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SENSIBILITY OF PROFESSIONALS TO INFORMATION NEEDS: EXPERIENCE OF THE FAMILY AT THE INTENSIVE CARE UNIT

Anabela Pereira Mendes¹

¹ Ph.D. in Nursing. Professor, *Escola Superior de Enfermagem de Lisboa*. Lisboa, Portugal. E-mail: anabelapmendes@esel.pt

ABSTRACT: This study aimed to interpret, in the experience the family has at the intensive care unit, the sensitivity of professionals regarding their need for information. We held open interviews with 21 adults, family members of adults hospitalized in intensive care. The analysis and interpretation of the narratives, with the support of the software Nvivo8®, was undertaken in accordance with the phenomenological approach suggested by Van Manen. Two situations were found: the presence and absence of information. The family states that the sensitivity of the professional was essential in the response to their needs. The care taken in the content that it is transmitted and how it is transmitted were significant in the experience lived. Knowledge of the family's true and potential needs is decisive in the professional practice of nurses. Answering the need for information was essential in the transition process experienced in view of the family's member's health-disease.

DESCRIPTORS: Family. Information. Intensive care. Nursing.

SENSIBILIDADE DOS PROFISSIONAIS FACE À NECESSIDADE DE INFORMAÇÃO: EXPERIÊNCIA VIVIDA PELA FAMÍLIA NA UNIDADE DE CUIDADOS INTENSIVOS

RESUMO: Este estudo objetivou interpretar, na experiência vivida pela família na unidade de cuidados intensivos, a sensibilidade dos profissionais relativamente à sua necessidade de informação. Realizaram-se entrevistas abertas a 21 pessoas adultas, familiares dos pacientes que estiveram internados em cuidados intensivos. A análise e interpretação das narrativas, tendo como suporte o programa Nvivo8®, realizou-se de acordo com a abordagem fenomenológica sugerida por Van Manen. Verificou-se a existência de duas situações: a presença e a ausência de informação. A família refere que a sensibilidade do profissional foi determinante, na resposta encontrada às suas necessidades. O cuidado colocado, no conteúdo que foi transmitido e na forma de o transmitir, foram significativos na experiência vivida. Constatou-se que o conhecimento das necessidades, reais e potenciais, da família é determinante no exercício profissional dos enfermeiros. A resposta à necessidade de informação foi essencial no processo de transição situacional experienciado, face à transição saúde-doença do seu familiar.

DESCRIPTORIOS: Família. Informação. Terapia Intensiva. Enfermagem.

SENSIBILIDAD DE LOS PROFESIONALES PARA LA NECESIDAD DE INFORMACIÓN: EXPERIENCIA VIVIDA DE LA FAMILIA EN LOS CUIDADOS INTENSIVOS

RESUMEN: Este estudio tuvo como objetivo interpretar la experiencia vivida por la familia en la unidad de cuidados intensivos, la sensibilidad de los profesionales en cuanto a su necesidad de información. Se entrevistaron 21 miembros de familia del adulto hospitalizado en los cuidados intensivos. El análisis y la interpretación de los relatos, con el apoyo del programa Nvivo8® se llevó a cabo de acuerdo con el enfoque fenomenológico propuesto por Van Manen. Se encontró que hay dos situaciones: la presencia y ausencia de información. La sensibilidad de los profesionales yació significativa en la respuesta a sus necesidades. El cuidado en el contenido que se transmite y cómo transmitir fueron significativas en la experiencia vivida. El conocimiento de las necesidades, reales y potenciales, de la familia es decisivo para la práctica profesional de las enfermeras. La respuesta a la necesidad de información es esencial en el proceso de transición salud / enfermedad.

DESCRIPTORIOS: Familia. Información. Cuidados intensivos. Enfermería.

INTRODUCTION

The vulnerability experienced in view of a critical disease situation confronts the family with times of great instability. The people experience processes that designate transition, because of the impact they entail for their personal, family or social life.¹ The transition health-disease involves an acute or chronic register.

