos:** La investigación del tipo descriptiva, cualitativa, con soporte teórico-conceptual de la Teoría de las Representaciones Sociales, con 40 familiares de pacientes internados en la unidad de terapia intensiva, en el período del 11 al 29 de noviembre de 2014. **Resultados:** Los testimonios se sintetizaron en tres unidades temáticas. Así denominadas: "Unidad de Terapia Intensiva: Muerte versus Cuidado", "Cambios en el cuidado de sí: familiares de pacientes internados en la Unidad de Terapia Intensiva" y "Cuidado: Acto de amor". **Conclusión:** A través de esta investigación, fue posible describir las representaciones sociales de los familiares de pacientes internados en la unidad de terapia intensiva sobre el cuidado y la unidad de terapia intensiva, y sus implicaciones para el cuidado de sí.

Descriptores: Cuidado, Cuidados Intensivos, Enfermería, Psicología Social.

INTRODUCTION

The care has been present in man's life since the dawn of antiquity as a way of survival, of protecting life and averting death, and it is typical of the human condition and essential to its existence.[1] The word "caring" is directly related to nursing, which is concerned with "taking good care", which is understood as the possibility to provide well-being and to prevail for the good quality of life of both caregivers and their caregivers. For nursing professionals, caring can be understood as performing the care with the desire to do, provide and obtain the best result.[2]

This concern began with Florence Nightingale, during the Crimean War in the 19th century, she and other volunteers sought to select more serious individuals, accommodating them in a way that favored immediate care.[3] Aiming to this, the Intensive Care Unit (ICU) were created for taking care of patients in a serious condition and requiring constant monitoring and much more complex care than other patients.[2]

The establishment of the ICU represented a major milestone in the history of medicine since it enabled the most appropriate care for patients, ensuring better recovery conditions and reducing deaths by about 70%.[4] Despite all the technological advances used for maintenance of life, ICU hospitalization associated with its negative interpretation still causes the family member to experience a situation of constant fear of the possibility of imminent loss, resulting in a sense of sadness, anguish and even despair.[5] Such ideology maintains through the various popular knowledge about the environment of intensive care, myths and taboos, which are still strongly anchored and associated with the image of death, in the imaginary of the people.[6]

The changes experienced by the family from the hospitalization process of one of its members tend to generate feelings of unconcern or fear, which vary according to the level of enlightenment and emotional maturity.[7] In this context, this objective study analyzes and describe the meanings associated with care and intensive care unit, and its implications for caring for oneself by relatives of patients hospitalized at the ICU from the *Hospital Universitário João de Barros Barreto (HUJBB)* [University Hospital], being this delimited representation as an object of study. Put together the Care and the ICU have become a psychosocial object when they are part of the individual's cognitive and sharing with his or her group of belonging. For this reason, such representation is a legitimate object for the use of Social Representations, since it is present in the daily life of the various groups that make up society.

Social representations are constituted through a system of values, ideas, and practices, in which an order is established that allows people to orient themselves in their material and social world in order to be able to control it, and later to diffuse it through the communication between the members of a particular group and/or community, in order to name and classify, the aspects originated from their world and their individual and social history, generating new ideologies.[8]

Therefore, it is evident the relevance in revealing the social representations of the relatives of patients hospitalized in intensive care units and the intensive care unit, because only through this knowledge will it be possible to implement health care that value the quality of the life of the caregiver and his or her family caregiver. Consequently, understanding the social representations of family members of inpatients in intensive care units and the intensive care unit will contribute to nursing care practices, which might offer care based on the actual needs of their clients, considering that the familiar member is also the target of health care, and minimize the gaps in their mentality.

Bearing in mind that this is a descriptive research, a design will be developed on the representations of the relatives of patients hospitalized in intensive care units and the intensive care unit, in order to provide the creation of new strategies for care and welcoming the family in the intensivist context. As far as research is concerned, this

study will contribute to the practice of nursing as a caring science, due to the information it will offer about the relatives of patients hospitalized in intensive care units, and how to dedicate time to this public, in terms of allowing them to express their doubts and desires, can improve health care and make it more humanized.

METHODS

It is a descriptive research with a qualitative approach, having as theoretical-conceptual support the Social Representations Theory, given that it is intended to value the consensual universe of the population served, in a way that promotes changes in healthcare models.[9]

The study population consisted of 40 family members who entered the ICU from the *HUJBB* of *Belém* city, *Pará* State, from November 11th to 29th, 2014, and who met the following inclusion criteria: age equal to or greater than 18 years old; have a family member hospitalized in the ICU for more than 24 hours after admission; agreeing to participate in the study, signing the Free and Informed Consent Term and having previous experience as a visitor in this intensive environment. Failure to meet these criteria implied the exclusion of subjects.

