RESEARCH | PESQUISA

Uncertainty in critical illness and the unexpected: important mediators in the process of nurse-family communication

A incerteza na doença critica e o imprevisto: mediadores importantes no processo de comunicação enfermeiro-família

La incertidumbre en la enfermedad crítica y lo imprevisto: mediadores importantes en el proceso de comunicación enfermero-familia

Anabela Pereira Mendes¹

ABSTRACT

¹Escola Superior de Enfermagem de Lisboa (ESEL), Unidade de Investigação & Desenvolvimento em Enfermagem (UI&DE). Lisboa, Portugal. Objective: The purpose of this study was to understand, based on the Mishel's Theory of Uncertainty in Illness and the Theory of Transitions of Meleis, in which way uncertainty in illness and the unexpected mediated the process of nurse-family communication and are translated into lived experience of the family. **Method**: Considering the intentionality of the research, it fits into a qualitative paradigm and a phenomenological approach, according to Van Manen. Participants were referred to as "snowball" and the data collection was performed by interview with open questions. **Results:** In the analysis of the data, three essential themes were identified: The antecedents of uncertainty: condition inherent to the subject; The process of assessing uncertainty: capacities and opportunities; The way to deal with uncertainty: coping strategies. **Conclusion and implications for practice:** Family member who lives the uncertainty has personal conditions that influence the process of appreciation and deal with uncertainty. The communication that establishes with the nurses, in particular in the search for information, will be mediated by the experience of uncertainty, in a constant unforeseen. The adaptation that is desired and demanded arises from coping strategies developed, with the nurses too, considering uncertainty a danger or an opportunity.

www.scielo.br/ FAN

Keywords: Family; Uncertainty; Transitional Care; Patient-Centered Care.

RESUMO

Objetivo: Este trabalho teve como finalidade compreender, tendo por base a Teoria da Incerteza na doença de Mishel e a Teoria das Transições de Meleis, o modo como a incerteza na doença e o imprevisto mediam o processo de comunicação enfermeirofamília e se traduzem na experiência vivida da família. Método: Considerando a intencionalidade da pesquisa, enquadra-se num paradigma qualitativo e numa abordagem fenomenológica, de acordo com Van Manen. Os participantes foram referenciados em "bola de neve" e a recolha de dados foi realizada por entrevista com questões abertas. **Resultados:** Na análise dos dados, identificaram-se três temas essenciais: Os antecedentes da incerteza: condição inerente ao sujeito; O processo de apreciação da incerteza: capacidades e oportunidades; O modo de lidar com a incerteza: estratégias de coping. **Conclusão e implicações para a prática:** Constatou-se que a pessoa, membro da família que vive a incerteza, tem condições pessoais que influenciam o processo de apreciação que estabelece com os enfermeiros, nomeadamente na procura de informação, será mediada pela vivência da incerteza, num imprevisto constante. A adaptação que deseja e procura decorre das estratégias de coping desenvolvidas também com os enfermeiros, considerando a incerteza um perigo ou uma oportunidade.

Palavras-chave: Família; Incerteza; Cuidado Transicional; Assistência Centrada no Paciente.

RESUMEN

Objetivo: Este trabajo tuvo como finalidad comprender, teniendo como base la Teoría de la Incertidumbre en la enfermedad de Mishel y la Teoría de las Transiciones de Meleis, el modo como la incertidumbre en la enfermedad y el imprevisto medían el proceso de comunicación enfermero-familia y se traducen en la experiencia vivida de la familia. **Método:** Considerando la intencionalidad de la investigación, se enmarca en un paradigma cualitativo y en un enfoque fenomenológico, de acuerdo con Van Manen. Los participantes fueron referenciados en "bola de nieve" y la recogida de datos fue realizada por entrevista con cuestiones abiertas. **Resultados:** En el análisis de los datos se identificaron tres temas esenciales: Los antecedentes de incertidumbre: condición inherente al sujeto; El proceso de apreciación de la incertidumbre: capacidades y oportunidades; El modo de lidiar con la incertidumbre: estrategias de coping. **Conclusión e implicaciones para la práctica:** Se constató que la persona, miembro de la familia que vive la incertidumbre tiene condiciones personales que influencian el proceso de apreciación y lidiar con la incertidumbre. La comunicación que establece con los enfermeros, en particular en la búsqueda de información, será mediada por la vivencia de la incertidumbre, en un imprevisto constante. La adaptación que desea y busca deriva, de las estrategias de coping desarrolladas, también con los enfermeiros, considerando la incertidumbre un peligro o una oportunidade.

Palabras clave: Familia; Incertidumbre; Cuidado de Transición; Atención Dirigida al Paciente.

Corresponding author: Anabela Pereira Mendes E-mail: anabelapmendes@esel.pt

Submitted on 03/03/2019. Accepted on 06/11/2019.