In view of the transition health-disease, the family discovers significant changes in its wellbeing, deriving from the situation, but also from the context it happens in. It is confronted with a disease process that it generally is not familiar with and a stigmatizing hospitalization context, because of the technology used and the conditioned access. It was verified that the family becomes a nursing client, due to the experience of this health-disease transition process and finds, at preset times access to the hospitalization unit and doubts that arise, the nurses' presence.²⁻³

For the family, daily life unveils a frightening unpredictability that always ends with the possibility of finiteness of the sick person. The context and the circumstances condition the rationality and give rise to new needs in the family's experience at the Intensive Care Unit (ICU).⁴

The existing relational and emotional register between the sick person and the family that person is part of tend to act as determining factors in the vulnerability found. The family emerges as "... something beyond the individuals and their blood bond, parenthood, emotional or legal relationship, including people who are important for the client, who constitute the parts of the group".^{5:171} The suffering experienced shows to be highly significant when there is a family bond. This situation becomes even more punitive when it is perceived that it is impossible to revert a whole situation that tends to get beyond control. They gradually perceive that their common ability to respond to and solve critical situations they are confronted with daily is limited and insufficient. They progressively learn to get to know the context, the situation and their current ability to respond.

When they get access to the hospitalization unit, the people in the family construct the possibility of making everything clearer and finding some comfort. They verify that some professionals, due to constant clinical practice with the patient and family members, are particularly attentive to the experience

they are going through. They search for the need to be informed, the contact with these professionals so as to allow them to gain some knowledge and thus achieve wellbeing. They feel that the possibility of being informed conveniently is a determining variable to take into account in the experience lived.

From their experience, the people preserve what granted them a particular meaning in the positive or negative sense, considering the way it affected them and how they let themselves get affected. It leaves a unique and characteristic register in a personal matrix that reveals itself in the meaning that emerges from it.⁶

Based on a research trajectory that was focused on the experience of adult people's family in view of internment at an ICU, the goal in this article is to interpret how the family members at the ICU experience the professionals' sensitivity to their information needs.

METHODS

In view of the intention to get to know the family members' experience, this study fit into a qualitative paradigm and a phenomenological approach. The phenomenological approach according to Van Manen was chosen as, in that perspective, "the experience lived is the starting and end point of the phenomenological research".^{7:36} The researcher should always develop and rest the analysis and interpretation on the data instead of previously known theoretical constructs.⁷

It was verified that the intentional return to the experience through the resulting descriptive narrative was the kernel of the study, because of the possibility to reach the essence of the experience.⁸ According to the author who is the methodological reference for the study, it was consider that "the goal of phenomenology is to transform the experience lived into a textual expression of its essence (...) the text is at the same time a reflexive reliving and reflexive appropriation of something significant: a concept through which the reader is powerfully animated in his/her experience lived".^{7:36}

The participants (N=21) were indicated using the snowball technique. The following inclusion factors were defined: 1) being a family member of an adult hospitalized at ICU; 2) being over 18 years of age; 3) having visited the person at the hospital at least once; 4) understanding and talking Portuguese, English or Spanish. The observed or reported

physical or emotional instability of the possible participant was considered an exclusion criterion.

People between 23 and 58 years of age were interviewed; 16 women and five men. Among the participants: 20 were part of the traditional family nucleus (parents and children) and the extended family (expanded family with different generations) and one of the participants was a significant element (boyfriend).

The data were collected using interviews with open questions, considering the referral orientations.⁷ The interview with open questions "permits exploring the experience-based narrative" and makes possible to "talk about the meaning"^{7:66} of one's experience.⁹ Thus, the participants were asked the following guiding question: Tell me about your experience of having a relative hospitalized at an ICU. Twenty-one individual interviews were held with adult family members of an adult person hospitalized at an ICU. The mean length of the interviews was 60 minutes and they took place at a location the participant suggested, most frequently the family member's house.

Permission was requested to record the interviews and they were transcribed verbatim. The use of the support software Nvivo8® was considered fundamental to organize and analyze the data, in view of their length.

