REFLECTION

DEATH AND THE DYING PROCESS: WE STILL NEED TO TALK ABOUT IT

A MORTE E O PROCESSO DE MORRER: AINDA É PRECISO CONVERSAR SOBRE ISSO

LA MUERTE Y EL PROCESO DE MORIR: TODAVÍA SE PRECISA HABLAR DE ESO

Roberta de Lima [1]
Alessandra Zanei Borsatto [2]
Danielle Copello Vaz [3]
Anne Caroline da Fonseca Pires [4]
Valéria de Paiva Cypriano [5]
Márcia de Assunção Ferreira [6]

[1] RN. PhD student. Instituto Nacional de Câncer José de Alencar Gomes da Silva – INCA. Rio de Janeiro, RJ – Brazil.
[2] RN. Stomatotherapist. INCA, Interdisciplinary outpatient clinic of the Palliative Care Unit. Rio de Janeiro, RJ – Brazil.
[3] RN. MS. INCA, Palliative Care Unit. Rio de Janeiro, RJ – Brazil.
[4] RN. Specialist in Clinical Oncology. INCA, Palliative Care Unit. Rio de Janeiro, RJ – Brazil.
[5] RN. Specialist in Oncology Nursing. INCA, Palliative Care Unit. Rio de Janeiro, RJ – Brazil.
[6] RN. PhD. Professor. Federal University of Rio de Janeiro – UFRJ, Anna Nery School of Nursing – EEAN, Department of Fundamental Nursing – DEF. Rio de Janeiro, RJ – Brazil.

Corresponding author: Márcia de Assunção Ferreira. E-mail: marcia.eean@gmail.com
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ABSTRACT

The objective is to provoke reflection on the process of death and dying and the necessary care associated with this phase of the life of people who experience death and their families, aiming to contribute to the debate of education for death and humanization of the process of death and dying. Death is a phase of life and is present in health professionals' daily life, but the healthcare model has not been effective in dealing with the demands of people in situation of death and their families. There are many challenges to be faced in vocational training, such as limitations in curricula and the multicultural approach to death. The teaching of technological and scientific aspects has been privileged, with little space for approaching the emotional, spiritual and social aspects of the human being. It is necessary to talk more about death and the dying process in order to increase knowledge about this theme and the acquisition of professional skills to deal with relatives and end-of-life care situations, with death in daily care and with the professionals who experience such care experiences.

Keywords: Death; Palliative Care; Nursing.

RESUMO

Objetiva-se refletir sobre o processo de morte e morrer e dos cuidados necessários associados a essa fase da vida das pessoas que vivenciam a morte e de suas famílias, visando contribuir para o debate da educação para a morte e da humanização do processo de morte e morrer. A morte é uma fase da vida e está presente no cotidiano dos profissionais de saúde, mas o modelo de atenção à saúde não se mostra efetivo para lidar com as demandas das pessoas e de suas famílias na morte. Há muitos desafios a serem enfrentados na formação profissional, como limitações nos currículos e na abordagem multicultural da morte. Privilegia-se o ensino da tecnociência, com pouco espaço para a abordagem dos aspectos emocionais, espirituais e sociais do ser humano. Concluiu-se que é preciso conversar mais sobre a morte e o processo de morrer, ampliar a geração de conhecimentos sobre o tema e a aquisição de habilidades profissionais para lidar com os familiares e com as situações de cuidados de fim de vida, com a morte no cotidiano assistencial e com os próprios profissionais que vivenciam tais experiências de cuidado.

Palavras-chave: *Morte; Cuidados Paliativos; Enfermagem.*

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RESUMEN

El objetivo del presente estudio es reflexionar sobre la muerte y el proceso de morir y los cuidados necesarios para las personas y familiares involucrados en dicho proceso, con miras a contribuir al debate de educación para la muerte y humanización de la muerte y del proceso de morir. La muerte es una etapa de la vida que está presente en el cotidiano de los profesionales de la salud, pero el modelo de atención de la salud no parece ser eficaz para lidiar con las demandas de las personas y de sus familias en la muerte. Hay muchos retos por enfrentar en la formación profesional, tales como las limitaciones en el plan de estudios y en el enfoque multicultural de la muerte. Se privilegia la enseñanza de la tecnociencia , con poco espacio para los aspectos emocionales, espirituales y sociales del ser humano. Se concluye que debemos hablar más sobre la muerte y el proceso de morir, aumentar la generación de conocimiento sobre el tema y la adquisición de competencias profesionales para lidiar con la familia y con las situaciones de cuidados al final de la vida, con la muerte en el cotidiano de la atención y con los propios profesionales que viven tales experiencias de cuidados.

