ORIGINAL ARTICLE

Caring for the patient in the process of dying at the Intensive Care Unit

CUIDANDO DO PACIENTE NO PROCESSO DE MORTE NA UNIDADE DE TERAPIA INTENSIVA

CUIDANDO AL PACIENTE EN PROCESO DE MUERTE EN LA UNIDAD DE TERAPIA INTENSIVA

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ABSTRACT

The objective of this study is to characterize how nursing care is performed at the ICU to patients with no possibility of cure. Ten nurses were interviewed. The field study was performed at the Intensive Care Unit of a public teaching hospital. For the nurses, there is no uniform pattern of care. Furthermore, according to their reports, it was observed that there is an overestimation of the technical care over the emotional, social and spiritual aspects. It was, however, observed that nurses are strongly with the suffering of the family in view of their loss. Results show that nurses must understand death as a part of the life cycle and review care as the essence of nursing, thus increasing the discussions on the issue in both the academic and daily practice environments.

DESCRIPTORS

Death
Nursing care
Terminal care
Intensive Care Units
Attitude to death

RESUMO

Este estudo busca caracterizar o desenvolvimento do cuidar/cuidado de Enfermagem numa UTI ao paciente fora de possibilidade de cura (PFPC) por enfermeiros. Foram entrevistadas dez enfermeiras. A pesquisa de campo foi realizada em uma Unidade de Terapia Intensiva de um hospital público de ensino. Para estas enfermeiras, não há uma uniformidade no cuidado. Além disso, evidenciou-se pelos relatos a existência de uma supervalorização dos cuidados técnicos em detrimento dos aspectos emocional, social e espiritual. Contudo, observou-se grande preocupação das enfermeiras com o sofrimento da família diante da perda. Os resultados evidenciam que as(os) enfermeiras(os) necessitam compreender a morte como parte do ciclo vital e repensar o cuidar/cuidado como essência da Enfermagem, ampliando as discussões sobre a temática tanto no âmbito acadêmico quanto na prática diária.

DESCRITORES

Morte
Cuidados de enfermagem
Assistência terminal
Unidades de Terapia Intensiva
Atitude frente a morte

RESUMEN

Este estudio busca caracterizar el desarrollo del cuidar/cuidado de Enfermería en UTI al paciente sin posibilidad de cura (PFPC) por enfermeros. Fueron entrevistadas diez enfermeras. La investigación de campo se realizó en una Unidad de Terapia Intensiva de hospital público de enseñanza. Para las enfermeras, no hay una uniformidad de cuidado. Además de eso, se evidenció en los relatos la existencia de una sobrevaloración de los cuidados técnicos en detrimento de aspectos emocionales, sociales y espirituales. Sin embargo, se observó gran preocupación de las enfermeras con el sufrimiento familiar ante la pérdida. Los resultados evidenciaron que los enfermeros/as necesitan entender a la muerte como parte del ciclo vital y repensar el cuidar/cuidado como esencia de la Enfermería, ampliando las discusiones sobre la temática tanto en el ámbito académico como en la práctica diaria.

DESCRIPTORES

Muerte
Atención de enfermería
Cuidado terminal
Unidades de Terapia Intensiva
Actitud frente a la muerte

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INTRODUCTION

The act of caring involves human actions in the process of assisting patients, family members or the community so that it equally involves interpersonal relationships based on humanistic values and scientific knowledge. Caring for another requires procedures more complex than healing. Even though this practice is not a prerogative of a single profession, it is undeniable that nursing has more opportunities to accomplish the act of caring, since nurses spend 24 hours a day with patients[1].

Caring, care and professional nursing care generally present distinct concepts. Hence, in this study we adopt the conception that caring is related to acts that facilitate the human condition; care is associated with activities that require ability and affection, and professional nursing care encompasses cognitive and culturally learned behavior, techniques and processes that aim to improve or maintain health in living or dying[1].

Caring is a practice inherent to the human condition and has accompanied humanity since our earliest days, from conception to death, as well as all the circumstances triggered after this practice[2]. Consequently, from this perspective, one expects a change of paradigm based on the awareness that care is an indispensable element both throughout life and at the moment of death.

