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The experience of family members of patients staying in intensive care units

Vivência de familiares de pacientes internados em unidades de terapia intensiva

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ABSTRACT

Purpose: The aim of this study was to understand the experience of family members, during a patient's stay in the intensive care unit of public and private hospitals using an approximation to the phenomenology referential.

Methods: We interviewed 27 relatives of adult patients, 10 from a public institution and 17 from a private one.

Results: From analyses of interviews in a public institution, four thematic categories emerged. In a private institution six categories were identified. Searching for differences and similarities, four similar thematic categories were perceived in both institutions and two categories were absent in the public hospital.

Conclusion: There are no significant differences between categories in private and public hospitals. This indicates that family behavior and reactions to patient's admission to the ICU are not associated with social or financial aspects. However, a greater knowledge of government policies and programs is necessary, because they favor humanization by allowing family members to accompany the patient in tertiary services.

Keywords: Intensive care units; In-patients; Professional-family relations; Family relations; Qualitative research

INTRODUCTION

Studies including the process of admission to an intensive care unit (ICU) have been a subject for investigation by the scientific community, focusing on the need for action aiming at humanization of the personnel acting in this unequaled ambient of health assistance.[1-3] In our professional experience we have observed the impacts of this process on the family members, patients and team.

The ICU is an environment intended for the care of severe patients at risk of life requiring uninterrupted medical and nursing assistance. Patients in the ICU are submitted to constant monitoring of organic functions and to highly complex cares in the endeavor to reestablish their health condition and ensure their survival. It is an environment characterized by a constant anticipation of an emergency situation with patients subject to sudden changes in their general condition, constant activities, light, noise and peculiar equipment. This situation make the ambient stressful for all who come together and work in intensive care units (ICU).[1]

Another noteworthy aspect is the stigma of admission to the ICU regard-

ing the culture about the characteristics of this sector experienced by society and that does not change over time. Feelings that arise may seem contradictory, as they are often associated with the issue of death and also a place of attendance that offers safety and tranquility.[4]

Hospitalization of a family member in the ICU, usually takes place in an acute and unexpected way, a fact that reverberates in the family changing the daily life. The crisis situation experienced by family members may be observed by the disorganization of interpersonal relationships due to the patient's physical distance, to financial problems and to fear of loss of the loved one. Families show this unbalance by the reduced number of sleeping hours, nutritional disorders and increased use of anxiolytics.

During this experience we observed that many questionings are brought forth by the family, issues regarding possible sequels, general condition and possibility of death, pervade the different ways in which the family members react to this experience requiring that the team be responsive to the family demands at this time, in search of effective ways to be helpful.

Are there differences in the feelings, in the experiencing of family members of patients admitted to an ICU of a public or private institution? In view of this question, the purpose of this survey was to disclose the experiences of family members of patients admitted to the ICUs of a public and private hospital, considering their similarities and differences, to contribute to the emergence of effective actions intended to humanize care in this sector.

METHODS

A qualitative study with approximation to a phenomenological approach, focusing on the experience of the family members of patients in the ICU, considering issues of an objective and social nature directed to the understanding of an individual's experiencing, was carried out.

In phenomenological research, the researcher does not face a problem, but an interrogation focusing the phenomenon, not the fact. The inquietude of something concealed that needs to be disclosed is the genesis of an interrogation that orients the search for understanding of this phenomenon.[5]

To understand how the family experiences hospitalization of a member implies having to address what is experienced, just like it is experienced. It is not a question of knowing about the phenomenon, but indeed, the phenomenon of admission as it is revealed to the family in its essence. In this study we tried to elucidate the phenomenon of the family's experiencing as it goes through admission of a beloved one to the ICU, considering ICU with similar admission characteristics, however in different institutions, one public and one private.

Both ICUs had 10 beds for patients needing intensive care, they allowed the same number of visiting hours (duration and period) and information asked by family members was supplied by the medical and or nursing team in the sector.

Differences between the surveyed sites are that one ICU is located in a private institution "Santa Casa de Londrina" while the other is in a public Institution "Hospital Universitário de Londrina". Seventeen and 10 family members of patients in the general ICU of each institution respectively, were interviewed.