***Palabras clave**: Muerte; Cuidados Paliativos; Enfermería.*

INTRODUCTION

Death and the process of dying are phenomena that generate anguish, fear and anxiety, and although they are part of life, they are still considered taboo.[1,2] People's attitudes toward death are influenced by personal, cultural, social, and philosophical belief systems that will shape their conscious or unconscious behaviors.[3]

Healthcare professionals face physical, emotional, social and spiritual suffering of people and, in many cases, difficult-to-solve situations. The current healthcare model is based on prevention, diagnosis, effective treatment and cure of diseases, but when faced with the incurability of certain diseases, this model becomes ineffective.[4] Relieving symptoms, in this case, requires medication, but also approaches to emotional, social, and spiritual symptoms, which are quite complex to deal with.

Advanced stages of certain diseases, such as cancer, are feared situations because they are linked to physical and moral suffering, pain, mutilation and death. Often suffering extends throughout the family and friends, generating fear and insecurity, and generally few professionals are prepared to deal with all the complexity of a patient with advanced disease and progression.

In general, there is a lack of debates in elementary, middle and high schools, which demands an expansion of the scope of education to death, given the interdiction of this theme.[2] In nursing, there are many challenges to be faced in training, such as the limitations in school curricula on the death and dying process, especially in multicultural settings.[5]

With regard to models of care, there are also different policies and practices in health systems that imply the acquisition of professional skills to deal with end-of-life and death care situations.[5]

Therefore, this article aims to reflect on the process of death and dying and the necessary care associated with this phase of the life of people who experience death and their families, aiming to contribute to the debate of education for death and the humanization of the process of death and dying.

LIFE, CARE AND DEATH

Life is the great triumph of healthcare and exalting it obscures the view of health professionals and interdicts the understanding that when death is inevitable, because the course in life was completed due to illness or fatality, taking care of one's death is a worthy and necessary action, being also an important function of the health professional. Death is present in the daily life of these professionals, but the formal training is still insufficient, with teaching focused on the technological and scientific aspects and little space to approach the emotional, spiritual and social aspects of the human being.[4] This insufficiency raises questions about what to do in incurable cases that will fatally lead the individual to death.

But it is necessary to consider that professionals also suffer in this process, because talking about death and the process of dying requires a great cognitive and emotional effort, since this language was not taught to them or was incipiently taught in the pedagogical training process. There is insufficient and adequate investment in the training, both at the technical and higher levels, to allow them to interpret the feelings that emerge at this moment, which is unique in one's life. Health professionals take care of other's pain, but they do not find the adequate shelter for their own sufferings and many have become ill.[6]

Few professionals had experiences that could clarify the various questions that arise in this unusual moment of encounter. It is also added that, since the process of dying is a subjective experience, care is unique and always on demand, requiring the professional to have a unique disposition to care for, as well as verbal and non-verbal communication abilities for establishing a humanized relationship, which is so essential to health care.[7,8]

A review study showed that younger nurses have consistently reported stronger fear of death and more negative attitudes toward end-of-life care.[3] On the other hand, Nursing students in the first year of training reported that thinking about death is more frightening than the actual experience of dealing with it.[9] These results show how much the experience of dealing with death can be diverse, depending on the preparation and the disposition of each human being.

Death integrates human development into its life cycle; it is a reality and no matter how much one tries to abstract it and make it distant, it will be present someday in everyone's life. Accompanying one's death raises awareness of our own mor-

tal condition, thus generating anxiety and discomfort.[3] This awareness differentiates the human being from other animals. Denying it is one of the ways to not get in touch with painful experiences and feeling unique and unforgettable. This idealization emphasizes human frailty, finitude and vulnerability.[2]

Thinking that one day all will die, without knowing what from or how, generates an existential anguish. That is why it is so common to take a defensive posture to stand back from the idea by distancing from the concrete situations of death. Standing back generates in the imagination a way of self-protection as if, by not entering into a contract with death, it might not exist.