DOI: 10.1590/2177-9465-EAN-2019-0056

Escola Anna Nery 24(1) 2020

INTRODUCTION

The concept of family is closely related to the concepts of linkage, proximity and group. We can note that the individual dynamics is recorded in a group exercise. From the perspective of Alarcão¹ it is important to see the family as a whole, but because of the elements that constitute it, that make it single and confer it particularity. It is in this joint experience, in which they experience transitions that can prove to be processes of happiness or enormous restlessness.

People live significant processes, which Meleis, Sawyer, Im, Messias, & Schumacher² call Transition, due to the impact that they generate in their personal, family, communitarian or social life. The transition, as a process and what results from it, can be of situational, developmental, health-illness or organizational type,² they are presented in a cumulative and/or sequential way. They may be foreseen, such as the birth of a child and the emergence of parental role, but may be triggered by unforeseen events such as a diagnosis of acute or chronic illness. In the particular case of Health-illness transitions, namely acute illness, it has associated with it the idea of interrupting the life process and uncertainty in the face of the response to therapy. The unpredictability of facts and events generates restlessness in the exercise of daily life that they know and dominate. Being associated with any phase of its life cycle, the situation of critical illness emerges suddenly in the daily life of the family and reveals itself as transition because of the weakness experienced. From Mendes' perspective³, the acute illness conditions the way each family member feels and acts, since they tend to focus their concerns and focus of attention. It weakens them in a particular, individual and collective way.

Aware of the peculiarity of the whole, but essentially of the peculiarity of each of their elements, it is necessarily important for the nurses how the situation affects them. It implies perceiving how they identify themselves in daily life with the ill person, the way they know each other and are significant.⁴

The suffering experienced by the persons and families is considered to be mediated by the more private or more social life contexts, to which they belong and in which they participate, it does not occur separately or in off mode.⁵ Meleis and collaborators² propose that in the construction of the therapeutic intervention, we analyze in details the factors that can make all the difference in the experience lived by people. It is important centralizing the care in the sense of minimizing the suffering by the families, knowing that at every moment they are put to the test, are called to deal with the human weakness and to answer accordingly, in the sense of adaptation, of subsistence and of growth, until a new test of strength, with more uncertainties and more unforeseen presents itself to them.³ In this sense, one assumes that the family's involvement in the nursing therapeutic intervention is crucial, making room so that the uncertainty becomes more discussed and little present in the experience. It is considered that nursing interventions should focus on "the processes and the experiences of human beings during the course of transitions, in which health and the well-being perception are the results/gains".^{6:257} It is recognized that in the daily interaction in clinical aspect, nurses may be one of the facilitator conditions in the experience of this transition process by the family ⁷, namely relating to a critical illness situation.^{8,9}

Assuming that the nursing intervention can and should be a facilitator condition in the health-illness transition process, this became interesting to understand from the family's narratives how the uncertainty in the illness and the unexpected mediate the nurse-family communication process and translate in the family's lived experience.

LITERATURE REVIEW

In the face of having someone critically ill nearby, the movement, so rapidly as possible, move the idea away. One perceives that only the possibility already disturbs. When, in unexpected moment, the possibility of critical illness comes true, the pain that has been thought to be felt is now unbearable. The new generates new news, which simultaneously generate more uncertainties and more suffering for what is known and what is not desired to know, in a constant unpredictability.

In this new reality the person, as a family member, constructs a proximity, with possible sources of information, that support a clinical knowledge that they believe they have and in the proximity they now have with their relative.¹⁰ They search, in moments of communication with nurses, who perceive their needs and find in their potential knowledge of intervention, they intend to become a client and care context.¹¹ From Harrison's perspective ¹², the relationship between family and health professionals is the nucleus of family-centered care, considering the family as a partnership in providing health care.

Uncertainty in the illness is defined by Mishel^{13,14} as the inability to infer the meaning of the events that emerge from the illness process, associated with the cognition limitation, to skill, to physical and emotional load, to structure, organize or foresee, relatively to what is presented to the person.

It is noticed that family members who experience the hospitalization in intensive care, namely for the first time, requires the nurses to give them a greater attention, considering the changes found and the sequelae that can emerge from then on.^{15,16} It is noticed that when the family find answers to their needs, it develops a huge skill to manage the situations that arises namely with coping strategies.¹⁵⁻¹⁷ the coping concept reveals itself, in the thought of Merle Mishel^{14,18} and Afaf Meleis and collaborators², always associated with the exercise of "dealing with". For Mishel¹⁹ it is important to deal with the uncertainty in the sense of adaptation, as a final state, that enables the realization in a personal matter, by acquisition of balance. For Meleis and collaborators² it is important for the individual to

feel connected, to interact, be situated and develop confidence, thus arising what he identifies as indicators of (dealing with the...) process, in living transition processes. For both authors it allows the nurses to sustainable appreciate the client's stage in events that condition its certainty or capacity to respond. The essential point is the process and the result of the process, in a before and an after the experience.

