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Nurses' challenges in view of the pain and suffering of families of terminal patients

DESAFIOS DO ENFERMEIRO DIANTE DA DOR E DO SOFRIMENTO DA FAMÍLIA DE PACIENTES FORA DE POSSIBILIDADES TERAPÊUTICAS

DESAFÍOS DEL ENFERMERO ANTE EL DOLOR Y EL SUFRIMIENTO DE LA FAMILIA DE PACIENTES FUERA DE POSIBILIDADES TERAPÉUTICAS

Maria de Fátima Prado Fernandes¹, Janete Hatsuko Komessu²

ABSTRACT

This qualitative study was performed with the objective to identify the challenges faced by nurses who assist families of patients with no hope of cure, in view of their pain and suffering. Data collection was performed in 2008 using semi-structured interviews, including eighteen nurses who worked in the Intensive Care Units of a private hospital located in São Paulo, after receiving approval from the Research Ethics Committee. The content analysis of the data revealed three categories: *facing the challenges of assisting the family, expected attitude, and guiding yourself by experience*. It was revealed that, in order to assist the families, nurses must reflect on their personal and ethical values, as well as examine their feelings regarding the process of dying. It is expected that experienced nurses will exchange their knowledge with those beginning their practice in this health care setting.

DESCRIPTORS

Nursing care
Critical illness
Family
Pain

RESUMO

O presente trabalho trata-se de um estudo de abordagem qualitativa com o objetivo de identificar os desafios dos enfermeiros para assistir às famílias de pacientes fora de possibilidades terapêuticas diante da dor e do sofrimento. A coleta de dados ocorreu no ano de 2008, mediante entrevista semiestruturada, com dezoito enfermeiros que trabalhavam em Unidades de Terapia Intensiva de um hospital privado localizado no município de São Paulo, após aprovação do Comitê de Ética em Pesquisa. Utilizou-se a análise de conteúdo para a avaliação dos dados. Obtiveram-se três categorias: *enfrentando os desafios para assistir a família, posicionamento esperado e orientar-se a partir da experiência*. Evidenciou-se que, para assistir às famílias, há necessidade dos enfermeiros refletirem a respeito dos valores pessoais e éticos, bem como sobre o processo do morrer. Espera-se que haja troca de experiências entre os enfermeiros já experientes com os que iniciam tal prática no âmbito do cuidar.

DESCRIPTORES

Cuidados de enfermagem
Estado terminal
Família
Dor

RESUMEN

Estudio cualitativo que objetivó identificar los desafíos de los enfermeros para atender a las familias de pacientes sin posibilidades terapéuticas, ante su dolor y sufrimiento. Datos recolectados en 2008, mediante entrevista semiestructurada, realizada a dieciocho enfermeros que trabajaban en Unidades de Terapia Intensiva de un hospital privado del municipio de São Paulo, luego de conseguirse la aprobación del Comité de Ética en Investigaciones. Se utilizó análisis de contenido para evaluar los datos. Los mismos determinaron tres categorías: *Enfrentando los desafíos para atender a la familia, Postura esperada y Orientarse a partir de la experiencia*. Se demostró que, para atender a las familias, existe necesidad de reflexión por parte de los enfermeros respecto de los valores personales y éticos, así como sobre el proceso del morir. Se espera que haya intercambio de experiencias entre los enfermeros con trayectoria y aquellos que inician su práctica en este ámbito del cuidado.

DESCRIPTORES

Atención de enfermería
Enfermedad crítica
Familia
Dolor

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INTRODUCTION

Assisting a family of patients with no hope of cure is a hard and complex task even for an experienced nurse, who sometimes may bear the difficulty of assisting a family that is experiencing pain and suffering. However, for a newly graduated nurse with no experience, assisting critical patients who face an imminent risk of death is even more complicated.

Assisting critical patients who face an imminent risk of death constitutes a constant challenge for experienced and inexperienced nurses alike, and the burden they take on is made heavier only if a nurse begins his professional performance in a critical care unit. More experienced nurses often develop personal resources over time to face these situations, but the obstacles new nurses face can be substantial and draining.