Death is an unavoidable fact for all, is part of the life cycle and to treat it as if it were an avoidable biological accident is a mistake. Another misconception is to believe that nothing else can be done for patients with no chance of survival. Additionally, the acknowledgement of this trajectory exemplifies that while there is life, care is needed. Hence, nurses and the nursing staff should deliver care to these patients during their entire treatment, especially when a cure is no longer possible and the patient is then destined for palliative care[3-5].

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Palliative care enables a humanized death. And despite the fact it is not a common practice in Brazilian Intensive Care Units (ICUs), the international literature already presents differentiated and innovative practices with the development of instruments and protocols to improve palliative care delivery to patients with no chance of survival in ICUs[6].

The philosophy of palliative care seeks the understanding that death is part of life, neither rushing nor delaying its arrival, and also includes psycho-social-spiritual aspects in care delivery, supporting family members in the experience of elaborating mourning[5].

To implement this philosophy, nursing professionals play a preponderant role within the multidisciplinary team because they spend more time with patients and family members and function as links, intermediaries of interaction among all those involved. They seek resources to enable the patient to have a better quality of life, and, if this is not possible, a dignified death.

However, the issues of caring and practices of health care seem to suffer a great influence from the curative paradigm, since it has a great tendency to provide critical care, a high level of technological care to the detriment of care with the aim of promoting comfort, not only physical comfort, but also emotional and spiritual comfort[3].

There are situations that, despite all the health team's efforts, result in the death of the patient, and it is experienced as an intense frustration on the part of the professionals who feel they were not capable of saving the life entrusted to them[7-8]. It occurs due to the proximity of situations that reveal the human possibility of death, conditions in which these professionals see themselves in the face of the expectation that their role is to cure and reestablish the health of all those who seek them, losing sight of the fact that death is inherent to the human condition[7].

This way of thinking arises from professional education in which nurses feel committed to life, and feel qualified to preserve life, forgetting however that death is part of life; academic education is based on cures and finds in that the greatest gratification. Hence, when professionals need to deal with death in their daily practice, they feel in general unprepared and tend to move away from it[7].

The concept of death is always relative, complex and suffers changes influenced by the situational, social and cultural context. There are some approaches that should be taken into account to define and determine it such as the irreversible loss of vital fluids when most deaths are determined by the absence of vital signs; irreversible loss of soul; irreversible loss of the capacity of body integrity and the irreversible loss of consciousness or the capacity for social interaction[9]. Therefore, with the new definition of cerebral death, there is a change of parameters from a cardio-centered to a brain-centered model.

Death and dying are seen differently depending on the historical and cultural context in which the individual is included, thus a very complex subject. According to a French historian[10] from the middle Ages—the 11th to 15th centuries—people saw death in a dramatic way; it was a phenomenon that was part of daily life and was seen with *simplicity*. Death at this time was called *tamed death* referring to the basic idea that death is part of life, we know about it and live based on this knowledge, which is collective and public. With the development of industry and medical technology, a great change in the representation of *tamed death* is observed. The moment of death loses importance; one no longer sees the warnings.

Death in the 20th century is seen as taboo. It is no longer a moment, it is a process – death expected in bed is something that happens in a hospital; the patient is often unconscious in an ICU and has no right to decide his/her own death. Even this right is forbidden, of knowing when the end is near[10].

ICUs were created and are maintained with the objective of concentrating three critical components: the most severe patients, the most expensive technical equipment and a staff with knowledge and experience to care for these patients and deal with this specific apparatus[11].

This care therefore involves a search for a cure but also being able to deal with death in relation to that patient in critical condition, with family members and also with oneself as a human being who faces death on a daily basis. Hence, knowing more about the reactions and relationships of nurses with death when working in ICUs is important.