One considers that high levels of uncertainty about the illness and anxiety, individually, may condition the family members' strategies of adaptation.^{17,18} Marques and colaborators²⁰ found that the moment of uncertainty by the individual is determinant. They evidenced that when listing it as a danger or an opportunity, through the information obtained, they seek to adapt through different strategies.²⁰ They assume that health professionals can act, "encouraging this adaptation, from interventions that favor the uncertainty reduction assessed as a danger", listing that the access to information is among the nursing interventions that most contribute to this.^{20: 5366}

METHOD

We considered as a strategy to analyze the family members' narratives aiming to study the family's lived experience. This study is included in a qualitative paradigm and in a phenomenological approach. For van Manen^{21:36}, "The lived experience is the start and arrival point of the phenomenological research point". One intends to "change the lived experience into a textual expression of its essence (...)".^{21: 36} From Davidsen' perspective ^{22:319} "the phenomenological methods are focused on the rich description of some experience aspects, described through the language".

In this approach, the concept of time, or time interval must be considered, since "...the lived experience has always a time structure: it can never be perceived as an immediate manifestation, but only reflexively as a past presence".^{21:36;23} It involves a retrospective and reflexive intention, considering Giorgi and Sousa^{24:64} that phenomenology "impels men to reflect (...) to develop a reflexive look [... to ...] describe this act of consciousness as much as possible". Benner, Kyriakidis, and Stannard¹⁶ consider that for a structured construction of nursing intervention, in accordance with the clients 'needs, nurses should invest in understanding the essence and meaning of the experience for the care receiver.

Van Manen^{21:30} propose a sequence of research activities that establish a close relationship with each other. Every one of these stages was observed in a logic and sequential way: "Turn to a phenomenon that interests you; Investigate the experience such as it is lived and not as it is conceptualized; Reflect on the essential themes that characterize the phenomenon; Describe the phenomenon through the art of writing and rewriting; Maintain a consistent pedagogical relationship to the phenomenon; Take stock of the research context, considering the whole and the parts". With the aim of understanding how the uncertainty in the illness and the unforeseen mediate the nurse-family communication process and translate into the lived experience of the family, two research questions were defined in the methodological design: How did the uncertainty in the illness influence the experience lived by the family in the face of a critical illness situation? How did the family deal with the uncertainty in the illness and the unforeseen in the critical illness situation?

Participants in the study were intentionally selected, considering the research purpose, the relevance of the cases $^{\rm 25}$ and their suitability. $^{\rm 26}$

The participants in the study were defined as family members of a person with critical illness who was hospitalized in ICU. For these participants four indicators were considered: Understand and speak Portuguese, English or Spanish; be over 18 years; have visited the person at the hospital at least once. Feel comfortable, physical or psychologically, to talk about the phenomenon under study.

Data collection began with a first interview under the researcher's proposal, in which the participant in knowing the purpose of the research, and finding a meaning in its carrying out, was able to refer other possible participants. ²⁷ Thus, the remaining participants were referenced in "Snowball" -Snowball.²⁸ Thus, an interesting and of natural diversity contacts network was constructed. 27 The contact and interaction with the possible participant took place after declaring availability and interest. The availability and comfort of the involved persons, participant and researcher were considered in the planning of the moment and place for carrying out the interview. 3 After being duly informed with regard to the study and what was requested as a participant, the voluntary acceptance to participate in the study be obtained in own document, named a statement of informed consent. This document assumes that the appropriate information has been transmitted, ensuring that the participant was able to understand and to deliberate and decide freely to participate, or not, in the investigation.29,30

In the ethical appreciation of the investigation procedures, the responsible entity (UCP) guaranteed and verified that the research complied, along the way, with the ethical principles regarding the research.

Intending to have access to the lived experience, Van Manen^{21:66} proposes the interview with open questions, considering that in the hermeneutic ["interpretative"] phenomenological approach, the interview with open questions "enables you to explore the experiential narrative" and provides the "conversation about the meaning" of your experience.

In this data collection record, by the detailed description inherent in the narratives, the possibility to compromise the confidentiality and anonymity is significant. Therefore, and to guarantee each one of these principles, the participant, source of data was always presented in a codified way [Family Member + Interview Number – Example: FM2]. Twenty-one individual interviews, with adult family members of adult person who had been hospitalized in an ICU were carried out. The average duration of the interviews was 60 minutes. Participants were between 23 and 58 years old, 16 women and 5 men. Of the total participants: 20 were from the traditional nuclear family (parents and children) and the extended family (family extended with several generations) and one of the participants was a significant element (boyfriend).

The recording interviews and transcribing verbatim were requested. It is assumed that the moment of collection is itself a moment of analysis. Cohen, Kahn, and Steeves^{31:74} state that the researcher as a person discovers in the listening exercise, the simultaneous exercise of codification and analysis, and mention that "the data analysis begins with the data collection". The use of Nvivo® in the organization, codification and data analysis was considered as essential, knowing its extension. This support allows the codification validation and subsidies the rigor of the process.

