

RELATIVES' EXPERIENCE OF INTENSIVE CARE: THE OTHER SIDE OF HOSPITALIZATION¹

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This study aims at understanding the experience concerning family members of patients in the Intensive Care Unit (ICU), with the purpose of contributing to care humanization in this context. Considering the nature of the research object, this research was carried out to understand the phenomenon "Being a family that experiences the hospitalization of a family member in ICU". Phenomenology was used as a methodological reference framework. Seventeen family members of adult patients in the Intensive Care Unit (ICU) at the Santa Casa in Londrina were interviewed from September to December 2004. Through analysis of these interviews, some theme categories emerged: difficult, painful, speechless experience; experiencing and recognizing somebody's life: approaching the patient's suffering; break-up of the family's daily routine; fear of having a family member die; ICU: a fearsome scene, but necessary; concern with family care. Some issues related to the family's attendance in the ICU were discussed, contributing to the establishment of humanized care delivery to critical patients and their families' uniqueness.

DESCRIPTORS: family; intensive care; qualitative research

VIVENCIAS DE FAMILIARES EN TERAPIA INTENSIVA: EL OTRO LADO DEL INGRESO

La propuesta de este estudio es comprender las vivencias de familiares de pacientes ingresados en Unidad de Terapia Intensiva (UTI), con la intención de contribuir para la humanización del cuidado en ese contexto. Considerando la naturaleza del objeto de investigación, el estudio fue conducido en la búsqueda de la comprensión del fenómeno "Ser una familia que pasa por la experiencia del ingreso de un familiar en la UTI". La fenomenología se utilizó como referencial metodológico. Se entrevistaron a 17 familias de pacientes adultos ingresados en un UTI de la Santa Casa de Londrina, de septiembre hasta diciembre de 2004. Del análisis de esas entrevistas, emergieron las categorías temáticas: experiencia difícil, dolorosa, sin palabras; ponerse en el lugar y percibir el otro: proximidad al sufrimiento del paciente; rompimiento de la relación con el cotidiano familiar; el miedo de la muerte del familiar; UTI: escenario temido, pero necesario; preocupación con el cuidado del familiar. Algunas facetas relativas la vivencia de la familia en UTI han sido desveladas, contribuyendo para la construcción de un cuidado humanizado vuelto para la singularidad de la familia y del paciente crítico.

DESCRIPTORES: familia; terapia intensiva; investigación cualitativa

VIVÊNCIAS DE FAMILIARES EM TERAPIA INTENSIVA: O OUTRO LADO DA INTERNAÇÃO

A proposta deste estudo é compreender as vivências de familiares de pacientes internados em Unidade de Terapia Intensiva (UTI), com a intenção de contribuir para a humanização do cuidado nesse contexto. Considerando a natureza do objeto de investigação, o estudo foi conduzido na busca de compreensão do fenômeno "Ser família que experiencia a hospitalização de um familiar na UTI", tendo como referencial metodológico a fenomenologia. Foram entrevistados 17 familiares de pacientes adultos, internados em uma UTI da Santa Casa de Londrina, de setembro a dezembro de 2004. Da análise dessas entrevistas, emergiram as seguintes categorias temáticas: experiência difícil, dolorosa, sem palavras; colocar-se no lugar e perceber o outro: aproximação do sofrimento do paciente; rompimento da relação com o cotidiano familiar; o medo da morte do familiar; UTI: cenário temido, mas necessário; preocupação com o cuidado do familiar. Algumas facetas relativas à vivência da família em UTI foram desveladas, contribuindo para a construção de cuidado humanizado, voltado para a singularidade da família e do paciente crítico.

DESCRIPTORES: família; terapia intensiva; pesquisa qualitativa

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INTRODUCTION

The authors' professional practice in Intensive Care Units (ICU) has raised considerations regarding the experiences that take place in this particular place concerning the health care of severe patients. One of the significant issues is the experience of patients' relatives, which is the theme of this study: what is this experience like to the family? What implications can this have for the health team?

The interest in this theme is not related exclusively with the authors' past and present experiences as nurses at this place, but also with the health context, which increasingly demands humanized welcoming actions, which would contribute to the construction of integral health care.