The interest in studying care delivered to patients in the dying process in the ICUs emerged from the work of one of the authors. Her concerns in the face of the act of caring given the process of dying emerged when she was attending her undergraduate nursing program at the time she initiated her research in the field of thanatology. She had various questions in relation to care, especially when delivered to patients hospitalized in an ICU in the process of dying and death.

OBJECTIVE

To characterize the development of nursing care/caring delivered by nurses to patients with no chance of a cure in an ICU.

METHOD

The exploratory-descriptive method with qualitative approach was chosen as the most appropriate for the study's objective. The qualitative approach addresses the universe of meanings and attitudes that correspond to a deeper space of relationships and processes[12]. Semi-structured interviews were individually held and recorded. The guiding question was: How do you deliver nursing care/caring to patients with no chance of a cure in an ICU?

Study setting

The study was conducted in an ICU of a public university hospital in Salvador, BA, Brazil, chosen for being a large referral unit with 22 beds for the Adult General ICU.

Study's participants

A total of ten nurses out of about 20 professionals were selected according to the established criterion: minimum of two years working in an ICU. The number of studied individuals was defined by saturation of answers. Saturation occurs when information shared with the researchers become repetitive[13].

To ensure the confidentiality of the study's participants, the names of butterfly species were used as aliases: *Delias hyparete, Parthenos salentia, Actias luna, Samia Cynthua, Vanessa Atalante, Gonepteryx cleopata, Heraclides astyalus* and *Parthenos Sylvia.* These transmit a symbolism related to death[14].

The study project was previously authorized by the studied facility and was also submitted to and approved by the Research Ethics Committee from SESAB (protocol nº 267/2008 July 9th 2008). The participants signed free and informed consent forms.

Data collection

Data were collected in August and September 2008. The study was initiated after contacting the nurses who voluntarily consented to cooperate. The study's objective and methodology was explained and they were assured of the confidentially of their names and information provided. Finally they were informed they were free to withdraw at any time.

Data analysis

After data were collected, the transcribed text was systematized using the Content Analysis technique proposed by Bardin, which is a *set of techniques of analysis of communications that uses systematic and objective procedures to describe the content of messages*[15].

The data were organized according the following steps of content analysis as proposed by Bardin: 1) pre-analysis; 2) exploration of material; 3) treatment of results and interpretation. Therefore, based on exhaustive readings of the interviewees' answers, key expressions of each answer contained in the reports were identified as well as similarities and divergences.

Four categories emerged from the analysis and composed this study's corpus of discussion: uniform care; technical care; care with attention, respect, dignity; and care related to the family.

RESULTS AND DISCUSSION

The daily practice of nursing work tends to be a technical, fragmented care impregnated by standards and routines[16]. Hence, when asked about their practice of nursing care/caring delivered to patients with no chance of being cured in an ICU, the interviewees answered guided by a practice of how care should be delivered based on standardization and routines and seldom expressed their daily attitude in the face of their care practice. A super valorization of technology to the detriment of the essence of hu-

man care favoring a process of death and dying with dignity was observed.

Issues involving death, particularly subjective ones, have always been among the greatest difficulties experienced by health professionals, mainly nurses, when they need to deliver care to patients experiencing the death process[8].

The daily attitude, that is, the actual conduct of the interviewees, tended to value technical care more, corroborating what the study addresses[17], when it highlights that patients should be seen as a unique, individual being, not merely from the viewpoint of a given pathology.

A practice, where the means of transmitting nursing actions is the disease, does not make an interrelation between what the person who needs care experiences and what such care represents in its different statutes and social roles[18]. There is a perception that nurses increasingly distance themselves from patients because they focus on technical care, delivering a professional care almost exclusively guided by technology that directs the biomedical model.

The following categories emerged from the types of care identified in the nurses' reports, taking into account a study[19] that mapped various manners of caring/care, of which we selected those related to the study: decisive care, supportive care, continuing care, and challenging care.

Uniform care

This was the most striking category in the reports because it reveals a lack of concern with the human being as a unique being, based on a non-individualized care. It is worth noting that most of the interviewees, when they answered the question of how care was delivered to the patients with no chance of survival, said that it was normal care, equivalent to that provided to patients with a chance of survival, as evidenced in the following reports:

> Yes, I try to care in the same way you know, as if I was caring for a viable patient, so to speak (Actias luna).