According to Van Manen²¹, a sequence of activities was respected. With view to codifying the data, approaches or approximations to the text or narratives produced, namely the holistic or sententious approach, the selective or highlighted approach and the detailed or line-to-line approach.²¹ It concerned "...to reflect about the essential themes that characterize the phenomenon ..." and describe it "...through the art of write and rewritting".^{21:32} It has been found that the approximation to data is essential and fundamental, when it is aimed to know the persons' lived experience who become or reveal nursing clients and it wants to ensure a centered care.⁸

In considering the lived experience, Cohen, Kahn, and Steeves³¹ mention that the phenomenological approach is centered in its understanding and reveals itself as pertinent in the investigation in relation to the nursing care in the different domains of intervention, namely of acute or chronic illness. They add, "The meaning that the persons give to a certain experience will make it possible to know the needs that arise from it and how to respond accordingly" Figure 1.^{31:4}

Figure 1. Methodological Design – The problem [phenomenon under study] and the answer to the research questions (Source: author of this article)



RESULTS

In a course of detailed data analysis it was intended to reveal by the lived experience, how the experience of uncertainty in illness and unexpected influenced individual and collectively the experience and which strategies emerged. Thus, we intended, from the data and supported by Mishel's theory of uncertainty in illness and the Theory of transitions of Meleis, to answer the research questions. Process obtained by listing the themes that unveil in itself the phenomenon under study.

It was found from the analysis and interpretation carried out that the conditions inherent to the subject who experiences the uncertainty and the interaction that establishes with health professionals, namely, with the nurses, are decisive. It can be seen that the uncertainty and unexpected are the motto for communication as a strategy, but may also limit the possibility of communication. It can be confirmed that the uncertainty in the critical illness and the unexpected mediate the communication processes and are many times responsible for its effectiveness or ineffectiveness. In this sense, we can note that the continued and fruitful communication with nurses, in a record of probability analysis and consistent information assumes itself as a facilitator factor in the lived experience. By contrast, the narratives reveal that ambiguity, doubt, lack of information or inconsistent or possible to be acquired by the subject, contribute to the maintenance or growth of uncertainty.

People reveal that the personal, community and social conditions influence the process and what results from it. In this domain, we identified three essential themes: The antecedents of uncertainty: condition inherent to the subject; the process of appreciation of uncertainty: skills and opportunities; the way to deal with uncertainty: coping strategies, Figure 2.

DISCUSSION

The three essential themes that emerge make you understand that the uncertainty does not arise out of the subject who experiences it or of the context in which it occurs. The aim now is to work each of the essential themes, moving on from seeing what the participants' narratives "says" in a phenomenological approach that incorporates the study.

Figure 2. The three essential themes: From uncertainty in illness, to appreciation and adaptation strategies (Source: author of this article)



The antecedents of uncertainty: condition inherent to subject

The person who experiences the uncertainty lived transition processes, namely, inherent to the life cycle stages, that interactively (re) defined it (re) and gave it an own identity. Meleis and Chick³² mention that the transition is a personal phenomenon, being that the process and the transition result relates to the definition and redefinition of the self. What each person brings to the uncertainty experience, in the situational transition process, faced with the health-illness transition process of its family member, influences how welcome the uncertainty, appreciate it and deal with it.¹⁸ In the antecedents of the uncertainty we found the motivation, the cognitive skills and the mechanisms that function as an stimulus. These components, as defined by Mishel and Clayton¹⁸, confer, or allow the person the ability to trigger the process, from the appreciation to decision making. Cognitive skill is "the individual ability to process information".^{18:59} They also mention, that it is from the stimuli that a person develops the cognitive skill and reaches the facts structuration. In experiencing the critical illness, the start point "compromises" this dynamic, since the weakness experienced conditions the cognitive skill, and consequently the information processing.

[...] a total despair... I couldn't speak or cry [...] (MF2).

[...] that was so a whirlwind of emotions inside my head that I was in shock...I was completely disoriented, it wasn't me [...] (MF3).

[...] I did panic ... it's something we never forget [...] (MF5). [...] the world fell on us ... it was a tremendous blow [...] (MF7).

[...] it was as if the ceiling crashed down [...] (MF8).

[...] my brain did not record anything, even nothing. She was talking to me and I could not believe it. I had to stop talking, stop listening, I had to calm down and mentalize myself... there was not a word that calm me down [...] (MF13).

[...] It is like a bomb that falls on our lap [...] (MF15).

[...] I was in shock... I walked around... I found myself in D. I don't know how I got there [...] (MF16).