The interviews took the form of a registered conversation with a view to allowing the participants to freely discuss their experience. The resulting descriptive narrative permitted reaching the subjectivity of the human experience, its meaning.⁸ Hence, the experience is "the breathing of the meaning (...) has a certain essence, a 'quality' we acknowledge retrospectively"^{7:36}

The decision to participate in the study should be based on detailed and consistently transmitted information, in view of the possibility of clarification and validation. The possibility to drop out of the study at any time was clearly informed, if the person decided so, thus guaranteeing the participant's autonomy. The document of consent to participate in the study, signed by the participant, was made available in advance whenever possible for the sake of gaining familiarity and making a decision comfortably.

The participant's availability and the possibility to conveniently obtain audio records were taken into account when programming the place and time for the interview. In the course of the interview,

the person's vulnerability was considered, making the researcher adopt an attentive and responsible position with regard to the tone of voice and posture. Thus, the researcher's ethical sensitivity was revealed. It was verified that each of these persons is another "sufferer".^{10:266}

In those situations in which the hospitalized person had deceased, the interview was held only 90 days later.¹¹ The family member should find physical and emotional stability to intentionally revisit the experience lived.

The data analysis was aimed at revealing or isolating the themes that unveil the research phenomenon. Thus, the text or produced narratives were approached, using the holistic or sententious approach, the selective or highlighting approximation and the detailed or line-by-line approximation.⁷ It was of interest to "reflect on the essential themes that characterize the phenomenon" and "describe the phenomenon through the art of writing and rewriting"^{7:32}

The participants' confidentiality and anonymity were guaranteed, coding each of the narratives from 1 to 21, preceded by the abbreviation FM (family member).

In the ethical evaluation of the research procedures, the responsible committee guaranteed and verified that the study complied with the ethical research principles.

RESULTS

In daily and close contact with the professionals, in view of the need to be informed or get the possibility to clarify their doubts, the family members are particularly sensitive to the way they are welcomed. They verify that the professionals perceive their presence and intention, but they consider that the response they get is related to the professional's sensitivity.

They understand the need for the professional to be regular and constantly present at the sick person's side, but verify that certain professionals also understand and accept the family's needs, resulting in the experience of transition health-disease they are going through. For these professionals, according to the family members interviewed, it is natural for the family to need information, knowing that information grants them distinct feelings in view of its content, quantity, pertinence and transmission made. They reveal that, the content of the

information and the way it was transmitted being fundamental, they exerted determinant influence on the experience.

In the presence or absence of information, they find the professional's sensitivity direct or indirectly, considering that what they transmit or not reveals a bit of what they are or are not. The professionals are thus assumed to be the final link the information goes through, depending on whether they take care with what arrived and how it reached the family member. Thus, they considered the vulnerability in the presence and what would result from their intervention.

Then, three dimensions were listed for interpretation, in the sense of understanding the way they influenced the experience, that is: the information content; the way the information was transmitted; the absence of information (Figure 1). In each of them, the professional's sensitivity to the vulnerability of the receiver and his/her information need was considered.

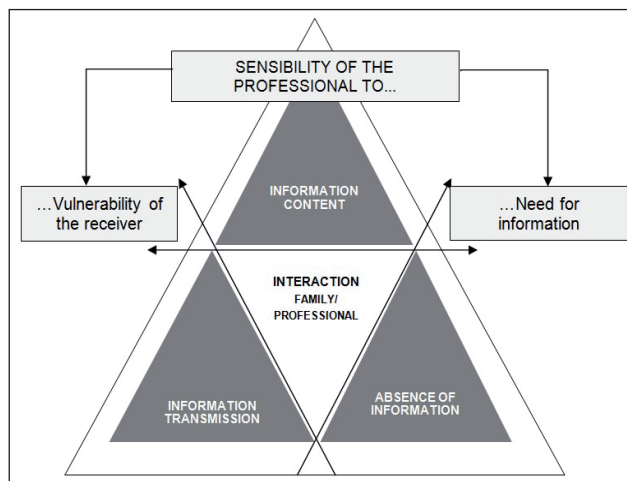


Figure 1 - In the information: the dimensions found and the perceived sensitivity

Each of these dimensions is addressed now, aiming to understand the sensitivity the family perceives in the professionals regarding their need for information and the vulnerability they experience.