The care of family members is one of the most important parts of the global care of patients in intensive therapy units. It is regrettable that the care of the family receives so little attention in most graduate courses in the health care field. The current literature is full of evidence that the strategies aimed at family members, such as communication improvement, conflict prevention and spiritual comfort, among others, result in the family's greater satisfaction in the perceived quality of assistance provided for the patient in the ITU⁽¹⁾.

It is difficult for schools to address with this topic, for many nursing students have not matured yet, particularly in the emotional aspect. Emotional maturity, especially when faced with these weighty situations, is only possible to develop through professional performance or life experience in view of the dying process.

In this way, the authors of this study consider how beneficial to nurses' health it would be if nurses could express what they have learned over time to more meaningfully assist the families of patients with no hope of cure as they face pain and suffering and if more experienced nurses could talk to newer nurses to help them reflect on how best to assist these families.

Studies have established a method to interact with people in view of the process of life and death, identifying five steps that represent the reactions of those with no hope of living⁽²⁻⁴⁾. From the overall feelings concerning death emerged such elements as the following: indifference, sadness, impotence and fear of expressing guilty feelings⁽⁵⁾.

Alongside other health professionals, nurses must look for strategies to assist the family in the best possible way, remaining by their sides in moments of deep

anguish⁽⁶⁾ and being aware that the family, to the best of their ability, must maintain their work and social obligations. A nurse must also keep his own identity and little by little, begin to recognize the identity and family structure without the terminal patient⁽⁷⁾.

Faced with this situation, a nurse should be attentive in communicating with the patient's family because for them, this is a unique loss that affects the lives of the family, friends, colleagues and health professionals who have cared for this patient⁽⁸⁾.

In these situations, it is essential that a nurse who is just beginning his practice to be accompanied by a more experienced nurse. Although newly graduated nurses have acquired technical skills and knowledge of the scientific field, they still must learn how to address certain ethical dilemmas related to the process of death and dying and linked to the relationship between the nurse and the family.

Experienced nurses know that providing care for a family draws upon knowledge that exceeds their technical backgrounds. A combination of ethical principles and individual and collective values guides a nurse's actions while assisting a family dealing with pain and suffering; the meaning of care changes every day. Each of these considerations is present in a very real way for professionals who care for these families, as their beliefs about the dying process may end up strongly affecting the assistance process.

Each nurse must reckon with his own thoughts, actions and feelings concerning death and the dying process in a larger scope, identifying the concepts that determine his behavior and confronting his fears and beliefs⁽⁹⁾. These become very real in the face of the dying process, and while caring for the family, a nurse may encounter values and life stories that implicate different coping mechanisms and strategies. Assisting these families, nursing professionals may end up being influenced by their conceptions, values and experiences regarding death and dying, and in this situation, they may need to put their own emotions aside.

A nurse must learn to forge relationships and also to put his will into practice by means of his speech, actions and choices⁽⁹⁾. The life experience of a nurse who faces the families of patients with no hope of cure should consist of affection and ethical attention, not limited to suffering and pain; this experience must be shared with patients.

Nursing professionals experience a greater closeness to death, requiring them to prepare for and improve their attentiveness to patients and their family members facing pain and suffering,⁽¹⁰⁾ which are distinguished feelings and components of the human existence. It is impossible to claim the right of not suffering.

The life experience of a nurse who faces the families of patients with no hope of cure should consist of affection and ethical attention, not limited to suffering and pain...

Thus, it is left up to the healthcare professional to alleviate this pain, whether it is organic or psychic. Pain can be brought about by any situation that has unleashed strong negative emotions that are often unshared; this causes discomfort and is characterized as an unfavorable process for the immediate amelioration of these feelings⁽¹¹⁾. Therefore, it takes some time for the family to alleviate and transform that feeling. In general, the existing anguish sets the family apart from the possibility of having a more positive reaction, and the nurse should be prepared to help the family at this moment.

In the face of providing assistance to the family, a nurse must open a space within himself to consult other professionals about the dying process and to allow changes in his own patterns of conduct. The way through which a nurse manages his own means and resources to attend to the family at moments of pain and suffering will reflect in the overall care that he can provide.