> [...] Not a bit different from any other human being who may be under my care here in the ICU (Samia cynthia).

> Look, I care the same way I care for any patient with chance of being cured, because we are not God, to determine the time a patient will pass away (Delia hyparete).

Care delivered to patients with no chance of being cured does not receive any priority of care or when they do, such care is not directed to their condition as a human being but it is related to the complexity of the technological apparatus the patient is using. For instance, at the time of developing a daily schedule of services, this priority may be observed if the patient is using many technological resources[7].

Hence, it is necessary to think in another way about care, such as *decisive care*[19], based on the rigorous observation of the patient in a rational approach in the relationship of life and death, where resuscitating or offering a dignified death is a difficult situation. Additionally, there is *supportive care*[19], which seeks to recover the essence of life even without the possibility of a cure, seeking a meaning for the patient while there is life. These perspectives were not identified in the reports of the interviewees; the absence of a view of individualized care was predominant in their answers: no special care for the patient in process of dying.

Therefore, one should avoid saying: *unfortunately there is nothing we can to for your loved one*. On the contrary, there is a lot one can do! The most appropriate question a professional should ask at a time like this is: *what else can I do to help you to cope with this difficult situation?*[20].

Technical care

There is great emphasis on the hyper-technicism while care provided at an emotional and spiritual level is seldom, if ever, provided to patients.

> We apply dressings, change them, give the medication, evaluate the patient you know, everything is monitored, we evaluate the patient, communicate some intercurrences to the physician (Vanessa atalanta).

> [...]we work the same way, do the same things, change dressings, change the dressings daily, give all the medications, everything is prescribed […] some actions we don't do anymore, like a special dressing, like hydrocolloid for protection, we end up not using it (Actias luna).

> It's [noise] the same provided to the other patients we care for, like bathing, hygiene, what is prescribed, care actions provided to patients who have a chance of being cured (Gonepteryx cleopata).

The reports of the interviewees privilege technical care, a situation very common in ICUs, advanced services where nurses can justify being distant from patients and even from care due to highly complex technical tasks, tasks that take all the time of nurses[18].

We conclude, based on the results of a study conducted with health professionals[8] that included nurses, that nursing programs do not emphasize issues related to emotion and spirituality, rather they focus on technical and practical aspects of nurses' education.

Nursing practices involving technical care such as hygiene, hydration, medication, etc. become routine; they become the same for various days with no significant alteration in content[7]. This characterizes *continuing care*[19], in which there is a predominance of mechanical care, despite all the discussion around nursing care to respect the individuality of patients.

A prevalence of the technical dimension of care is frequently noted in the reports, though one interview did stand out, as the following excerpt reveals, showing that the daily routine of an ICU causes the practice of profes-

sionals to become mechanical. This risk requires a constant vigilance and willpower on the part of professionals to avoid becoming alienated by technology, since the daily routine of monitoring favors mechanization, turning the patient into a parametrical conglomerate.

> We get cold while working in the ICU, you know? We see so many patients, so much disease, so many things that we kind of get immune to these things, we look at all the patients and end up seeing only illness, illness, illness, we get used to it (Heraclides astyalus).

One author[7] corroborates this report when he stresses that the health team is always impersonal and its decisions are anonymous. The term itself already suggests this anonymity and, when related to a person with no chance of survival, this impersonality is perceived with a greater intensity.

Care with attention, respect and dignity

The study also revealed nurses who are attentive to the demands of patients with no chance of experiencing a cure. This professional shows that the care delivered to patients with no chance of survival is an attempt to provide quality care, enabling the patient to experience moments of dignity and peace while awaiting his/her final moment.

> Now, when this patient is passing away, I try to be the most humane as possible […]to provide the most humanized care as possible, from what depends on my practice, at the point (Parthenos salentia).

> [...] we try to level up not down, care for the patient with dignity up to the time [pause] (Delias hyparete).