The information content

In daily life, the people in the family were confronted with a series of doubts related to the diagnosis, prognosis and therapeutic and diagnostic interventions. When they had access to the hospitalization context, they tried to contact the professional responsible for taking care of their relative to get

concrete and true information. The need for information mobilizes the people in the family. The need to get information, in view of the constant and close experience of the unknown and persistent doubts, ends up gaining meaning in the experience lived

The length of experience showed to them that, independently to their expressed need to know, the response to their need significantly depended on the professional they had contact with. Their initial indicators were the professionals' availability and initiative for this to happen: [...] *we start to perceive who is available or not to give us information, sometimes through the people's attitudes [...]* (FM12); [...] *I got in and soon there was a nurse who was treating her that day, in that shift. Even without asking, there was initiative on that side to more or less establish the situation. They said 'She's already had a bath, we turned her over, we did, we massaged, we changed the catheter from this to that side [...]*' (FM9).

Two very different situations are experienced with regard to the content. They perceived that, for certain professionals, the information is assumed in a structured way and periodically verified: [...] *it was important to inform us of the situation, and we noticed from some professionals that that work was done... almost as a team, they said: 'look tomorrow we're going to do the lift', that served as motivation for the patient and us relatives, to be informed of the process [...]* (FM2)

Nevertheless, their expectation that the content to be transmitted would be detailed, extensive and up-to-date was not always verified. They reveal that this situation was embarrassing, as they did not perceive why this happened. They verified that it was hard to accept that what was happening and what they intended to do was not always specifically described to them. They reveal that this posture hampered a transition process health-disease. In view of these professionals' continuing experience with families in identical situations, they believed that they were able to receive, accept the presence and the needs of the family member whom they interacted with direct and indirectly. They disclose that it would be comforting for the information to go beyond the barrier of superficiality, of the lightened discourse, which was greatly due to the humanized care they wanted: [...] *the nurses were superficial. They did not go deeper, they made us understand if she had been good or bad and whether the night had been complicated or calmer. They did not elaborate any further* (FM15).

In these situations, they felt that they tended to assume a register of continuous presence and great

insistence. When they were granted access, they intended to join small pieces of information. They intended to acquire the parts in order to appropriate themselves of the whole.

At certain times, the sensitivity they found in the nurses was reduced to sympathetic welcoming. They felt that it mattered to take into account their professional duty in their actions, in the sense that the information was considered necessary and fundamental. They found that it was important for the professionals to allow themselves to prepare and comfort through this intervention. It mattered to answer in line with their needs, considering their knowledge of the family and the transition process health-disease that involved them: [...] *they don't know what it is that we already know... sometimes they treat us as if it were the first day ... they know we're here every day and that, probably, if they talked a bit more to us they would know... that we knew a bit more about the disease [...]* (FM4).

The information transmission

According to the family, the ICU internment and the critical disease situation experiences should be considered in the way the news is transmitted. They considered that this sequence of situations tends to weaken the family and conditions its ability to receive. It mattered to inform, without ever ceasing to comfort. They verified that they received care through what was said to them, but also through how it was said: [...] *as time went by at the hospital, we noticed that care was taken in the information that was given... when we addressed the physician on duty or the nurse, they were greatly available in the information they transmitted... in a way they tried to give some relief, some support, with some reservation, which the situation itself implied [...]* (FM1); [...] *on the day I arrived at the intensive care, it was fundamental, it made me feel very confident in that team that was there, but undoubtedly some information. I think that, in intensive care, the way it is transmitted, what is transmitted is important [...]* (FM2).