It is convenient that a more experienced nurse would help newer nurses care for the families of patients with no hope of cure; they are well-positioned to show them how to balance commitment, autonomy and ethical positions and how best to correlate their assistance with the limits and possibilities of intervention. This study intended to investigate how experienced nurses assist the families of patients with no hope of cure and ultimately may aid nurses who have no specific knowledge of this field to develop these practices.

Our research aimed at identifying how the nurse, through his experience of assisting the families of patients with no hope of cure, in the face of pain and suffering, may help inexperienced nurses and new graduates develop their professional practice in this context.

METHODS

This investigative and descriptive study was performed using qualitative methods in a private hospital located in São Paulo City.

Interviews were conducted with 18 nurses working in intensive therapy units. The number of subjects was determined by speech repetition, that is, exhaustion.

The median age of the 18 nurses was 37 years, whose ages varied between 27 and 53 years old, and only one was male. The mean duration of experience assisting the families of critical patients was 11 years. All had pursued advanced degrees, with four having masters degrees, two being masters candidates and two being doctoral students.

The inclusion criterion was determined as having a minimum of two years experience in assisting the families of patients with serious conditions in the role of a nurse in the intensive therapy unit. This criterion is important, as the

experienced nurses who assist these families have much to contribute to support those who are just beginning their professional practice of caring for families who are in pain and suffering. The guiding question of this study was

How would you guide a nurse with no experience or a new graduate in the assistance of the families of patients with no hope of cure in the context of their pain and suffering and considering the inherent challenges of the family's pain and suffering in this situation?

The data were acquired only after the approval of the Ethics Committee and the Institutional Research Board (Opinion on 28-7); these data were collected between March and May 2008 by means of semi-structured interviews that were set and recorded in audio, according to the Terms of Free and Explained Permission (TFEP), protecting the anonymity of those interviewed and respecting the language they used in the interview.

To investigate the testimonies, the data were analyzed through a content analysis in three stages: pre-analysis (floating reading and data preparation); investigation of material (in which mutual exclusion, homogeneity, pertinence, objectivity and productivity were considered); and the treatment of outcomes, inference and interpretation⁽¹²⁾.

The content structures were made by selecting units of context and register through the analysis and selection of the sentences present in the speeches that expressed sense and adhering to the study objective. Afterwards, themes emerged concerning the content representation. Therefore, through consideration of the nurses' speeches, the categories obtained were as follows: 1) facing the challenges of assisting the family, 2) the expected attitude, and 3) guiding oneself through experience.

PRESENTATION AND DATA ANALYSIS

From the speeches submitted for analysis, a certain continuity among the nurses' experiences regarding the confrontation with death was observed. While describing their stances, many mentioned possible challenges in assisting the family and pointed out the expected professional positions. They stated that the extent of their experience in assisting the families in pain and suffering was considered an important issue in the guidance of new professionals, as the academic backgrounds of newer nurses was largely considered insufficient in face of the complexity of care required to assist the families of patients with no hope of cure; as such, newer nurses should appreciate their colleagues' experience.

1) Facing challenges in assisting the family

To assist the families of patients with no hope of cure, healthcare professionals are required to acquire

knowledge about the dying process and to learn to overcome their own fears. Their scientific backgrounds often are insufficient to prepare them to think about their life philosophies and personal and ethical values, and even the knowledge that religious cultures may help them better understand human reactions in the face of imminent loss can help them better meet the needs presented by families upset by pain and suffering.

Another challenge is accommodating the spiritual needs of the family, or at least providing space for their attendance. To understand their spiritual pain, one may consider that spirituality may be defined as something that brings meaning and purpose to people's lives. Transcendence in the search for meaningfulness and spirituality is one of the many emotions experienced by these families⁽¹³⁾.

In the face of spiritual pain, it is common for families to appeal to religious faith as a source of help as they search for the meaning of life and death. Therefore, spiritual assistance according to their beliefs is considered a gesture of love and understanding for them⁽¹⁴⁾.