For the collection of data the semi-structured interview was used, containing the following questions: What does the ICU mean for you? What comes to your mind when I tell you the word care? After the hospitalization of your loved one has there been any changes in your self-care? They provided the necessary inputs for interpretations and achievement of the proposed objectives. The interviews were individual, held in the waiting room of the ICU, with an average duration of 10 minutes. The statements were recorded and later transcribed. In order to analyze the data, the Content Analysis technique was used.

The analysis technique adopted is divided into the following stages: 1) Familiarization with the data, in which there is the transcription of the data, active reading of the data and annotations of the first ideas; 2) Code generation, since this is done the systematic coding of data considered relevant to the research; 3) Search for themes, in this there is the grouping of codes to later turn them into potential themes; 4) Continuous review of the themes, promotes the creation of a thematic "map of analysis"; 5) Definition of the themes, aims to improve the specificities of each theme; and finally, 6) Synthesis of an explanatory conception.[10]

The testimonials were synthesized in the three following thematic units: "Intensive Care Unit: Death versus Care", "Changes in Self-Caring: The relatives of patients hospitalized in an intensive care unit" and "Care: Act of love". As a means of maintaining the anonymity of the participants, the identification of the fragments of the reports was adopted through alphanumeric type coding.

The ethical aspects required in research with human beings were all respected throughout this research, and are in accordance with the Resolution No. 466/12, with Legal Opinion No. 867.598 through the Ethics and Research Committee involving Human Beings from the *HUJBB*.

RESULTS AND DISCUSSION

Considering the 40 family members that participated in the research, thirty corresponded to the female gender and ten to the male gender. Observing the age group, the interval was between 18 and 75 years old, with predominance from 41 to 50 years old, married, with complete secondary education, family income ranging from one to three minimum wages and with the Catholic religion. Regarding the kinship, the brothers were the main visitors, followed by the children. Concerning the interval of hospital stay, the mean duration was 10 days.

Unit 1- Intensive Care Unit: Death versus Care

The sudden hospitalization of a family member tends to generate a crisis situation for all the members of a family because together with the life-threatening illness, comes the experience of a new environment with its own characteristics, norms, and routines, of the way to increase the sharing of feelings of fear, insecurity and loss. (Vagner Ferreira do Nascimento, lemes 2015).[11]

In the relatives' testimonies, it was possible to observe a certain negative stigma regarding ICU hospitalizations, since for many individuals the characteristics of this sector tend to provide feelings contrary to the recovery of the patient that is there, being the ICU easily interpreted as the "runner of death,"[12] as can be seen in the testimonials below:

> *"It's a sad word, because I think, that when you go to the ICU, it's because you're very bad, you're almost dying" (Relative 1).*

> *"I already think that the patient is almost dying, that he is very bad, very bad, that there is no way he can stay anywhere but [...]" (Relative 11).*

> *"Many people tell me, that whoever comes here, does not come back, is already dead, they call me sometimes, and they say: Oh! He died, he is dead, he will not live any longer. You know? It seems so to me [...] "(Relative 28).*

Because it is a totally different scenario from the other spaces of the hospital, where the visiting hours are different, the assistance is more specialized, with a high level of technologies and devices, as a means of maintaining life and reestablishing health,[7] the experience of having a loved one hospitalized in an ICU can become somewhat difficult in view of the emotional weakness that pervades them on this occasion and that they need to have the opportunity to talk about their fears and fantasies about death as well as express their feelings.[13]

Although death is the only certainty about life, the human species, when dealing with the death process, learns that it is not just a specific destiny, for the moment of death is never seen as an event without expression feelings, on the contrary, it is loaded with pain and suffering, in order to represent a tragedy in the lives of human beings.[5]

In the fragments "ICU is death", "goes there and does not come back" and "is almost dying" it is noted that relatives suffer from hopelessness and, to a certain extent, are conformed to inevitable death. Even with the technological advances used to maintain life, the ICU is still seen by many as the "death row", and when it comes to a relative, this conception is linked to feelings by the uncertain and unknown, in order to harm the development of positive attitudes and thoughts of the family member on behalf of their loved one.[7]

Another very well represented point, revealed the ICU as a place of more specific patient care and recovery, note below:

"People talk about death, but for me, it is a place of recovery [...], the person comes to receive better, more specific care, I think" (Relative 13).

