

Care to terminal patients. Perception of nurses from the intensive care unit of a hospital

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Objective. To identify the perception of nurses with regard to the process of providing care to patients in the context of hospice care. **Methodology.** Qualitative study using the methodological framework Collective Subject Discourse. A total of 18 nursing professionals of the adult intensive care unit of a public hospital in São Paulo, Brazil were interviewed between June and August 2012. **Results.** The process of providing care to terminal patients is permeated by negative, conflictive and mixed feelings. As regards communication, while the participants acknowledge its importance as a therapeutic resource, they also admit a lack of professional qualification. **Conclusion.** The interviewees have difficulties to deal with care provided to terminal patients. The qualification of these professionals needs to be improved, starting in the undergraduate program.

Key words: palliative care; communication; intensive care units; nursing.

Cuidar a pacientes terminales. Percepción de los enfermeros de una unidad de terapia intensiva de un hospital público

Objetivo. Identificar la percepción de los enfermeros sobre el proceso del cuidado de pacientes en el contexto de la asistencia paliativa. **Metodología.** Estudio cualitativo que utilizó el referencial metodológico del Discurso del Sujeto Colectivo. Fueron entrevistados 18 profesionales de enfermería en una unidad de terapia intensiva adulta de un hospital público de Sao Paulo, Brasil, entre junio y agosto del 2012. **Resultados.** El proceso de cuidar de un paciente sin posibilidades de curación es permeado por sentimientos negativos, conflictivos e incongruentes. Con relación a la comunicación admiten la falta de preparación profesional, aunque reconocen su importancia como recurso terapéutico. **Conclusión.** Los enfermeros tienen dificultades con el cuidado del paciente terminal. Es necesario reforzar su preparación desde la formación de pregrado.

Palabras claves: cuidados paliativos; comunicación; unidades de terapia intensivos; enfermería.

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Cuidar de pacientes terminais. Percepção dos enfermeiros de uma unidade de terapia intensiva de hospital público

Objetivo: identificar a percepção dos enfermeiros sobre o processo de cuidar de pacientes no contexto da assistência paliativa. **Metodologia:** Estudo qualitativo que utilizou o referencial metodológico do Discurso do Sujeito Coletivo. Foram entrevistados 18 profissionais de enfermagem, em uma unidade de terapia intensiva adulta de um hospital público de São Paulo, Brasil, entre junho e agosto de 2012. **Resultados:** O processo de cuidar de um paciente sem possibilidades de cura é permeado por sentimentos negativos, conflitantes e incongruentes. Com relação à comunicação, há o reconhecimento de sua importância, até mesmo como recurso terapêutico, embora admitam o despreparo profissional. **Conclusão:** Os enfermeiros têm dificuldades no cuidado ao paciente terminal. Deve-se reforçar a preparação desses profissionais desde a graduação.

Palavras chave: cuidados paliativos; comunicação; unidades de terapia intensiva; enfermagem.

Introduction

Intensive care units (ICUs) are marked by the complexity of care delivery and technologies that often evidence an interventionist and curative model.¹ There is a group of patients, however, who despite the use of the most sophisticated technological resources used to maintain life, still face the end of life and, at a certain point, as the disease advances, therapeutic possibilities exhaust and death becomes inevitable.² The care delivered to these patients is no longer curative but palliative, i.e. hospice care. Euthanasia, the practice of shortening life to avoid or minimize suffering,³ is not the purpose of such care. Its purpose is to relieve pain and other stressful symptoms within the conception of reaffirmation of life and death as a natural process.^{3,4} Additionally, the hospice care's premise is to enable a dignified and humanized death process, without fear or pain. Therefore, patients should be monitored by a multidisciplinary team that respects ethical principles³ and is prepared to share anxieties, concerns, insecurities, and weaknesses that surround this process.⁴

Experiencing the process of death in one's professional routine is complex because the care that is provided at the end of life entices ethical dilemmas in the healthcare staff, which is trained according to the precepts of the curative

model.⁵ One study conducted with the nurses from a general ICU shows that these dilemmas are linked to personal values and beliefs, to the relationships established with families, patients, and other professionals, in addition to the dynamics of the care provided in this unit.¹ In the context of terminality in ICUs, we should also consider the emotional toll taken on healthcare workers. Studies have shown that nurses feel extremely distressed and emotionally exhausted when dealing with patients in this phase of the treatment, also experiencing insecurity, frustration, helplessness, and emotional distress in the face of the patient's suffering.^{1,6} Death, in addition to being a biological event, is characterized by a construction that is influenced by historical, social and cultural contexts, and therefore may be experienced differently by the professionals according to the meanings they attribute to it.⁷ Hence, death may be conceived as a process, not an end, and care provided in the last days of life may mean understanding, listening and respecting the patient.