Faced with the shock, the imbalance, the chaos ¹⁸, in that the disorganization is present and the reformulation is essential and positive ^{2,11}, the nurses guaranteed an effective presence along with the family members, acted in accordance with its theoretical and practical preparation, in the sense of being prepared and preparing. In the narrative of the participants one gets the perception that upon their arrival in the context, in the daily welcoming, were felt with emphasis by the team, because they were significant to the ill person. ⁸

Considering that this situation reveals itself in the daily a "time of crisis for the family"^{33:1} the communication achieved, moved by the uncertainty felt, reveals itself a facilitating condition in the face of the experienced transition. The team constructs in detail, and documents, the needs and the way of giving comfort. Their well-being achieved was significantly subsidized, when feeling that were estimated.^{10,11} The care of proximity, due to its centrality and individuality, enables some well-being and the creation of a therapeutic environment for the family.^{34, 35}

The process of appreciation of uncertainty: skills and opportunities

In the daily experience with nurses, the person as a family member creates opportunities to strengthen itself and be able to strengthen those who are significant to it. It takes to these moments its belief and culture, the inference of reality, but also its dream, the desire and the determination. In his appreciation, he gradually identifies that in the weakness the hope strengthens.

Family members find in the effective presence in the context of care, aspects that strengthen them physical and emotionally, enable them to the new unexpected and subsidize the opportunity of (re) construction ², in the sense that their resources are used as a starting point and enable to generate others. From Mishel's perspective³⁶, in addition to the diagnosis of critical disease or its severity, other situations present themselves and compromise the appreciation of the uncertainty namely the no clear explanation of therapeutic procedures or the no previous intervention in pain or discomfort. However, they add that, the greatest discomfort factor, that limits the appreciation of uncertainty, is the attempt to understand the clinical language, the technical terms used. They state that the "used language impairs a clear communication and the understanding of the events (...) the explanation relatively to therapeutic intervention will reduce the uncertainty, the fear and the lack of knowledge relatively to the nature of the used procedures". 36:163 It is noted that the concern of the team in constructing the communication with family arises as facilitator condition, because it trains and produce opportunities for appreciation of uncertainty.

[...] it was important for us to be aware of the situation

(...) we noticed with some professionals that this work was done [...] to make us aware of the process (...) to feel an integral part of the process [...] (MF2).

[...] having a sense of communication in its training is very important, to know how they will address people (...) they can study behaviors (...) in order to get a better approach [...] (MF6). [...] explained the seriousness of the situation (...) they had conversations with me a little longer [...] (MF9).

[...] there was always a lot of follow-up (...) there was always a very sincere conversation, much openness (...) they invited me to enter and explained what was going on [...] (MF10).

In its clinical exercise, the nurses find the continuing learning needs, which structures their thoughts. From Benner's perspective ³⁷:17, "learning to meet other persons in different conditions of vulnerability and suffering requires openness and a experiential learning over time". The family perceives that the communication they are seeking is that, which, in the immediate and by the continuity, enables them to appreciate the uncertain and the unexpected. Notes that the communication, inherent to human beings, should have a professional component, exercised with competence. Benner, Kyriakidis, and Stannard^{16:288} state that nurses are requested to have"... patience, understanding and high competence in communication, which includes active listening and a firm understanding so that the content can be simplified and updated in many ways to ensure the family's understanding". Mishel¹⁹ emphasizes that the exercise should be attentive and leaves some examples, namely that the uncertainty relatively to the effect of a drug therapeutic intervention for an illness situation, creates uncertainty relatively to the existence of a system. In this situation, the person will tend to question itself relatively to the symptom origin, whether it arises from the illness condition or it is

associated with the established treatment. It evidences that the therapeutic intervention should not be exercised with responsibility, in ensuring not to cyclically generate more uncertainty.¹⁹ The uncertainty appreciation phase is capital for the person, living with hope its presence, in the health-illness transition process.

The way to deal with uncertainty: coping strategies

The appreciation of the uncertainty makes it apparent that strategies are being sought to give it some sense. The stimuli, such as want to know and want to participate, strengthen the persons's characteristics to use its cognitive skill and to connect the facts. In this sense, it develops strategies that overcome its daily exercise towards adaptation. One defines adaptation as "The process and the result of physical, biological and psychological changes of an organism or a population to adjust to some environment."38 Coping strategies, which look for clear information from enlightened and affectionate informants, leave the possibility of facing the uncertainty, safeguard the unexpected and be attentive. So, allow them to find any mastery in the health illness transition ², comfort themselves, giving space to live their spirituality and their emotions. Mishel¹⁹ states that if the coping strategies used are effective, the adaptation occurs. She contextualizes, by exposing, that if signs of difficulties are present in the adaptation, they are not due to the uncertainty in itself, but to the skill of the coping strategies to deal with the uncertainty towards the desired direction, that is "reduce it if it is considered a danger or maintain it, if it is considered an opportunity".^{19: 256}

In the narratives, there are strategies such as the search for strategical information, with some professionals, the discussion about the situation in family to situate themselves and find affection and the effective presence to be attentive. They find that the strategies have to be constantly redefined since the adaptation not always is achieved. The uncertainty is simultaneously considered as a danger and an opportunity, which worries them, but turns from the interaction and partnership in the experience.