"The ICU I think is the apex of a patient, if he went to the ICU is because he is very bad, then I am discouraged, but I think the ICU also takes very good care [...]" (Relative 19).

"[...] I think the ICU is right, for those who are already in a very critical stage, here to improve, right?" (Relative 21).

The words "is a resumption", "recovery place", and "receiving better and more specific care" reveal that some family members already have/had a more differentiated view of the ICU, a positive outlook. It is noted that the experience allowed them to get to know the ICU by another face, and a new interface can be perceived in which it is possible to move away from the concept of being a sector where the patient goes to die and begins to perceive it as a place of recovery and more intensive care provider.

Such idealizations are in accordance with the definition of the ICU, in which it states that the ICUs are places dedicated to the provision of specialized assistance to patients under critical condition through strict control of vital parameters and continuous assistance promoted by the multi-professional team with the aid of advanced technologies, as a means to promote an advanced life support and thus improve the client's prognosis.[14]

For patients and their families, ICU hospitalization is a stressful and singular event caused by several factors such as: the risk of death, uncertainty about treatment and recovery, fear about the possibility of not being successful or a good prognosis, and unknown, anxiety, sadness, suffering, impotence and also the great limitation by the distance of relatives from this scenario.[15]

Thus, ICU stay is usually not perceived as pleasant or hospitable. Because of this, the daily visits of these subjects have required changes in nursing practice, causing the team to take new attitudes and postures in relationships, in order to become more sensitive and receptive to the presence of the family member in the daily care.[16]

This fact is most often not practiced, due to the intense and complex daily routine that surrounds the ICU environment so that members of the nursing team, for the most part, forget to touch, talk and listen to the human being that is in front of you. The idea is not that they get emotionally involved, but that they host the family, for example by giving information in an accessible way and unscientific language.

Insofar as social representations are concerned, they incorporate positive and negative feelings of each individual's life, according to the situations, and are structured according to what one can and what should be shown to others, in order to be configured in a type of knowledge elaborated and shared by society with a practical vision for the construction of a reality common to a social group.[17,8]

Hence, we can infer that such meanings associated with ICU are due to people's lack of knowledge about the hospital environment, added to beliefs and fantasies about the ICU, which is seen as a place destined to death, unfriendly and that causes much suffering. Given these representations, we can also see a hopeful vision in which the relatives could observe the ICU as a place destined for the care and recovery, which is understood, when taking into account the time of hospital experience and degree of education, that allowed knowing the ICU from another angle, than that of death.

Unit 2 - Changes in Self-Caring: The relatives of patients hospitalized in an intensive care unit

In the scenario of intensive care, it is notorious that family members modify their habits of life, facing the state of health of their loved one hospitalized, which often also influences their care. The self-care is defined by the Greek term "*epimeleia heautou*," a term that is considered complex and rich, as it encompasses the concept of caring, caring, and caring for oneself.[18]

This term involves not only a concern but a whole set of interactions that intertwine in the daily affairs and that influence the relation of the individual with itself.18 In the face of this, we ask these relatives if the way of taking care of themselves changed after the hospitalization of the while 77.5% of respondents reported significant changes in their lives, given their dedication and efforts to be with their relative hospitalized, as can be seen below:

"I do not feel like anything, I know it's necessary to do some hygiene, but sometimes time, anxiety, nervousness, it does not give you pleasure for it..." (Relative 3).

"... my life has changed because now I just focus on taking care of it and I forget, so, a little of me, you know?" (Relative 9).

"Everything has changed... I stopped going, I stopped talking because sometimes it shakes my nerves and I avoid, I only sometimes kneel and cry, I have no pleasure for anything, nothing, nothing [...] " (Relative 15).

The change in the family dynamics is a common fact in relation to the illness and hospitalization of a loved one in the ICU since the hospitalization tends to withdraw the patient from his routine and the conviviality with friends and family. In this process of disease, a distressing and disorganizing anguish is lived, being necessary to be able to the alterations of the routine that the illness imposes. Caring for oneself in this context is influenced, according to the events of daily life, either in the attitudes taken or in the way of behaving, since the care of oneself permeates the way of life of each individual.[19:55]

The change in self-care is expressed, according to the deponents, by the difficulty in maintaining the care that was previously dispensed to oneself, being evidenced in the following fragments "now I only focus on taking care of him and I forget a bit of me"; "I stopped going, I stopped talking." In this context, it can be said that the form of deprivation is nothing more than a care of oneself, in which one has the act of collecting oneself to avoid undesirable consequences.