The selected quotes below illustrate these issues.

(...) if the nurse has a religious, spiritual or philosophical belief, he/she will help understand the dying process and the assistance he/she can give to the family members. This gives confidence (E5). (...) one should try to know this family... (E15)

It was mentioned that the nurse's possessing a religious belief may help the family to also access their beliefs and spiritual values; they should be assisted in their anguish and fearfulness. This attitude is not always expressed by the nurses, mainly by those who do not have much experience.

(...) in the graduate course, only the legal aspect is discussed, but not how to deal with the family. At specialization, it was talked over a little more. However, at the moment, nobody talks about how one must take action regarding the family members, and this is needed (E9).

It is also worrisome for the experienced nurse to know that the *new* nurse almost always comes in without adequate preparation to take care of the family, and many times, he is alone in this situation without receiving any help from the other professionals.

(...) the newly graduated nurse has his basis .. he/she may fear death. Fearing death leads to him/her not facing it. She must face that fear by considering the dying process... and taking other attitudes (E5).

Even today, it is very uncomfortable for a nurse lacking experience with loss and/or in assisting families through suffering. Even more difficult is wanting to provide care but not knowing how to do it. The insecurity is brought about by their lack of knowledge, either in the academic area or in the daily routine of assisting.

At nursing schools, it is very common that the student shows fear. Researchers have mentioned speeches that reflect this anguish; the student often expresses her discomfort concerning death in his/her stage every day and refuses to accept it. This denial emerges as a coat protecting him/her from the fear of death, and they unconsciously seek to run away from death or anything related to it...⁽¹⁵⁾.

If I had to give instructions to the nurse, at first I would tell him/her to take the place of the family who is losing a beloved one We as professionals have to understand the process of dying as part of life cycle... So it is difficult for one to assist someone who is dying (E8. E10).

The proximity to pain and suffering seems to warrant a critical empathy in these nurses to build a therapeutic link to provide better nursing assistance; at the same time, this proximity results in an emotional stress linked to the difficulties of dealing with the terminal condition⁽¹⁶⁾.

Assisting the family means that the nurse encounters any concerns that arise, as well as his own life philosophy and spiritual values. When getting close to the families, he must understand this particular type of care involves an ontological skill set that is essential to the maturity and emotional survival of the nurses⁽¹⁷⁾. This can be developed through events in the daily life of assisting families in the face of pain and suffering.

(...) as you see a family that is facing this situation, both they and we know what is going to happen by the end of the process. There is no way to escape from that, and we are not prepared to give this support to the family (E10).

The statement above reflects the conscious presence of a nurse who realizes he/she is not prepared to give support to the family. Additionally, the nurse does not receive support from the institution he works for and faces difficulties in offering emotional support to these families.

If the nurse is afraid or has doubt about the care, it will always be superficial. He will not be by the family's side and will act according to the hospital rules rather than attend to the family's needs (...) ⁽⁵⁾.

This attitude may cause discomfort to the family. The family members usually express emotional stress when they encounter loss, mainly with the lack of specific information about the probable evolution and real knowledge of the situation⁽¹⁸⁾. The experienced nurse should keep the family informed and still think over his position assisting the families appropriately in the loss and pain process.

helping the newly graduated nurse think of care so that the patient does not suffer.... and showing that to the family in the best way as possible (E15).

I think that maybe I could have taken a different approach to my training course to help the nurse a little (E3).

Providing a *training course* largely depends on how it would be run, and still, this preparation would not be enough. An experienced nurse must help a less experienced nurse so that he is able to assist the family of a patient with no hope of cure. As the family expresses their pain, which evolves as a unique experience depending on their life stories and ties to the loved one, the nurse must be able to guide them through the coping process. At this moment, the professional may help the family to understand better its own story.

The newly graduated nurse faces the challenge of maintaining a dialogue with the family and at the same time, sustaining them through difficult moments by providing support. He must also be sensitive to their emotional needs while conducting these interventions⁽¹⁹⁾.