Nevertheless, the people in the family assume that, for some professionals, the response to the information need boiled down to the set of words to pronounce. In the triad: issuer, receiver and message, the receiver of the message was not considered, in view of his present vulnerability and the anxiety the arrival of the information could cause. In this register, they verified that the issuer disclaim any responsibility in care for the other, the receiver. It

was verified that the lack of engagement or compassion for the family members when they receive particularly negative news revealed to be particularly significant in their experience. As they refer: [...] *she comes in, comes close to us and says, 'It's like this, your daughter has got leukemia', like that without any further detail [...]* (FM5); [...] *there was no magical powder... there was nothing it's right to the bone, the naked truth is that, and it's like that, assimilate the information as you like it.... She was very harsh, there was no room there whatsoever for anything else but the truth* (FM7).

They considered in the information that reached them the way it affected them. They report the professional's sensitivity in saying what needs to be said. They mention it rude and rushing way of how they do this. Although they openly prefer the truth, what matters is that the way it is said is taken into account in the content.

The absence of information

They perceive that the impact certain information exerts on them tends to be overcome by the possibility that they know nothing. They indicate that it was complicated to cope with the unknown, with the return home without a prediction of facts and events. The possibility of not finding a space, a time in which the professionals consider their need to be informed was particularly burdensome. The discomfort results from what they do not know, knowing that someone probably knows but does not consider the need to inform them. They probably do not know the importance of this information in their experience: [...] *what is even worse is when they do not inform us that all will go well or not, or what is going on, at least for me it was complicated [...]* (FM12); [...] *not knowing what was happening was the harshest... there was something there... the very strong, strongly installed bacteria [...]* (FM21).

They consider that the absence of information they are subject to clarifies that the family gains a different emphasis that clearly is not central in the care planning and, in the case, in the care that is due. They somewhat sadly consider the position they are in. In a broader team context, they perceive that they have no space in the dynamics met thus far: [...] *I experienced a lot of difficulty to get information. I have no idea how many people are there, many, but the relatives are quite forgotten, they give no information [...]* (FM16).

In comparison, in the cases in which that happened, that is, in which the possibility of being informed was attended to, they considered the

situation very positive. They acknowledge feeling weakly comforted by the possibility of knowing and questioning: [...] *they explained the severity of the situation very well, but they had somewhat lengthier talks with me [...] (FM9); [...] there was always plenty of information, plenty of monitoring, always very sincere conversation, a lot of opening... they invited me in and explained everything to me [...]* (FM10).

The perceived sensitivity emerges from the experience lived: in the professional's responsibility to inform; in the content transmitted; in the way it was transmitted (Figure 2). Based on the above, it was verified that the perceived sensitivity found in the team promoted the family's wellbeing and influenced the experience of the transition process health-disease.