The concern with the condition of their hospitalized member is so great that they do not feel often enough to satisfy their own needs. In this relationship between the caregiver and the care is established a deep renunciation of the caregiver to the detriment of the one who needs. One of the principles of caring for oneself is to be careful with oneself, this care being a necessity of the individual, in which one must know how to guide their development and organize their daily practices.[19:54]

The testimonies beyond self-renunciation also reflect the complexity of the present lived experience of these relatives, of honoring their commitments satisfactorily, since the family burdened with the responsibilities feels emotionally shaken, leading to a loss of their professional, personal and of leisure.

It should be noted that the interaction of the human being with elements of the environment tends to promote positive and/or negative effects on the health of the human being. In the case of hospitalization, we have a whole drama that involves the individual and the one that surrounds him, being able to induce effects of illness on the body and mind. For this reason, it is necessary that the relative determine some care to take with him.[19:119]

Caring for oneself is taken by an ethical notion of caring, which is only possible through virtue practices, which open the possibility of a singular path capable of leading the action of an individual and thus produces changes in the individual.[20] For such, care should be seen as a set of practical, rational and voluntary attitudes in which the human being should take as a rule and thus seek transformation, given the situation in which it is.

Within the context of changes, we observed that 22.5% of those interviewed confessed that they thought or intended to make changes in the way they take care of their loved one's hospitalization in the ICU since they play an important role in helping this member. Here the familiar caregiver realizes that changes in self-care will lead to your well-being and consequently will provide you with a better life quality.

"I almost do not exercise, I do not go to the physician because in fact, my time is understood of her, the main one is her, but I already thought of taking care of myself, of changing, right, God willing, only let her improve" (Relative 17).

"I've already thought about taking care of myself, because I've been taking medicine for a while, [...] I'm careful about my health, I'm not going to tell you that it's 80% or 100%, but I take care of the food, the exercises, I do my periodic exams always "(Relative 19).

"[...] I am prone to be changing, let her improve a little more, then I will do the exams, take care of myself..." (Relative 34).

The interest for the caregiving action is increasingly complex, which has increasingly demanded the performance of different subjects and professionals, since being care requires attention, responsibility, zeal, and care with their desires, aspirations, and specificities, so that their insertion occurs in the decision-making process on their own health.[21]

By assessing the testimonies it can be seen in the expressions "I am prone to be changing" and "I have already thought about taking care of myself, changing oneself", these are evidenced the desire of the family in transforming their habits to improve their life quality. The thinking on physical care and healthy attitudes are important strategies for self-caring.[19]

For a good life quality, one of the fundamental factors is the practice of physical activity on a regular basis, which in addition to acting in the prevention of diseases, also helps in self-esteem and the promotion of well-being. Despite the many benefits, the practice of physical activity is not performed recommended frequency, by a large portion of the population.[22]

Given the aforementioned, it is well known that the process of care in intensive care involves relationships between patients, professionals and family members. This care takes on a certain complexity and is carried out in the field of language and affectivity of its members. It is extremely relevant that these changes reflect the well-being and quality of life of these caregivers. In order to do so, it is important to highlight the role of health professionals so that attention is also given to family members, in order to facilitate the coping of this new experience and, consequently, to advise and assist in the self-care of these caregivers.

Unit 3 - Care: Act of love

The word "care" is derived from the Latin cure, which is a scholarly synonym of care. The same is understood as a commitment to the world through the development of actions, behavior, and attitudes, involving knowledge and experience, in order to promote, maintain and or restore human dignity and totality.

When we observed the testimonies obtained in the research, we noticed that for 52.5% of the interviewed family members, the term care was associated with the feeling of love and zeal for the neighbor. In which, it is possible to show in regard to the act of caring, attitudes, and idealizations charged with attention, zeal and care, in which the other is respected in his individuality and subjectivity.[14,24]

"Caring is to be able to be with the person you love, to be zeal, to want, to love, to love, to do everything in order to be with them well, [...]" (Relative 15).

"I think it's the extreme of love, because the sick person who is cared for, when looked at and cared for by all people, feels more comforted and cared for" (Relative 19).

"Careful, it comes from the word love, if you do not have love, you do not care and if you do not love yourself you do not take care either... care is not to mistreat" (Relative 32).