> I talk a lot with the patient, these are the patients who draw my special attention, because I really think that patients with no chance of cure listen, feel, and I have to treat them as if they could feel everything I'm doing to them (Heraclides astyalus).

Health professionals are those who have the responsibility for zeal for quality caring/care delivered to patients with no chance of survival, in order to enable them to have a dignified death. However, this fact is evidenced by only a minority. The interviewees' reports reveal the need for patients to have someone to listen to them, who accept talking about the disease, their real condition, for a while. Someone who talks without euphemisms, who acknowledges the patient is aware of his/her condition, who goes straight to the point, with clear and simple language, talks about questions patients ask and have a real disposition to talk. This individual has a comforting role, transmitting strength and hope[21].

It is a *challenging care*[19], a daily challenge to deal with the aggravating condition of patients, acceptance, fear, anxiety, and trust, caring for a patient with no chance of survival but not with no chance at all.

Care related to the family

It is essential, not only, but especially, inside an ICU, to understand the family as an extension of the patient. As shown in this category, family members were considered as those most in need of nursing care to better understand and minimize their suffering in the face of death and dying. These results demonstrate a concern on the part of the interviewees with family members, as seen in the following excerpts:

> We should better support the family also, while in an ICU, especially here, since the service is intense, very intense, you know? We end up not supporting the family as we should, you know? (Parthenos sylvia).

> Give more attention to the family of this patient, to the patient's wellbeing and the family's […] if I get more concerned with the patient it is because the family suffers more than the patient and like we should not take away the family's hopes, but let them be aware of what is happening (Heraclides astyalus).

> We allow the family to visit the patient outside of visiting hours [noise] because we are working from humanization, the patient will pass away and they won't see him anymore, you know? (Gonepteryx cleopatra).

This relationship between the family and health professionals[21] is important, it is a search for support and trust, both through technical procedures and a differentiated attention provided by the team, which is valued in the reports.

Health professionals, especially from the nursing staff, given their peculiarity of being 24 hours a day with the patient and their closeness with family members, have the difficult responsibility to prepare the patient for what is often not a satisfactory prognosis of their loved one[22].

What is shown by the interviewees is that the time of death is the most difficult for the family, hence the team has a very important role if they are able to understand that suffering is something experienced in a unique and very personal way for each of the people involved and linked to a context. Therefore, respect occupies a prominent place at this point[23-24].

CONCLUSION

Based on the interviews performed with nurses from an ICU of a public university hospital in Salvador, four categories of analysis emerged in seeking understanding of how these professionals develop nursing care/caring delivered to patients with no chance of survival in an ICU.

The study's results indicated that nurses show a certain difficulty in understanding that patients with no chance of experiencing a cure are people with particularities in the face of their condition of being at the end of life. Hence, in addition to an individualized care, which is an inherent need for every human being, this patient with no chance of a cure needs more attention and support, especially his/her family members, who need to elaborate their mourning process. Attention to respect and truth, being aware of the patient's real condition, is essential.

A super-valorization of technical care to the detriment of care involving psychosocialspiritual dimensions drew our attention. It is worth noting that the syllabus provided in the undergraduate program of these professionals significantly fails to include the amount of knowledge necessary to provide care to patients with no chance of survival: palliative care.

However, there was a great demonstration of respect for the person experiencing death and dying; the greater concern for the family members also draws our attention. Family members show great suffering in the face of the loss of a loved one, a fact that indicates the great affirmation that is given to life.

Caring for a patient in death and the dying process should be considered as gratifying as resuscitating a patient who has suffered cardiac arrest, considering death as part of life. Enabling someone to have a good death is to provide nursing care with dignity and respect, with a minimum of suffering and without pain.

Based on the results, we consider it essential that nurses understand death as part of life and hence caring/care should be rethought as the essence of nursing, discussing the theme of death both in the academic milieu and in daily practice. Considering caring provided to a patient with no chance of survival as an element necessary for life to establish its limits is a crucial aspect of nursing care.

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