The change in the health care paradigm incorporates the proposal of health care humanization, at all levels of health service organization. It involves articulating, more effectively, the distinct system levels, and understanding that the principles that rule the Single Health System (SHS) should also be assured in tertiary care contexts.

Valuing man brings a new view to health care; massification is replaced by a view of the singularity of considering the individual as someone unique, inserted in a family and social context that permits feeling healthy or sick in their own way.

Hence, in this study, the sample was specifically focused on the experience of hospitalized patients' relatives, considering the ICU context. The ways relatives experience hospitalization of one of their family members reveal important aspects that would help to reconsider health care humanization.

Thus, the study proposal is to understand the experiences of ICU patients' relatives, in order to contribute to health care humanization in this context.

METHOD

It is a qualitative study, founded on understanding the subject's experience and using phenomenology as the methodological framework.

The ICU in this study has ten beds for adults with various pathologies, who need intensive care, except for cases of trauma and infection by multiresistant microorganisms. There are two daily visiting hours, of 30 minutes each, one in the morning and one in the afternoon, in which three relatives exchange turns. Information regarding the evolution,

exams and procedures are given by the unit's nurse.

In the ICU context in this study, visitors are usually members of the hospitalized patients' nuclear family. They accompany the patient and demand information from the health team: a group formed by father, mother and children; who live in the same house; connected by marriage or other kinship. Hence⁽¹⁾, the subjects in this study were people from the nuclear family, which portrays everyday life.

Since it is not a phenomenological study, neither diagnosis nor hospitalization time was previously considered when selecting research subjects, because this kind of investigation is not restricted to the relationship between variables. The context experienced by patients includes aspects like severity and prognosis. These aspects, if considered relevant to differentiate the relative's particular experience, are stated implicitly or explicitly, and the researcher should be able to understand their significance.

Before starting the family interviews, the researchers visited the study setting, during visiting hours, inhabiting the ICU world, in order to capture information regarding the relationship ICU-family, which were recorded in a field diary. Moreover, this approach aimed to build trust and observe the most appropriate moment to interview the relatives, considering that they were going through a painful experience.

When relatives were approached specifically for the interview, the study proposal was presented and the pertinent ethical aspects were assured. Subjects were also informed about the Informed Consent Form, according to the fundamental principles of research ethics, as well as about the previous approval by the Institutional Review Board of the *Irmandade Santa Casa* in Londrina-PR, Brazil.

Interviews were carried out during visiting hours, from September to December 2004, with the relatives of ICU patients hospitalized at the Santa Casa Hospital in the city of Londrina-PR. A tape recorder was used, and 17 interviews were held: 15 were recorded and two were transcribed immediately after completion. The guiding question was: What is it like for you to have a relative hospitalized here? Please explain.

During the interviews, the researcher observed the gesticulation, movements, voice intonation and silence, understood as forms of experiencing the world that the subject expresses, and which have an intimate relationship with uncovering the research phenomenon. The researcher

needs to have the intuition and sensitivity to notice and capture these moments⁽²⁾.

Interviews were ended when the statements were sufficient to understand the research phenomenon, considering its convergences and divergences.

After organizing and transcribing the data, each statement was carefully read, seeking the significant units, considering the study proposal. Next, the statements were compared for convergences and divergences and thematic categories were established⁽³⁾.

She statements were numbered, and those marked with the letter "E" refer to the relatives.

RESULTS AND DISCUSSION

Difficult, painful experience, no words to explain

During the interviews, relatives showed the suffering they experience by having a family member hospitalized in ICU. Some of the words used to express this feeling are: difficult, sad, suffering and terrible. This is shown in the statements below:

Is has been, like, really difficult ... because it is, you know, an ICU and because you know what might happen, you know, so it is very difficult, it is terrible (...) Like, so far all I have experienced is a lot of pain. E3

It has been very difficult, very sad. E14

Terrible... there are no words, there is no specific word to explain ... E7

Terrible, it is hard to explain, but I'll say what it is like, because we see it like people from outside think this will never happen to us, you know, and when it is with someone from our family it is very difficult. E8

In most statements (11 of the 17 interviews), the word difficult was stated as the first expression, which emphasizes that this difficulty is related to the pain the situation arouses.