[...] the doctor on the day I arrived at the IC, was essential, also gave me much confidence in that team that was there, but undoubtedly the information ... it is important how it is transmitted, what is transmitted, everything that concerns the information [...] (MF2).

[...] I was talking to the nurse... he saw my suffering ... And I got better with that time I was talking to him [...] (MF3).

[...] I arrived there, I asked, I wanted to talk with the doctor who was on duty or the nurse who was responsible for her and clarified my doubts so that when her parents arrived there [...] (MF6).

"My son would go, when...I told him: "Son, we needed to know more information" ... he would go there many times without me knowing how to talk to the doctor [...] (MF8).

[...] we began to perceive who is or not available to give us information, sometimes through the persons' attitudes [...] (MF12)

[...] the visits are like this, I go, the father goes, the sister goes and nothing else, the closest family, and we transmit, that's what we did [...] (MF14).

[...] best of all was I have had the communication that I had and let me be to hear and see what they were doing [...] (MF18).

[...] it became someone with whom we were venting. It established itself a relationship [...] (MF19).

The family, focused on the intention of misaligning the uncertainty, assumed a position of taking-for-yourself or declining, immediately, a strategy that had defined as correct. The constant of the ill person, and the other family members, requested to define by the cognition what actually qualified it to deal with the uncertainty. Health professionals can be a facilitator condition in the experience, by the information transmitted and by the communication achieved.^{8, 10, 11} Mishel^{19:} ²⁶¹ states that "when the family and health professionals support a probabilistic view of the life and the illness, the recognizing of the uncertainty removes a barrier to the confidence. The perception that the uncertainty is an unavoidable part of the reality can motivate persons to work in the creation of reliable relationships and mutual support needed in a world where nobody can have a right or definitive answer". Health professionals namely nurses, acted focusing on the care centered in an experience that one knows as complex and distressing. ³⁹ This implied a human care that provide, and ensure, the particularity in accepting and living with the uncertainty in the illness, while danger and opportunity.^{8, 40-42}

FINAL CONSIDERATIONS AND IMPLICATIONS FOR PRACTICE

It aimed to understand from the family's narratives, how the uncertainty in the disease and the unexpected mediate the nurse-family communication process translate themselves in the lived experience of the same. The placed investigation questions revealed themselves as important and interesting. The methodological option was coherent with the purpose of the study, such as the participants' selection, who being intentional considered the relevance of the cases. It aimed at obtaining a set of expressive and consistent data, in order to answer the investigation questions.

The diversity of data sources and characteristics required a careful intervention in analysis and coding, always attentive to selected methodological theoretical framework.

The significant number of family members with whom they spoke produced a set of data that clearly allowed identifying three essential themes: The antecedents of uncertainty: condition inherent to the subject; the process of appreciation of uncertainty: skills and opportunities; the way of dealing with the uncertainty: coping strategies.

The uncertainty reveals itself as present, frequent, a danger and an opportunity. The Mishel's and Meleis's and collaborators' theoretical frameworks enabled us to understand in the face of a health-illness transition process, the family's situational transition, where the personal conditions, the constructed skill and the defined strategies influence the sense of adaptation.

Health professionals, namely nurses, have shown themselves to be decisive for the professionalism that embodies a fundamental human component. They considered, in the proximity care, the uncertainty in the illness and the constant unforeseen. They realized that mediate, soon they influence positive or negatively, the communication processes initiated by the family member, or by the nurse. The uncertainty, accepted by all as inevitable, calls for a careful vision to delimit it, with clear and reliable strategies, defined by and for all the involved persons. In this sense, the information, which has perceived to be decisive, when clear and understandable, enables the person's cognitive organization, the appreciation and the dealing with the uncertainty and, in the limit, the adaptation.

In the face of the results, it is important that nurses, who work in the daily with the person's family in situation of critical illness, reflect based on the concept of uncertainty in the illness. The Merle Mishel's theoretical framework must be mobilized to support the nursing thought structuration. It was found that its use in partnership with Afaf Meleis's transitions theory was a valid and interesting strategy, which enabled to analyze concepts such as coping and adaptation. In that way, it is possible to perceive the actual family's needs to live a transition process and know which nursing interventions emerge as facilitators in the experience, namely faced by the illness uncertainty.

The access to the family members's narratives and the knowledge of the experience meaning are essential and decisive for the construction of effective therapy interventions that enable well-being to the family.

The training institutions should concentrate their actions on qualifying the future and current nurses to use successfully qualitative methodologies that enable to gain access to their lived experience.

A limitation of this study can be identified by the not *allowing* the traditional generalization of the results, since the lived experience is unique. However, the possibility of their transferability is assumed since their use may have implications for practice of care in contexts with identical characteristics.