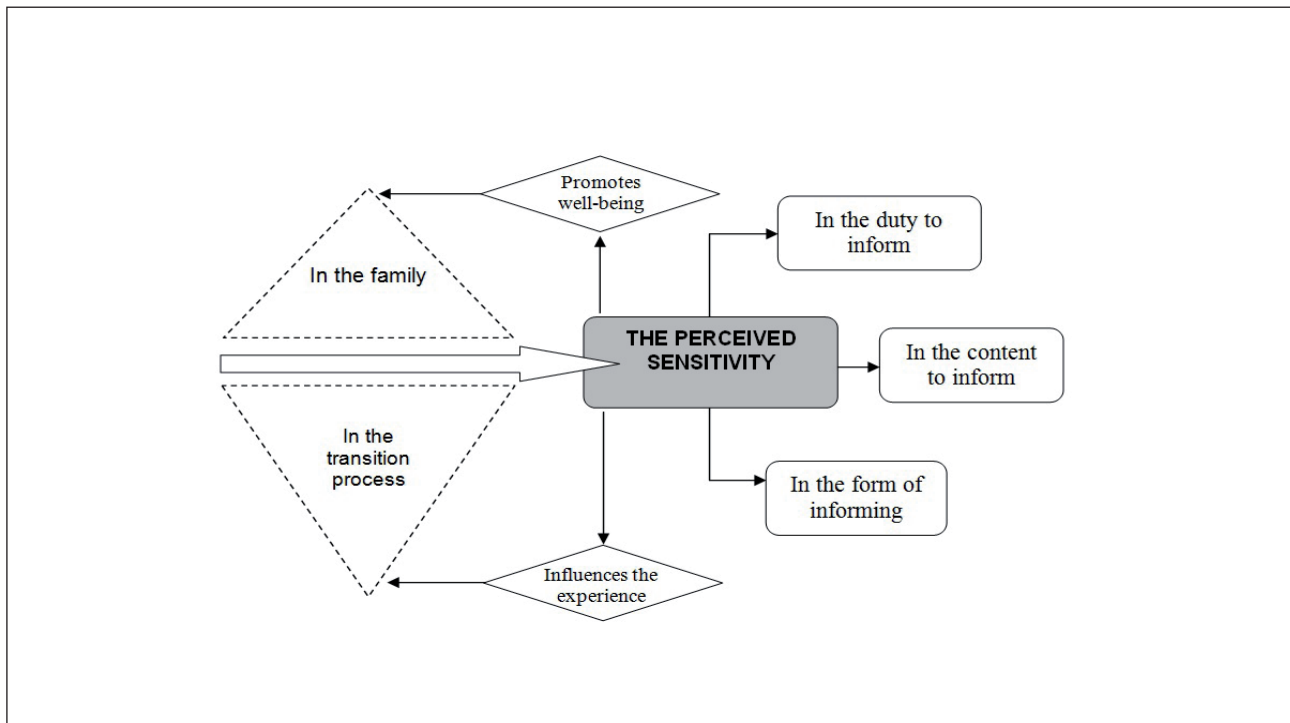


Figure 2 - The perceived sensitivity in the response to the information need

DISCUSSION

It was verified that the people in the family suddenly deal with the internment of one of its members at an ICU. They experienced the arrival of the information and what this offered them, namely the contact with the unknown, with the doubt, with the inability to be emotionally stable in their daily life. The situation and the circumstances of having a relative in this specific context makes them feel vulnerable.^{6,12} The team should be particularly attentive to this situation, considering that the communication between professionals and family grants support to the latter.¹¹⁻¹⁴

As perceived, the interaction established, whenever it rests on the intention to facilitate the experience, was considered as fundamental support for the wellbeing of people on the team and people in the family. In practice, it is assumed "what it

means to be a nurse from the perspective of our obligation and our commitment to the people".^{15:33}

It was verified that the experience, which leaves a register in the present, is extended and reflected in people's lives in both domains: individual and collective. The moments following the experience of the critical illness and internment at the ICU reveal significant physical and psychological disorders in the family.¹⁶

The people in the family recall the initial moments and the continuing experience of entering the hospitalization unit, the information whose content was frightening, or the absence of information. A set of determinants is verified, for which they are not prepared, making the people in the family experience moments of great physical and mental exhaustion. During the information moments, they perceived that what reached them revealed the

person's sensitivity, whether the register was more superficial or more detailed. Their vulnerability was revealed in the words.¹⁷⁻¹⁸ They considered the truth that gave body to the message essential and the concern with an updated message. The veracity of the answers plays a determinant role for the family members.¹⁹

The people in the family who were interviewed also felt the care in the choice of the words, the place, the tone of voice, a set of determinants that considered the condition of the person who receives it in a very particular way. Thus, the professional's responsibility emerged in a very sublime way. Assuming that only a responsible professional permits taking into account the vulnerability of the person one interacts with. The nurses' contribution can be irreplaceable due to the proximity with a very significant number of people, with distinct needs and abilities.²⁰ What matters is for them to be particularly sensitive and attentive to situations that by themselves generate great vulnerability.^{13,20}