Many relatives, despite their initially expressed difficulty and fear, report that they cannot find a specific word to express the painful situation they are living. During the interviews, it was clear that they tried to find, by gesticulation and silence, a word that would express their feelings, but they were not able to. The feeling was stronger than what could be expressed in words, since words sometimes do not translate the experienced situations.

The meanings assigned to the experienced situation are related to the subject's way of existing⁽⁴⁾.

Hence, it is important to consider, regarding family experience, that there are no previous definitions to express it, since human beings permanently live distinct situations, and assign meanings based on their subjectivity.

Nevertheless, logical thinking usually prevails in human relations because modern men, living their lives from this perspective, see a logic-rational world and create ways to control it and establish a subject-object relation. Hence, the meaning of existence is separated from men's concerns and the projected world surmounts the experienced world, the stage of our daily existence⁽⁵⁾.

This logic also prevails in the technical-scientific world of ICU, which limits health professionals' understanding of the relatives' experience. That is, families bring a life demand that needs to be considered in the health care context, surpassing the current perspective.

Putting yourself in the place of others and acknowledging them: approaching patients' suffering

In addition to referring to their own feelings, relatives significantly express their perception regarding the hospitalized relative's feelings. This perception involves putting themselves in the place of others, so that they could feel and state what the patient is experiencing:

As to being sick, he is conscious and I know how much he is suffering, he is suffering a lot. I feel that it is not our fault he is suffering, but because he recognizes himself like this, in bed, and because of knowing about my condition, since it was he who took care of me, he is suffering. E5

... we see she feels that we are leaving, her tears run, because she is scared... now, seeing her like this... scared, it hurts us because we know she was scared of being alone, even at home! She was scared when she got sick, she was scared, and you see, staying here all night... can you imagine her pain? I think she's ... hurt by being left alone... E8

These relationships become significant as empathy emerges, that is, the ability to put yourself in the place of others, feeling their pain and suffering, in an authentic relationship. Regarding empathy, it is highlighted that "(...) it means sharing the other's feelings, what they are feeling, without necessarily living their experience"⁽⁶⁾. This authentic form of perceiving the other shows it is possible to offer uniqueness and understanding in health care.

The analysis of the statements also showed that relatives, through their experience at the ICU,

develop different forms of perceiving the patient, reading their expressions, gesticulations, as well as the parameters of the equipment, though they are not familiar with them.

The authors observed the situations mentioned in the interViews, and noticed that relatives read the patient differently from the health team. This is because of their specific technical knowledge, which differentiates them from the visitors.

Breaking the everyday family life relationship

The relatives also live the rupture of their everyday family relationship, which is reported in almost every statement.

It has been very hard, you know, for me because I was always there, working and all, you know, and suddenly, it ended up like this, we feel desperate, you know, at least I did ... E10

Unexpected situations usually make people feel uncomfortable, because the uncertain and unsafe aspect of their lives is revealed; aspects that are commonly denied.

It is forgotten that the origin of human life experience contains the experience of constant fluidness, mutability, the world's inhospitality and freedom. There is no safety, and it is no deficiency of being human, but rather the condition⁽⁷⁾. Hence, human life is filled with insecurity and uncertainty.

Along with this unexpected change, which ensues with hospitalization, families miss this relative in their everyday family relationship. This leaves a gap to be filled. It is interesting to notice that, for the family, considering their history with the patient, who is now facing the reality of ICU hospitalization, the past becomes significant in the present moment. That is, it hurts to miss their relative in everyday life, considering their memories.

It has been really hard, you know? [...] you know, because we live together, and she's here, and I'm alone there now, I get home from work and the house is empty, I don't find her, so this point is difficult, you know, and she sleeps in my room, so her things are with mine, you know, so I open my wardrobe, and I see her things, you know, so it's really complicated [...]

On the other hand, the health care professional has little time to approach patients. This makes it difficult to understand what the patient has experienced. The focus at the ICU is on care for people exclusively in terms of their technical-biological dimension. Priority is given to the organic changes that demand specific controls and therapies, which

can be standardized and systemized. This does not mean that this dimension, essential at ICU, should be denied, but ill humans should not be reduced to it.

Significant contact with the family can be a resource that makes the health care professional closer to patients, in their family dimension, incorporating other elements into health care, which surpass the strictly biological view.