REFERENCES

- 1. Alarcão M. (Des) equilíbrios familiares: uma visão sistemática. Coimbra: Quarteto; 2002.
- Meleis AI, Sawyer LM, Im EO, Messias DKH, Schumacher K. Experiencing Transitions: An Emerging Middle-Range Theory. ANS Adv Nurs Sci. 2000 sep;23(1):12-28.
- 3. Mendes A. A informação à família na unidade de cuidados intensivos: Desalojar o desassossego que vive em si. Lisboa: Lusodidacta; 2015.
- Engström B, Uusitaloa A, Engström A. Relatives' involvement in nursing care: A qualitative study describing critical care nurses' experiences. Intensive Crit Care Nurs. 2011 feb;27(1):1-9.
- 5. Relvas A. Intervenção sistémica em Portugal. Coimbra: Quarteto; 2003.
- Meleis AI, Trangenstein PA. Facilitating transition: Redefinition of nursing mission. Nurs Outlook. 1994 nov/dec;42(6):255-259.
- Fernandes CS, Gomes JA, Martins MM, Gomes BP, Gonçalves LH. A Importância das Famílias nos Cuidados de Enfermagem: Atitudes dos Enfermeiros em meio hospitalar. Rev Enf Ref [Internet]. 2015 dec; [cited 2018 jul 14]; IV(7):21-30. Available from: http://www.scielo.mec. pt/pdf/ref/vserIVn7/serIVn7a03.pdf
- Mendes A. A interação enfermeiro-família na experiência vividade doença critica: O cuidado centrado na familia. Atas CIAIQ2018 -Investigação Qualitativa em Saúde. Ludomedia [Internet]. 2018; [cited 2018 jan 10]; 2:203-212. Available from: https://proceedings.ciaiq.org/ index.php/ciaiq2018/article/view/1780/1733
- 9. Beer J, Brysiewicz P. The conceptualization of family care during critical illness in KwaZulu-Natal, South Africa. Health SA Gesondheid [Internet]. 2017 dec; [cited 2018 feb 04]; 22:20-27. Available from: https://reader. elsevier.com/reader/sd/pii/S1025984816300436?token=FE6598CF7 287BB4975EF71BD5A4A7814339083530A53D04E5BA8586C593F7 3E3FB09461A4F3FE258A720D944D812592C
- Mendes AP. Sensibilidade dos profissionais face à necessidade de informação: a experiência vivida pela família na unidade de cuidados intensivos. Texto Contexto - Enferm [Internet]. 2016; [cited 2018 feb 04]; 25(1):e4470014 . Available from: http://www.scielo.br/pdf/tce/ v25n1/0104-0707-tce-25-01-4470014.pdf
- Mendes AP. Impact of critical illness news on the family: hermeneutic phenomenological study. Rev Bras Enferm [Internet]. 2018; [cited 2019 feb 10]; 71(1):170-177. Available from: http://www.scielo.br/pdf/ reben/v71n1/0034-7167-reben-71-01-0170.pdf DOI: http://dx.doi. org/10.1590/0034-7167-2016-0163

- Harrison TM. Family Centered Pediatric Nursing Care: State of the Science. J Pediatr Nurs [Internet]. 2010 oct; [cited 2019 jan 12]; 25(5):335-343. Available from: https://www.ncbi.nlm.nih.gov/pmc/ articles/PMC2965051/pdf/nihms240188.pdf
- Mishel MH. The measurement of uncertainty in illness. Nurs Res. 1981 sep/oct;30(5):258-63.
- 14. Mishel M. Uncertainty iln illness. J Nurs Scholarsh. 1988;20:225-232.
- Mitchell M, Chaboyer W, Burmeister E, Foster M. Positive effects of a nursing intervention on family-centered care in adult critical care. Am J Crit Care [Internet]. 2009 oct; [cited 2019 feb 10]; 18(6):543-552. Available from: http://ajcc.aacnjournals.org/content/18/6/543.full. pdf+html
- Benner P, Kyriakidis P, Stannard D. Clinical wisdom and interventions in acute and critical care. A Thinking-in-action approach. 2^a ed. New York: Springer Publishing Company; 2011.
- 17. Mitchell M, Courtney M. Reducing family members' anxiety and uncertainty iln illness around transfer from intensive care: an intervention study. Intensive Crit Care Nurs. 2004 aug;20(4):223-231.
- Mishel M, Clayton M. Theories of uncertainty in illness. In: Smith M e Lieh P. Middle Range Theory for Nursing. New York: Springer Publishing; 2018. p. 49-81.
- Mishel MH. Reconceptualization of the uncertainty in illness theory. Image J Nurs Scholarsh [Internet]. 1990; [cited 2018 dec 06]; 22(4):256-62. Available from: https://pdfs.semanticscholar.org/71be/ abcdd9dd0b7073283bfc7534721e70af9335.pdf
- Marques SFS, Oliveira TMG, Jesus CAC, Pinho DLM, Ribeiro LM. Incertezas dos pais de recém-nascidos internados em unidades de terapia intensiva. Rev Enferm UFPE On line [Internet]. 2017 dec; [cited 2019 feb 10]; 11(Suppl 12):5361-9. Available from: https://periodicos.ufpe.br/revistas/revistaenfermagem/article/ view/25179/25498
- 21. Van Manen M. Researching lived experience: human science for an action sensitive pedagogy. 2ª ed. Ontario: Althouse Press; 1997.
- Davidsen A. Phenomenological Approaches in Psychology and Health Sciences. Qual Res Psychol [Internet]. 2013; [cited 2018 dec 12]; 10:318-339. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/ PMC3627202/pdf/uqrp10_318.pdf
- 23. Van Manen M. Writing in the Dark. Phenomenological studies in interpretayive inquiry. Ontario: Althouse Press; 2002.
- 24. Giorgi A, Sousa D. Método fenomenológico de investigação em psicologia. Lisboa: Fim de Século; 2010.
- Flick U. Métodos qualitativos na Investigação Ciêntifica. Lisboa: Monitor; 2005.
- McKiernan M, McCarthy G. Family members' lived experience in the intensive care unit: a phemenological study. Intensive Crit Care Nurs. 2010 oct;26(5):254-61.
- Fernandes S. Decisão ética em enfermagem: do problema aos fundamentos para o agir [tese]. Lisboa: Universidade Católica Portuguesa - Instituto de Ciências da Saúde; 2010.