In the repeated and continuous access, the family believes it starts to be acknowledged as a significant "element" of the person hospitalized. This event is not confirmed when they verify their information need or care in the way it is transmitted are not attended to. They assume that their existence in the sick person's life is not considered. Hence, what matters is perceiving that "any care situation is by itself an anthropological situation in which men and women are the epicenter, inserted in their network of life habits, beliefs, affective, financial, social resources, the way they react".^{20:148} Knowing that, in many situations, the person is "turned into an object and removed from the bonds of symbolic significance that mark his existence".^{20:148} The family wants the sick person and the family in which (s) he constructed a daily life process to be taken into account.^{4,21}

The possibility to understand what happened to their relative allowed them to adapt and prepare for future events, even if often superficially. The way they are welcomed and the way the information was transmitted to them allowed them to find some tranquility in the care team. In that sense, they are listed as an essential resource in the transition health-disease that is experienced. The nurses take a privileged and appropriate position in the access to the people's physical and emotional needs during the transition process.¹ They are often referred to as facilitators in the experience the person and family go through.^{1,21}

As verified, the family members were faced with two distinct situations, the presence or absence of information. When the information was present, the content and transmission form made a difference. The attempt to respond to their needs exists, although not cross-sectional to all professionals' practices, specifically the nurses'. It is assumed to be intentional, lacking investment in view of its influence on the experience.²²⁻²³

The development of studies focused on the experience permits incursions through determining aspects. The fact that the narrative comes from the nursing care client is listed as a core aspect in the study of the family members of adult patients hospitalized at the ICU. Thus, as opposed to studies in which only the process can be analyzed, the experience of the process can be analyzed here. Thus, a concrete person can reach the meaning of the experience.

As verified, the meaning of the experience mainly emerged from the expectations created regarding the response to their needs and to the evolution in the clinical situation of the sick person. It reveals the continuous and continuing encounter of the family member with the care team and very closely with the nurses. It is considered that these study results will help in contexts similar to a reading of the nurses' interventions, in the sense of understanding how they facilitate the people's experience, namely how they support the meaning the person attributes to the experience.

The development of studies in which the current and future nurses' competence to respond to the information needs are monitored would be fundamental. This would imply covering a set of knowledge and an attentive look on what the professional duties are, namely the understanding of the person to experience a certain transition process. It is agreed upon that "a safe and effective practice implies that the current nurses understand a broad set of knowledge that range from pathology to physiology and the genome; from pharmacology to biochemistry... just like from the human experience to the disease [...] in the sense of defending and transmitting the fundamental values of the profession, preserving the people's safety and mitigating the human suffering".^{24:1-2}

CONCLUSION

In view of the need to get information about the adult sick person hospitalized at the ICU, the family

members discover that the answers found do not always correspond to their expectations. In response to this adversity, several intervention strategies are developed. One of the strategies was to be attentive to the professionals who, depending on their availability and initiative, permitted their access to a set of detailed, concrete and true information. Thus, they allowed themselves to know what was expected and, as such, prepare themselves predictively.

It is verified that, progressively, people in the family get to know the context and the professionals. They perceived that certain professionals were concerned with responding to their information need and, among them, some took care of the information content and made sure of the way it reached the family.

They verified that, beyond the content, the way it was transmitted granted them some wellbeing. They perceived that, beyond the words, the tone of voice, the availability, the initiative perceived and found made the difference. Thus, the verbal and non-verbal languages were partners and determinant factors in the professionals' intervention.

In an advanced nursing register, it is verified that the response focused on a diagnosed need will only produce an outcome when, beyond this need, the person who manifests it or reveals it is considered. It is considered that the issuer – professional – issues and lets it reach the receiver – family member – takes a lot of himself, namely the way he was willing to interact. His sensitivity for the interaction – the way the interaction occurred and what was left in the interaction – did not go by unnoticed to the people in the family. That is how they found and perceived the way each professional facilitated or not the health-disease transition process experienced.

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Correspondence: Anabela Pereira Mendes
Escola Superior de Enfermagem de Lisboa
Av. Professor Egas Moniz, 1600-190 Lisboa, Portugal
E-mail: anabelapmendes@esel.pt

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