It is also important to note that, due to life uncertainties they face during hospitalization, families often presume their future will also be filled with insecurity and uncertainty, expressed by their fear of death.

The fear of their relative's death

The analysis of the statements showed that the possibility of death was mentioned in many interviews. However, the word death was stated only in two:

*It is knowing that death is very close to you (...) E3
(...) you don't accept that your father is dying, in his mind, he'll live and go back home normal, walking, talking, so that's what we think. E4*

The others usually use the word "loss", which may be a subtle way to express their fear of death:

Oh! I'm scared! I'm scared of losing my father, ... E11

It is important to acknowledge that relatives present a succinct, brief report in this regard, and they do not give more details regarding the possibility of their family member dying. This possibility, in the ICU context, is very concrete. Thus, it is difficult to talk about death, considering that it is a possibility for all human beings, which is related to the way it has been constructed in the Western World.

Currently referred to as "taboo", and having been moved from one's home to the hospital, death is no longer considered natural. It is considered a cold, hidden and unwanted phenomenon, away from man's life and home. However, since death cannot be avoided, measures have been created to fight it. Hence, institutions for hospitalization have appeared, for that exact purpose⁽⁸⁾.

Another important point is that death is usually experienced as something impersonal. In everyday life, it appears as "death case": somebody, close or not, "dies". Strangers also die, every day and all the time. Eventually, everyone dies one day, but "(...) at first, you aren't affected by death"⁽⁹⁾. Thus, people perceive death as something common that they will only face as something known, but that will not

affect them because it is impersonal. "(...) you die because, thus, any other person, including impersonally, can say with conviction: but not me..."⁽⁹⁾.

The fear of death in the ICU context is related to the stigma this location implies. To relatives and patients, ICU means being between life and death, with the possibility of no return⁽¹⁰⁾.

Another phenomenological study states that, from the patients' point of view, the ICU is a place where they feel insecure because they understand the severity of their clinical condition, and experience the feeling of predicting their finitude⁽¹¹⁾.

It is worth emphasizing that health care professionals in the ICU context also try to move away from this issue, and therefore do not present subjective and objective conditions to create family care strategies. So, the gap persists. Thus, death is present in the ICU as something unknown and frightening; it is an enemy that is rarely considered a dimension of human existence.

ICU – a feared but necessary setting

The physical and structural characteristics of the ICU differentiate it from common hospitalization units. There is sophisticated equipment, different routines and specialized staff who use invasive techniques to recover and maintain life.

In the analyzed interviews, concerning the location's peculiar characteristics, relatives admit that it is the ideal place for severe patients' recovery, and express their hopes:

(...) but after he came here, I have hope, you know, because I know that here is where you recover, right ... so it's for the best, right ... E 10

On the other hand, relatives also perceive the ICU as a place that causes fear, apprehension and insecurity. These feelings, through their statements, are related to the possibility of loss and death, due to patient severity:

(...) yes, we're a little ... it's apprehensive because when he's in the ICU and our phone rings, we: Oh! Get kind of scared, it is different from being hospitalized in a room, right? In the ICU we feel more apprehensive, a little more afraid, but we know that he's getting all the care he needs there and that he might get better (...).

It's like I told you, we feel a bit more afraid, scared, because we know that the ICU is for people who are bad (her emphasis), right, I think it's really the last resource, the doctors will do all they can there, right, and with all that equipment, so that why we feel a little, right? But we know that he's being taken care of, but we feel a little scared. E9

This perception agrees with the perspective that ICU patients feel they are in a place for severe patients, which puts them closer to the possibility of death⁽¹⁰⁾.

In this study, salvation and the possibility of death are two related feelings that contrast with others, not so much in the sense of the location's oddness and specificities, in terms of physical and structural environment, but especially regarding having to face the life-death binomial, which causes uncertainties and challenges that relatives, patients, and staff have to face every day.

Concerns regarding the relative's care

In the statements, it is observed that family members notice the care the staff provides to their relative. Hence, distinct forms of noticing were described.