Many quotes reflected the presence of fear and the difficulty of transferring theoretical knowledge into practice, particularly without having had time or a consolidated preparation to learn how to assist these families at moments of anguish and pain. A space for conversation within the nursing team must exist so that the more experienced nurses may contribute to the growth of all.

Expected Stance

Another challenge for the experienced or inexperienced nurse who intends to take care of the dying other is understanding that the family expects him to possess the skills to perform his role⁽²⁰⁾. Therefore, the nurse is expected to acquire the knowledge, abilities and attitudes necessary and to add them to his own personal and ethical values. In so doing, he may adopt a professional demeanor appropriate to his role in assisting the family of the patient with no hope of cure.

Due to lack of maturity and possibly to the need to meet their colleagues' expectations, some nurses beginning this practice worry only about giving information to the families, restricting themselves to their professional roles. The professional is expected to perform his task with balance and efficiency, to spending time learning, and to receive support from the institution that employs him⁽²¹⁾.

The quotes below reveal the expected position of experienced nurses.

I accompanied a newly graduated nurse, and the family of the patient had a range of questions concerning which attitudes should be taken ... the nurse was worried about speaking technically when describing what was being done to the patient, but the family did not want to know if he was on a vasoactive drug but if he was comfortable (E1).

It is very difficult for the nurse assisting the patient with no hope of cure to understand what the family wants him to say in face of the pain they feel. An essential attitude is trying to listen to them, learning what they need and not judging their priorities in the moment⁽¹⁶⁾.

(...) the newly graduated nurse feels under pressure in this situation; he feels fearful, and the relationship becomes very mechanical, with only their worries about giving information prevailing. I would say one must be nearer to the family to realize their needs and try to supply them (E1).

The family needs to receive information.

(...) not conveying information to the family members about the actual condition of the patient and about the diagnosis and therapeutic strategies is a frequent complaint made by them. Information must be gradually provided and repeated several times all day long, always having the same approach...⁽²²⁾.

The authors make it clear that taking care of the family members entails understanding their emotions, gestures, conceptions and limits⁽²³⁾.

(...) telling the newly graduated nurse that the nurse goes on caring for the patient even if the forecast is closed by the team, such as for instance, food, prone change, hygiene... and giving comfort to the family (E5; E4; E14).

The statement above considers and approaches the issue of the needs of the family members to know that the beloved one is receiving comfort, which may in turn bring comfort to the family.

The nursing procedures, in accordance with the multidisciplinary team, are aimed at making possible and viable the peaceful death of the patient⁽²¹⁾. His condition should be conveyed to his family members, respecting their time to overcome the mourning process in advance.

(...) first of all, listen to what the family has to say. Realize what the family thinks of the situation and feel what it is expecting (E7; E18).

(...) I give instructions to talk to the family, but this is not what happens in daily life. So I think about how to improve that (E11).

(...) try to maintain a more consistent dialogue with the family, not giving false expectations regarding the situation (E12).

The importance of the direct contact of the nurse with the family members is evident, and frequently, the family turns to the nursing team to inform and better explain to them what is happening with the patient⁽²⁴⁾.

(...) each family member reacts in a way in view of the diagnosis of the patient with no hope of cure; there is not a cookie cutter approach. There are nurses who manage to talk and listen to the family (E13).

It is necessary to consider the multidisciplinary debate regarding the objectives of the care focused on the patient and his family. At the same time as patient discomfort is minimized, assistance for the patient's pain and suffering must be maximized⁽²⁵⁾.

Being conscious of the possibility of their relative's death in the ITU, the family suffers and ponders remembrances of other people's deaths, comparisons among their lived experiences, various understandings of the issue, decisions regarding new objectives and dilemmas that were previously unrealized, regardless of the search for a high quality of life and the attitude of their terminally ill family member⁽²⁶⁾.

While communicating with the nurses at the ITU, the family may express pain in several ways; thus, the professional must develop communication skills. This aspect is considered just as important as the ability to evaluate and provide specialized care to the critical patient in this unit⁽²²⁾.