Communication is the essence of care that sustains faith and hope in times of hardships. It is a complex and subjective process that encompasses perception, understanding, and the exchange of verbal and non-verbal messages

between patients and healthcare workers.⁸ Appropriate communication with the patient and family during a terminal process enables them to psychologically adjust to the situation of disease and death, understanding complex information and reducing anxiety.⁹ This study's objective was to identify the perception of nursing professionals concerning hospice care and describe the importance they attribute to interpersonal communication in the context of terminality.

Methodology

This is a descriptive study with a qualitative approach, which is defined as an approach that is concerned with the degree of reality that cannot be quantified and works with the universe of meanings, reasons, aspirations, beliefs, values and attitudes.¹⁰ In order to achieve these objectives, this study was based on the Social Representations Theory, which designates a set of phenomena and the concept encompassed. This theory comprises a phenomenon, particularly an urban phenomenon, in which mankind manifests its inventive ability to appropriate the world through concepts, statements, and explanations originating in daily life through social interactions with regard to any social or natural object.¹¹

Data were collected from June to August 2012 in the adult ICU of a public hospital in the interior of São Paulo with 24 beds for the care of patients from various specialties from the city of Botucatu and from the area covered by the Bauru Department of Health (DRS-6), SP, Brazil. An intentional sample was adopted with qualitative criteria for the collection and processing of data. When invariance of the studied phenomenon was verified, the sample size was established as 18 participants: nine nurses and the same number of nursing technicians. A semi-structured interview script composed of two parts was used. The first part addressed the characterization of patients and the second part was composed of four questions concerning hospice care and communication: What means, in your opinion, care provided to

a patient in hospice care?; Please tell me what contributes to facilitate the care provided to these patients?; What are, in your opinion, the difficulties faced when providing care to a patient under hospice care in an ICU?; How much importance do you attribute to communication in hospice care? After the interviews, the responses were transcribed and organized according to the methodological steps of the Collective Subject Discourse (CSD),¹² a technique used to tabulate and organize qualitative data. The steps of this technique consist in selecting key expressions of each individual answer to a given question, which are the most significant excerpts that correspond to the main ideas, synthesis of the discursive content.¹² Based on the key expressions of the core ideas, we construct the discourse synthesis in the first person singular; the thought of the group or collectivity appears as if it were an individual discourse.¹² Data were collected after the Institutional Review Board approved the study (Protocol 184/2012) and the participants signed free and informed consent forms providing the study's information.

Results

With regard to the socio-demographic characteristics, most participants were young, 30 years old on average, most were women (88.9%), Catholic (66.7%), and with experience of four years or more in intensive care units (33.3%). For 11 (61.1%) interviewees, the first contact with patients receiving hospice care took place during the undergraduate or technical program; only seven (38.9%) stated having received information on the topic during this period. The analysis of the interview transcripts enabled the identification of key expressions and main ideas and four themes that emerged from the guiding questions.

Theme 1. Meanings professionals attribute to the process of providing care to patients in the context of hospice care

Core ideas. There is no differentiation of care; feelings of sadness and hopelessness; difficulty in

dealing with death; possibility of humanized care; a concern with controlling pain; dignified death; providing comfort to the family; empathy.

Collective subject discourse. *I never stopped to think about it. In fact, this is a very sad situation that messes with personal feelings. But there is no distinction, because I'll care for him as if he were a regular patient. Patients receiving hospice care in ICU are those in critical conditions and near death. So, it's difficult to deal with death because we envision the patient leaving well, not dead. Also, I expect the patient who is dying to have a dignified death and receive basic care. But, professionals in general, distance themselves because they don't want to have contact, and it is precisely at this time that people perceive themselves to be equal. I believe that the estrangement on the part of the professionals with regard to terminal patients eliminate possibilities of the patient's last personal achievements.*

When I think about hospice care, I think of pain and the possibility of alleviating it. Then, I feel well and useful by knowing that I'm providing the patient with a more humanized care at the last moments of life. I know that I've made some difference to this patient. On the other hand, when we talk to the family and put ourselves in the condition and situation of patients, true empathy takes place... (CSD 1).