When you observe the following statements "if you do not have love, you do not care" and "caring is loving" you note that family members attribute care as the tender expression of love. According to a study, caring as well as love, grows with each individual and distinguishes us as human beings, without love there is no care, for caring in itself is a true act of love.[25]

In light of this, we emphasize the thought that reflects the idea that care does not only encompass feelings of affection, attachment, and pleasure but also submerges from this practice the collection and attention to promote and maintain the health of the individual. By this, it is emphasized that the individual in caring appropriately is prone to relate to and conduct himself in any relation to the other.[26,19:65]

In this paradigm that care expresses the idea of a special attention to those who live a specific situation, it becomes evident that this practice is part of the life of the human being from the beginning of humanity, as a response to attending to their needs and demonstration of feelings, which reveals the importance of the other to us.[25]

"Care is treating, to take good care of, to care for and care for what the person needs, to attend to the need at that moment because if you need care, you can not do some things, right?" (Relative 3).

"Care is for you to take care of a sick person because he can not do certain things, you are to be with him to help, treating the sick, it is a general care [...]" (Relative 4).

"Care is to pay attention, take in the bathroom, sometimes she needs me to put food in her mouth [...] All this in the measure. I think I'm taking care " (Relative 14).

The care for a given author is only produced when the existence of another is important for the caregiver, in which the caregiver starts to dedicate himself to his neighbor, preparing to participate in his sufferings and successes. Thus, care means solicitude, care, zeal, and attention.[24] In this sense, it is noted that in the expressions "taking care of what the person is needing" and "standing by to help" reflect the attitudes of family members who consider their loved one worthy of receiving moments of dedication and cooperation so that you can reestablish the comfort and well-being of your loved one.

Another relevant aspect highlighted in the testimonies of 43.5% of family members, reported Care as the practice of good habits and demonstration of feelings for others, as can be seen below:

"I think it's to take good care of our health, our food, our tests so that we do not get sick..." (Relative 1).

"It is to try to be with someone that we feel good, to exercise, to practice sports, to run, to maintain good health, not to depend on medicines" (Relative 13).

"[...] is to preserve, to look more at our health, to eat right, to take care of ourselves, to avoid worries, to go to the doctor instead while doing a checkup..." (Relative 40).

A healthy diet linked to the practice of exercises and frequent visits to the doctor are simple to care that reflect on the health of the individuals, being pointed out as one of the most important factors of prevention, reversion, and control of diseases.[27-8] The practice of physical activity besides promoting motor development, reduces the conditions for the development of chronic-degenerative diseases, such as diabetes, arterial hypertension, cardiac and expiratory diseases, as well as improving self-esteem, self-confidence and expressiveness.[29]

Through the statements a certain relative awareness is observed regarding the practice of good habits, given that the promotion of health and especially the prevention of diseases and injuries are considered fundamental yearnings of human beings, being the same highlighted in these expressions "for people not getting sick", "maintaining good health in order not to rely on medicine."

Given all the aforesaid, it is understood that care is an action that cannot be considered only as an activity or only a technical procedure because it encompasses attitudes and behaviors that involve feelings of respect for others, compassion, tolerance, and solicitude.[30,1] Observing the social representation, it is used here as a way of clarifying how

social activities are given, in order to anticipate and justify social behaviors and practices.[31]

CONCLUSIONS

Through this research, it was possible to describe the social representations of the relatives of patients hospitalized in the intensive care unit with regards to both the care and the intensive care unit, and its implications for self-caring as well. Supported by these social representations, it was possible to recognize the complexity of social representations and how factors such as time and experience can be strongly influential in their determination.

For these relatives, the term Care took on two basic representations, which are closely related to each other, the first being linked to the idea of love, care, solicitude, and attention to the other, and the second to the feeling of concern about maintaining habits healthy. Therefore, what differentiates care is the way it is done, regardless of its meaning, care is part of the human being and everything that has life calls for care.[32]

Concerning the ICU, it can be observed that the negative beliefs and fantasies about the ICU are still strong and persist in popular thought. On the other hand, it is believed that this is a reality to be changed, whereas it is possible to observe among these relatives a differentiated view, in which the ICU is associated with a place of care and recovery, but not of imminent death.

Hence, we believe that the realization of a more humanized host is the best instrument that nursing can have to lead these families during the hospitalization process, recognizing them as the target of their care, as well as the main client, so that the suffering exists, but do not suppress the hope of returning to family life together with your loved one.

Given the abovementioned, we understand that the path taken along this research cannot be summarized in this single work and, therefore, it is not exhausted with this trajectory, being open the invitation to the dialogue and the diffusion of these and new analyzes on the family in front of ICU.

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