Studies have come to the conclusion that, frequently, the professional working in the ITU is not prepared to listen to or address the concerns of the family members, thus not recognizing their emotional states or cares and neglecting to respect the patient. Most likely, this problem occurs by focusing only on the technological care of the patient while searching for positive clinical outcomes, to the detriment of the family's care⁽²⁷⁾.

It is important to listen to the family, and the nurse is expected to know when and how to answer their inquiries. Therefore, he must make the family aware of his presence and maintain a respectful attitude.

Family members may show discomfort resulting from experiencing the death process, such as anxiety, depression and post-traumatic stress disorders. In this situation, interventions should focus on communication with the families, and this may have meaningful effects on minimizing these consequences⁽²⁸⁾.

Guidance from experience

Appreciating the experience of caring for terminally ill patients is a great challenge. Within the technological domain of the healthcare field, the sensitivity a professional must develop to address families is rarely addressed, from their introduction to attendance attitudes regarding their emotional, social and spiritual needs. The statements below report this issue.

guiding the family about their possibility to open the visit schedule if the patient has no hope of cure (E2).

The team ends up not realizing the necessity of welcoming the family member, who comes in and leaves the ITU according to a visitation schedule without receiving the attention they need to the confront of the critical health condition of their family member⁽²⁴⁾.

(...) I would tell the nurse to give comfort to the family and the patient as well(E4).

(...) I would say it is important that one may speak openly to his team members about the difficulties in assisting the family... (E10).

These quotes highlight that the effectiveness of the nurse's actions toward the family in view of their pain and suffering facing of imminent loss depends on their own self-discipline, as well as the nursing team's work establishing a channel of communication between healthcare professionals and families.

There is a shortage of publications on nurses' performance in the context of the families of adult patients with no hope of cure. However, the daily routines in ITUs reveals that families need guidance and a space to address their emotional and spiritual needs when faced with imminent loss, even apart from the presence of professional concerns for family-focused care.

In this study, we showed that experienced nurses still encounter difficulties in fully expressing how they would help less experienced nurses at the beginning of their practice in the ITU. It is possible that participating in this study led these nurses to consider how they have been addressing the pain and suffering of the families of patients with no hope of cure.

The positions of nurses regarding the assistance of families in facing their pain and suffering have not been totally delineated, and greater preparation is needed from those who encounter this situation as part of their daily routines. All nurses consider it a challenge to learn to consider their values and beliefs to better care for these families as they face imminent loss. Moving forward from what has already been experienced and addressing that which has not yet been worked out within the interdisciplinary team, nurses may better meet the needs of the family members themselves.

CONCLUSION

Nurses who are more experienced in assisting the families of patients with no hope of cure, in view of their pain and suffering, need to open discussions with less experienced and newly graduated nurses who are beginning this type of practice. All of them work within a permanent learning process.

The nursing literature confirms that there are gaps in nurses' academic backgrounds in assisting the families of patients with no hope of cure. This is a hard task, as the pain and suffering of each family demands specific attention, often in discreet, but no less caring or important, ways.

This study has demonstrated that it is possible to identify that more experienced nurses have something to teach about the process of caring for the families in face of anguish, but it is still reasonable to further determine how this should be approached. Of course, this is not an easy task, and there are still many challenges to be worked out, including nurses' own fears of death. Spaces for constructive and sincere discussion among all involved in this process are needed.

The outcomes of this study show the limits of a qualitative, contextualized study regarding the place and time of investigation; however, they can contribute to guiding newer nurses, as well as the professors in the nursing field, in debates and investigation about assisting the families of patients with no hope of cure who face pain and suffering.

Learning to face these difficulties in assisting the family is a continual learning process, as each family is unique; however, each professional in this situation may also have unique attitudes. The challenges of the nurse starting his

professional activities are even larger, as in the beginning, they may have resistance on structural, environmental, or preparedness levels to dealing fully with the family's pain and suffering.

The guidance provided by experienced nurses is valid and necessary. In this study, the participants reinforced the importance of learning how to assist the family in face of pain and suffering, as all parties involved are searching for knowledge. Nurses must consider their experiences and learn to face together the inherent challenges in assisting a family during times of imminent loss.

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