- Johnson TP. Snowball Sampling. Encyclopedia of biostatistics. Cambridge: John Wiley & Sons; 2005.
- 29. Polit DF, Beck CT, Hungler BPH, Thorell A. Fundamentos de Pesquisa em Enfermagem. Porto Alegre: Artmed; 2004.
- Kvale S, Brinkmann S. Interviews: Learning the craft of qualitative research interviewing. 2nd ed. California: SAGE Publications, Inc.; 2009.
- Cohen MZ, Kahn DL, Steeves RH. Hermeneutic phenomenological research. A practical guide for nursing researchers. Thousand Oaks: Sage Publications, Inc.; 2000.
- Chick N, Meleis A. Transition: a nursing concern. In: Chinn PL. Nursing Research Methodology: Issues and Implantation. Gaitherburg, MD: Aspen Publishers; 1986. p. 237-257.
- Hinkle J, Fitzpatrick E. Needs of American relatives of intensive care patients: Perceptions of relatives, physicians and nurses. Intensive Crit Care Nurs. 2011 aug;27(4):218-25.
- Hetlanda B, McAndrew N, Perazzo J, Hickman R. A qualitative study of factors that influence active family involvement with patient care in the ICU: Survey of critical care nurses. Intensive Crit Care Nurs [Internet]. 2018; [cited 2019 jan 12]; 44:67-75. Available from: https://www.ncbi. nlm.nih.gov/pmc/articles/PMC5736422/pdf/nihms902737.pdf
- Queiroz TA, Ribeiro ACM, Guedes MVC, Coutinho DTR, Galiza FT, Freitas MC. Cuidados paliativos ao idoso na terapia intensiva: Olhar da Equipe de enfermagem. Texto Contexto - Enferm [Internet]. 2018; [cited 2019 jan 12]; 27(1):e1420016. Available from: http://www.scielo.br/pdf/ tce/v27n1/0104-0707-tce-27-01-e1420016.pdf
- Mishel MH. Perceived uncertainty and stress in illness. Res Nurs Health. 1984;7(3):163-171.
- Benner P. De Iniciado a Perito: Excelência e poder na prática clínica de enfermagem. Tradução de Ana Albuquerque Queirós e Belarmina Lourenço. Coimbra: Quarteto Editora; 2001.
- BIREME. DeCS Descritores em Ciências da Saúde [Internet]. 2019 jan; [cited 2019 jan 12]. Available from: http://decs.bvs.br/cgi-bin/wxis1660. exe/decsserver/
- LeBlanc A, Bourbonnais FF, Harrison D, Tousignant K. The experience of intensive care nurses caring for patients with delirium: A phenomenological study. Intensive Crit Care Nurs. 2018 feb;44:92-98.
- Benner P, Tanner C, Chesla C. Expertise in nursing practice. Caring, clinical judgement & ethics. New York: Springer Publishing; 2009.
- Michelan VCA, Spiri WC. Percepção da humanização dos trabalhadores de enfermagem em terapia intensiva. Rev Bras Enferm [Internet]. 2018; [cited 2019 jan 12]; 71(2):397-404. Available from: http://www.scielo.br/ pdf/reben/v71n2/pt_0034-7167-reben-71-02-0372.pdf
- Mishel MH, Germino BB, Gil KM, Belyea M, Laney IC, Stewart J, et al. Benefits from an uncertainty management intervention for African– American and Caucasian older long-term breast cancer survivors. Psychooncology. 2005 nov;14(11):962-78.