In the context of the ICU, for the choice of the individuals we observed that visits were made by persons that form patient's the family core. They portray the day-by-day, and are defined as the group formed by father, mother, and siblings; who live under the same roof; tied together by marriage or other relationships.[6]

Lengths of stay or diagnosis were not considered for the choice of the individuals surveyed, because this investigation was not restricted to relation among variables. Because it was a phenomenological study, researchers were obliged to learn aspects of significance in the comments, expressions and gestures of the unique experience of the interviewed individuals.

When approaching specifically a family member for an eventual interview, the study proposal was presented, warranting the pertinent ethical aspects. The individual was also told about the Free and Informed Consent, according to the fundamental principles of the Research Ethics as well as about previous approval by the Ethics and Research Committee of the institutions surveyed.

Surveys were carried out during visiting hours, from September to December, 2004 with families of patients admitted to the ICU of the "Santa Casa de Londrina" and from April to June of 2007 with family members of the ICU of the "Hospital Universitário de Londrina". A recorder was used, encompassing 17 interviews, 15 of them recorded and two transcribed immediately thereafter. Of the additional 10 interviews, eight were recorded and two were transcribed after the study, respectively. The leading question was: How are you facing having a family member admitted here? Tell me all about it.

During interviews researchers paid close attention to the gestures, movements, glances, voice intonation and silences. These are understood as forms of experienc-

ing the world that the individual expresses and that are closely related to disclosure of the phenomenon under study. The researcher must have intuition and sensitivity to perceive and seize such moments.[7]

When the number of reports was sufficient for the understanding of the surveyed phenomenon, considering their convergences and divergences, the interviews were ended.

After data organization and transcription, each report was carefully read, seeking the common portions, in view of the study's proposal. Afterwards, reports were approximated one to the other, for convergence and divergence and the thematic categories were formulated .[5] It should be mentioned that for the comments below the individuals' names are fictitious.

RESULTS

Considering the uneasiness when disclosing the similarities and differences of the feelings that emerge when experiencing admission of a family member to the ICU of a public and private institution, we will now describe the categories that were formulated from the comments of the family members. First will be the similar categories to be followed by the different ones found in both institutions.

In the private hospital ICU, six thematic categories became clear: difficult experience, painful, without words; put yourself in the place and perceive the other: approximation to the suffering of the patient; split in the relationship with family everyday life; fear of the family member death: ICU: a feared but necessary scenario; concern with care of the family member.

In the public hospital ICU four thematic categories became clear: difficult experience, terrible and painful; ICU – environment that implies fear and care; change in the family everyday life and possibility of death.

As can be seen, categories in the public hospital ICU are very similar to those found in the ICU of the private hospital. This leads to the conclusion that notwithstanding the characteristics of the institution, the procedure of a family member admission in the ICU is experienced in a similar way by the family. It is noteworthy that this analysis is restricted to the thematic categories that became clear in the comments, because the peculiar experience of each individual is unique and incomparable.

The comments about the changes that took place in the family with admission of a loved one to the ICU are significant. Everyday life changes, there is an accrual and maladjustment of the function previously carried out by the individual now experiencing the facticity of admission, who is now away from family life as noted in the comment of one of the interviewees:

"…from then on, so to speak everybody's story changed…. I was there for two years already… I was in Santa Catarina for six years, I went there, I was there as manager, I had a good position, earning well. I was even going to get married now… I am not gong to any more then I stopped paying everything. Then, I mean everything got messed up…. And that's it…(…) Have to get out, pay bills, and have to solve the problems of my baby brother who is in school…" (Rafael)

How the environment instills fear was also similar in the two institutions, and fear is related to the possibility of death of the hospitalized family member, because of the patient's severe condition. However as days of stay went by perceptions and readings about the dense and technological environment started to change:

"(…) but from my point of view the ICU is the best place in a hospital to treat a sick person, you understand? This is what I ….what one understands. Because one knows that it is an intensive treatment, there is a physician, and a nurse there 24 hours.(…)". (Jaime)

Anyhow, comments related to anxiety and fear about the physical structure and the environment in the ICU were significant aspects that must be taken into account if the intention is to care for each family in its singularity.

Another category common to both institutions was related to the experience of the possibility of the family member death. This aspect is strongly present in the ICU, because the unit is intended for the recovery of severely ill patients. Culturally, there is a preconceived idea that being in the ICU means being between life and death, so that it can be a one way trip with no return.[4]

" Oh… well I think like that, I believe that there is no coming back…, you understand? So one stays there, kind of waiting… for bad news. So one is already waiting for the worst". (Paula)

The veiled way of talking about death was also significant, the way it was structured in the Western world causes death to be experienced in an impersonal way and not envisaged as a dimension of human existence.