Theme 2. Facilitators identified in hospice care

Core ideas. There is no facilitator or, if facilitators are perceived, such a perception is misguided; time to dedicate to the patient and prepare for death; Having resources that minimize suffering; Possibilities to establish bonds.

Collective subject discourse. *For me, there are no facilitators when you're caring for a terminal patient. But, considering care provided in ICUs, this is an easy patient to care for because you don't invest, and it reduces time of care. It's easier when the patient is intubated, sedated,*

or using few medications, because, in a way, you don't have to be in contact with this patient. And the unit gives you resources so the patient suffers less and it relieves distress. In my perception, we have more time to comfort the patient, pay attention, listen more and understand better what is around. And it provides means that will ease the establishment of bonds with the patient. Also, you prepare yourself for the time of death because you already know that that patient has no prognosis and will die at any time. You have to enable an improved quality of life and provide the best care possible... (CSD 2).

Theme 3. Difficulties professionals face in the care process

Core ideas. Difficulty in dealing with death; The staff's emotional distress; Negative and conflictive feelings; Lack of humanization on the part of some professionals; Lack of qualification to provide hospice care.

Collective subject discourse. *The greatest difficulty when providing hospice care to terminal patients is the lack of professional qualification. It is precisely knowing that the care delivered will not result in the expected outcome, healthcare workers are trained to have a response, life, cure, and improvement. It is difficult to live with the fact that your care is restricted for the patient to have a dignified life and being aware that the patient won't leave the ICU. We deny it but it always leads to frustration, emotional stress, it's difficult to cope with, it hurts and affects us psychologically, we are very much affected. We are often unable to see that it may lead to a spiritual and psychological wellbeing. There are also difficulties with regard to the staff itself because you often see the patient has no prognosis and the technician doesn't perform some necessary and important care for the patient's comfort. There are workers who work with love, others don't, so it's difficult. The fact that the family doesn't acknowledge the patient's terminal condition often hinders the patient's treatment and even death. Because the family doesn't accept it, I guess nobody wants to lose a*

dear one. They want us to do the impossible but we know that there's nothing more to be done and then there is revolt, denial... (CSD 3).

Theme 4. Importance attributed to communication in hospice care

Core ideas. Lack of professionals' qualification; Communication restricted to the family members; Transmits comfort and wellbeing; Permits easing conflicts; Facilitates interaction with the family; Enables the establishment of bonds.

Collective subject discourse. *I think it's extremely important but we are not at an appropriate level of communication and we're far away from it. In fact, communication is restricted to the family because we don't have this communication with the patient. But I think it's very important to talk to the patient, even if sedated. And when the patient is not sedated, it is also worth it and makes a huge difference, communication calms the patient. It's communication that comforts and favors the patient's wellbeing through gestures and acts. If you don't communicate, you don't show trust. Therapeutic communication helps the patient to solve internal and family conflicts. It may give the patient peace to wait for death. The terminal patient needs to be listened to and understood so he feels assured that the staff will provide quality care at that time... (CSD 4).*

Discussion

Hospice care in Brazil is an emergent modality of care provided at the end of life. It has been more emphasized in recent years because of the population's increased life expectancy, change in the epidemiological profile of chronic diseases, and the need to provide a dignified death to patients whose disease no longer responds to the curative treatment.⁵ These factors have compelled healthcare workers to rethink the way terminal patients are cared for because there are various difficulties in providing care to these patients at home, which contribute to the institutionalization of death. Currently, in Brazil,

the estimation is that 70% of deaths take place in hospitals, specifically in intensive care units.¹³ This study shows that most participants face difficulties in providing care to terminal patients, while others are incapable of differentiating hospice care from that provided to other patients. Convergent data were found in one study conducted with oncological professionals, who also consider the care provided in the context of terminality to be a routine restricted to physical care and observation.¹⁴ Hospice care differs from curative care because it reaffirms life and death as a reality. In this change of paradigm, hospice care transcends the traditional care model because the first is based on a holistic, interdisciplinary and humanized approach.^{4,15} Therefore, hospice care depends on qualified professionals, family members and caregivers to deal with patients during this process in their last days of life. Thinking about death refers to reflecting on its power because it breaks bonds, interrupts dreams, and also imposes the need to rethink life, values and affections. The tendency of most people is to experience the good side of life, making plans, projects, without thinking about death, which is an inalienable part of life itself.¹⁶