Some feel satisfied, hopeful, happy and even thankful for their care. That can be noticed in the following statements:

Oh! And when I got here I found she's well taken care of, right, thank God I know they're taking good care of her, right, we feel really happy about that. E2

(...) we even feel happy about their work because there are many thoughtful people, from the entrance and front desk to the doctors, nurses, the janitors, so what we want to do is to thank them. E16

On the other hand, only one interview included a statement that reports a complaint regarding the staff's service:

So I saw that the nurse, that little apparatus that they put in the nose with no care, it's not put in correctly, it's like this, there's a mark there, like it is pressing my mother's face, so I, I felt like she didn't have love or care for the, the ... a patient and not like ... the thing itself [...] E8

In other interviews, relatives presented their questions regarding the routine established in that sector in terms of companions' stay:

(...) we feel comfortable to stay close and we can't, right, because visiting hours have to be controlled, we can understand that, but we'd like to be close, all the time if possible (...). E7

This desire of being more present is meaningful to relatives, who believe that this is valuable to the patient, and that it even helps in their recovery, as stated by E7:

(...) I think that, for her recovery, for her improvement, family presence is just as essential as medication. E7

In this sense, relatives ask for another form

of visiting permission that is not always valued at the ICU, neither by health professionals nor by service management, who do not offer the necessary conditions.

The ICU is structured so that its physical structure and organization, including the way the staff works, reproduce the idea that the family is "one more thing", and is not incorporated as another focus of care.

Nevertheless, the present study shows that relatives wish to accompany, stay close to their relatives, which often reveals that, regardless of its importance, objective information concerning patient clinical condition and evolution is not the most important thing, but increasing the perception of "giving the information" to ease family members, taking their suffering into consideration, and meeting their specific needs, which include: getting information, being present, being listened to and being comforted. Finally, "what do relatives need?" This question should guide the daily work of health care professionals.

FINAL CONSIDERATIONS

Considering ICU's prevailing technical-biological world, it is understood that the location's routine, associated with the staff's lack of preparation to deal with existential issues, covers patient and family singularity, which during this unique moment live the reality of hospitalization.

An approach to these experiences of the relatives of ICU hospitalized patients can provide the support for health professionals to reflect on their practice, involving welcoming, incorporating relatives as an important focus of health care, with a view to surpassing the prevailing biologicistic model. This implies rethinking the relationship established with the family, and the work conditions, involving institutional management and policies, as well as professional training.

As mentioned before, relatives put themselves in the patients' place to get closer to their experience. This resource is just as effective to bring health care professionals closer to relatives: putting yourself in the place of others, valuing their experience as something unique, and understanding that each family has its own way of dealing with the situation of hospitalization.

It needs to be considered that, in ICU practice, moving away from the affective-relational dimension is a prevailing behavior. The relationship established with the family can be marked by standardization and authoritarianism. That is, there may, in fact, be some family-centered routines, like determining visiting hours and giving instructions, but they are formatted as a task to be completed with an authoritarian logic. This authority results from the staff detaining specific knowledge, founded on the clinical model.

This way of dealing with relatives agrees with the current perspective of founding health care on integrality, a guideline that has been used in the Single Health System (SHS). Highly specialized areas, such as ICUs, are part of this health system and, as such, despite their specificities, health care should not be reduced to technical-biological service, since it is not sufficient to deliver care to patients considering their complexity, but relatives need to be welcomed too.

However, providing health care from another perspective remains a challenge, involving the effective articulation of this space with other health care levels, besides reviewing the current health care model.

An essential point to qualify family care refers to acknowledging their subjectivity and importance in being near the patient. Hence, recognizing and valuing relatives' experience demands that professionals admit that, although family members are unfamiliar with the technical ICU world, they have their own knowledge and it is from that knowledge and experience that they assign meanings to that place, which represents a new space in their everyday life.

These questions imply rethinking the staff's responsibility towards relatives. However, workers of this ICU have not discussed or reflected on this theme. Moreover, when the theme is discussed for some reason, the logic of this discussion is still mostly normative and impersonal, and does not involve the distinct professional categories of the several work shifts.

It is also worth emphasizing that transforming actions involves not only discussions among health care professionals, but also aspects concerning institution and sector management. In addition, small changes regarding the everyday relational dimension should be inserted in the day-to-day. They will not suffice, but is the beginning of significant processes in the search to create a more humanized health care.

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