Then there are the two different categories found only in the ICU of the private hospital: put yourself in the place and perceive the other: closeness to the patent's suffering and concern with care of the family member.

In addition to the family mentioning its own feelings, the expression about the perception of the feelings of the family member in the ICU is also significant, as if the

family could convey what the patient is experiencing.

"In the sense of getting sick, he is conscious and I know how much he is suffering, he is suffering a lot. I feel that he is suffering, not because of our fault, but because he is feeling like this, on a bed lying down and as he knows about my coondition, since it was he that was caring for me, he is suffering". (Joana)

This comment became significant when it comes from empathy, that is to say, in the ability to put oneself in the place of the other, experiencing an authentic relation.

If the intention is to humanize the service given , this authentic way of perceiving the other shows that there can be a unique and understanding assistance to the family, patient and team.

In the category related to concern with the care of the family member, the comment disclosed different ways of perceiving the care:

"(...) even the work of the personnel makes one happy, because there are a lot of people , very kind, from the people at the reception, yeah! To the physicians , the nurses, the cleaning personnel, so the only thing one wants to do is to be grateful". (Rodrigo)

"But I know he is in good hands, that he is well taken care off, the hygiene of the place, also one sees that he is treated with concern and attention, quite different from the other service where he was". (Laura)

Because this category appeared in the interviews of the private hospital, there is a questioning about the routine of the sector regarding the presence of a companion:

"(...) one wishes to be near and one can't yeah! Because visiting hours have to be controlled. One even understands that but, one would like to stay near, all the time if one could(...)". (Karina)

DISCUSSION

Various studies have found that the experience of the family of a patient in the ICU is one that brings about fear, anxiety, uncertainty and concern, from the point of view of the nurse as well as from the family. [4,8-9]

Work in an ICU has peculiar characteristics because of the physical and structural features of the sector. Special and advanced equipment, alarms at every moment, instability and severity of patients being cared for, contribute to the intense dynamics creating tensions for all in the sector, be they the team, patient or family members.

In view of the dynamics required by the sector together with the need to master technical- scientific knowledge about the equipment, drugs and routines conditions the team to act in a calm and cold manner for the recovery of the affected biological sphere. This action of the team also reflects on the assistance to the patient and the family, contributing to the non emotional involvement in the situation that may take place in the sector.

It must be considered that among the complex equipment and techniques, the human being that is there should be viewed, not only as a patient needing constant monitoring for vital functions, but as a unique human being experiencing a pathologic process which, as it encompasses existential totality, certainly leads him to experience a lack of assurance to be able to be healthy while facing disease and the risk of death.[10]

In this process the patient's family is included as it also begins to belong to the universe of health assistance and requires attention, not contemplated and also forgotten by the team on hand. ICU is further structured so that the physical layout, organization and attitudes of the professionals working there reproduce the idea that the family is something apart and, not incorporated in the center of attention.[8]

It must be emphasized that one of the interviewees was a health professional accompanying a sick family member. This experience brought about significant reflections on her professional attitudes and everyday dealings with the family of patients cared for. This sensibilization may bring about changes differing from generalizations of the feelings experienced by the family. It would allow the understanding that the companion of a family member in the ICU is a particular situation to be dealt with in unique and different ways.

The category referring to the ICU environment as a differentiated place, causing fear and concern, was cited in the two institutions. Surveys in different methodological approaches showed, paradoxically how the ambient was perceived by the family[4,11-12]

Professionals in intensive care, an environment predominantly technical-scientific, manifest a significant difficulty to express themselves and deal with death, as it is burdened with existential issues not thought about in the daily tasks of an intensive care unit. Studies showing how it is experienced: by denial, use of mechanisms to forget what has happened, defined as a stressing factor, aspect that has to be controlled in the name of professionalism stimulates impersonality that isolates professionals from the reality of pain and suffering.[13-16]

Such attitudes lead to the persistence of a breach between the family and the team. The family lives the threat of death and the team avoids this threat without devising

strategies to accept it at this moment. This further contributes to the gap between the individuals acting in this unpaired universe of health assistance.