Even though death is part of the routine of nursing professionals working in ICUs, dealing with it is still a difficult process permeated by frustration, suffering, emotional distress and helplessness, as this study's results show. Similar data were found in one study conducted with nursing professionals from a university hospital in the South of Brazil, in which the possibility of death was also negatively perceived, with much sorrow and suffering.¹⁷ Because these professionals believe that their function is only saving lives, they tend to reject hospitalized death and express different responses when witnessing a patient in the process of dying. Additionally, they tend to create defense mechanisms to cope with the situation and prefer to distance themselves from patients and families and also relegate nursing care as showed in the CSD. One study, seeking to reflect on care provided to terminal patients, shows that the way healthcare workers provide care to patients in this phase of life can be seen as a response to their own personal anxiety experienced when dealing with death.¹⁸

It is a fact that issues related to death and the death process are not sufficiently addressed during the training of healthcare workers. Education concerning care provided to people facing death requires a reflection on human existence and on acknowledging one's own finitude.¹⁹ Even though the way death is addressed has changed in many undergraduate and technical programs in the health field, even with the inclusion of specific courses, the content of these courses does not integrate the background knowledge necessary to care for patients facing the final moments of life.²⁰ One recent study conducted with 33 undergraduate nursing students at a public university in the interior of São Paulo shows that these students' perceptions with regard to the experience of caring for terminal patients portrays a professional education still focused on the biomedical and curative model. The analysis of reports show that the participants are not prepared to deal and experience the process of dying in ICUs.²¹ This context is also observed in a British study conducted with 20 undergraduate nursing students, who consider the experience of providing care to cancer patients to be distressing and exhausting, besides preferring to avoid contact with them. The authors consider there is a need to provide additional support to undergraduate students to demystify cancer through reflective practices and appropriate guidance, so that students feel supported and develop confidence in their ability to meet the need of these patients.²²

With regard to communication, the participants acknowledge its importance in the context of terminality even as an effective therapeutic resource, although they admit lack of professional qualification, as the results of this study show. Researchers who assessed the effectiveness of a program to train communication skills among nurses using a randomized study show the positive impact of this intervention on the quality of life of patients and on their satisfaction with the care provided by the healthcare workers.²³ Even though the ability of terminal patients to communicate is not always preserved, we observe that patients express their needs using different means, requiring ability and sensitiveness of

professionals to identify such needs. We note that none of this study's participants mentioned the therapeutic touch, even though it is considered one of the most important techniques of non-verbal communication.

Despite its importance in the context of terminality, communication has been simplified in most studies, limited to providing information on the diagnosis and prognosis, and often providing incomplete or summarized information regarding bad news to family members.²⁴ It reaffirms the assumption that professionals do not acquire communication skills as they acquire professional experience, but with appropriate qualification and in-service training. One study addressing the qualification of communication skills involving oncological nurses and hospice care providers reveals the positive impact of this improvement in the emotional dimension of care provided to patients facing the end of life.²⁵

This study's results indicate that the process of providing care to patients within the context of hospice care is multi-faceted, permeated of contradictions, negative feelings, little humanized care, and lack of qualification on the part of the staff to deal with terminal patients. Even though death is almost a daily event in the lives of the interviewees, it is still a singular and complex event that influences the care process. There is currently an emergent need to change the paradigm of death coping, which should begin in undergraduate and technical programs in the health field, with a broad, diversified, and interdisciplinary approach.

Concerning communication, its importance is recognized even as an effective resource, though the participants admit a lack of professional qualification. This finding reinforces the need to qualify healthcare workers to ensure improved quality of care delivered in ICUs. The delivery of care during the dying process requires the nursing staff to have knowledge inherent to care provided in this phase such as communication skills, teamwork, and knowledge to integrate biopsychosocial and spiritual aspects based on ethics and humanization into care.⁴

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