Another aspect that resulted from the comments made was about the different ways of perceiving the patient and how the family interpreted the parameters of the equipment when experiencing admission to the ICU. Situations that are normal and common for the team are not so for the family. This should alert the team that its concepts of good and bad are not applicable to those of the family. An idea that agrees with something essential in the phenomenological referential: permit that things are disclosed under their own perspective.[17] Therefore, as simple and familiar as it may seem to the professional eyes, the view of the family on the ICU world must be considered.

Regarding the stay of a companion in the ICU, the state of São Paulo, in Law n. 10,689 of November 30, 2000, under article one rules[18] that: “the stay of a companion with the person admitted in health units under the responsibility of the State is permitted, including in the rooms for intensive care or others equivalent”.

Also, since 2004, the “HumanizaSUS, by means of the “Política Nacional de Humanização” (PNH) (National Humanization Policy) establishes the Primer of PNH: “Open Visit and the Right to Companion” for the purpose of disseminating technologies for the humanization of care and management in the domain of health.[19]

Based upon the concept of expanded clinic such as: clinical work directed to the individual and disease, the family and context for the purpose of producing health and to increase the autonomy of the individual, the family and the community, the companion will act as a central point in the implementation of this proposal. It further complements that visits to the patient, corroborate his own existence and that this is a vital need of the human being and reinforces the strategy for receiving the companion.[19]

As this is a category that emerged from the experience of family members of patients in the ICU of the private hospital, it reveals that users of the service do not know their rights, even while both hospitals attend patients of the Official Health System, enrolled in the Humanniza-SUS and the national humanization policy.

The difficulty of breaking with the clinical model of health care must also be considered. It is based upon recovery of the biological body, with a pronounced social and technical division of work, with the medical act viewed as decisive, determining the allocation of tasks among the different professional categories.[20]

However, the fact that both hospitals belong to programs that aim at humanization is a positive aspect to be considered as it is understood that to trigger a change, articulation of institutional management and of the sector is needed. This is necessary to offer working conditions, human resources, physical space and professional qualification to receive this family member and the possibility of a more human assistance contemplating the guidelines of PNH.

This study shows that each family has its own peculiar way of facing the situation of admission of a loved one. Actions advocated by the humanization program are viewed as essential for the advent of significant changes in the humanization of care. However, if there is no recognition that the experience of each individual is unique and singular, it is quite probable that the relation established between the family and the health team will continue to be marked by standardization and autoritarism, of the team that dominates the specific knowledge experienced in an ICU.

CONCLUSION

Starting from the principle that the family is an integral part of the patient in the ICU, interest in knowing these requirements must be essential for the tertiary services that care for this population. However, there is a shortage of comparative studies on the subject in different types of institutions, making comparison of achieved results even more difficult.

In this study, the fact that the same categories were found in the comments of the family members interviewed was significant enabling us to state that families of patients in the ICU have similar fears, uncertainties and needs, notwithstanding the social or financial issue.

It was significant to observe however, that categories related to concern about the care of the family member occurred in the private hospital ICU, disclosing a lack of knowledge about the guidelines guaranteed by the Official Health System in programs and policies of humanization established by the federal government.

To assure this access becomes a challenge for the institutions that assist severe patients, since implementation of intervention with family members of a patient in the ICU is not an exclusive, individual responsibility of the team. Administrators of public or private institutions must take on the responsibility for the management of these changes.

RESUMO

Objetivos: A proposta deste estudo é compreender as vivências de familiares de pacientes internados em unidade de terapia intensiva de hospital público e privado através de uma aproximação ao referencial da fenomenologia.

Métodos: Foram entrevistados 27 familiares de pacientes adultos, sendo 10 de instituição pública e 17 de instituição privada.

Resultados: Da análise das entrevistas da instituição pública emergiram quatro categorias temáticas. Na instituição privada somaram-se seis categorias. Na busca de suas semelhanças e diferenças quatro categorias temáticas foram encontradas nas duas instituições e apenas duas não emergiram no estudo do hospital público.

Conclusão: Não há diferenças significativas das categorias dos hospitais público e privado, o que demonstra que a forma como a família vivencia a internação de um paciente na unidade de terapia intensiva não se relaciona a aspectos sociais ou financeiros. Entretanto, faz-se necessário um maior conhecimento de diretrizes e programas do governo federal que favorecem a humanização ao permitir o acompanhamento da família nos serviços terciários.

Descritores: Unidades de terapia intensiva; Pacientes internados; Relações profissional-família; Relações familiares; Pesquisa qualitativa

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