This withdrawal is not only existential, it has happened in the everyday life of families. Historically, death used to occur at home, with the participation of the family, and has been gradually institutionalized and incorporated into the hospital setting.[6] This migration has changed the entire perception about the dying process, which has reflected in the posture of people and families in face of it. There are no purposes and motivations to participate in the process of dying of relatives. On the contrary, there is the feeling of strangeness, since this process has not been built in the people's minds since childhood.

In order to reverse this estrangement, one must create a habit of thinking, discussing, talking about death and the questions that arise from that and from the moment when one decides to face their own finitude. Death raises questions about life: how one has lived life? What choices have been made up to that moment?[10] Death invites us all to look at life in all its nuances built up to that time. Some necessary questions to deepen the study of death and the dying process are: would you like to die acutely or chronically? In your home or in a hospital? Who would be your primary caregiver? What would you do (or not do) if you only had 24 hours to live? What if you had a week? What if you had six months left? What would you decide for you on intensive care unit, artificial feeding, dialysis and ventilatory support?[10] What is clearly and objectively identified is that death leads to questions about values and ways of living.

Death is something present and that can happen anytime, anywhere, at any time, unlike the collective imaginary that suggests a covenant that death will come only when it is allowed to come.[11] But when it is inevitable and imminent, people want to leave a legacy, something that translates into a memory, a record that they have lived here for some time. This legacy is not only translated into something great and noble. It can be the simple teaching of a cooking recipe, something that someone does in their intention, making the person alive in that moment of remembrance.

In the final moments of an individual, in addition to the need to leave a legacy, the need to settle unresolved issues throughout life appear as well as to discuss about social roles and how one's family will take on responsibilities in one's absence. The need for reconciliation with others, with oneself and with a supreme being is also very present in people who are dying. It is as if the end of life requires a termination of contract with him/her and with others. The need to say goodbye, to have the presence of people with whom one has established affective bonds and satisfaction in this relationship is almost a request for resigning in order to leave the world and the life of family and friends; it involves searching in the family members' gestures the message that they can leave and that those remaining will be able to restructure themselves without his/her presence.[11]

These reflections are necessary for palliative care teams that need to work together with firm and constant interpersonal communication among each other in order to strengthen interprofessional collaboration, since effective communication strengthens bonds and promotes more safety in care.[12] In addition, communication also needs to be improved with patients and families.

In the approach to death and the dying process, communication is crucial both in form and content. There needs to be clarity in the message and cultural adequacy so that there are no noises hampering its understanding. It is important to consider the sender, the message and the receiver, especially because this theme is difficult to approach and the receiver is in a situation of suffering.

Communication is part of the care and, in this process, the health professional needs to apply the acquired technical-scientific knowledge, as well as sensitivity, in which the humanitarian foundations of his/her training and personal trajectory will be of great value.[4]

Ways of caring for people dying and dying and their families need to be well approached in the training processes so that cultural and religious aspects, taboos and people's beliefs about death are addressed. Studies from several countries have shown that education programs in the workplace can reduce death anxiety and contribute to improving nursing care for people at the end of their lives.[3]

Furthermore, nursing actions in meeting the needs of relatives of people who are dying demonstrate the value of nurses' interpersonal skills in care. A study carried out with relatives of deceased persons in hospitals showed that the nursing team facilitates the presence of the family, keeping the members informed, involved and present, thus influencing their physical and emotional states.[13]

Taking care of the other is a social responsibility, and the care for the patient in the process of dying is understood by nurses as so. For this reason, it is beyond their professional functions, becoming a human obligation.[14] Dealing with someone else's death and pain makes nurses vulnerable, which requires support so they can better assist the person under their care, their family, and themselves in their emotional and well-being demands.[14,15]

Therefore, it is necessary to talk about death, both in care institutions and in training institutions because without conversation, death will remain as strength close to the other, but far from us and silenced in the caring process.

CONCLUSION

When one looks at these questions in a profound way, it is possible to perceive how laborious and complex the farewell phase of someone dying is, and how much study is necessary to learn how to deal professionally with this situation of one's death and his/her family, especially when the person is not used to thinking about it.

So it is still necessary to talk about death, to bring it close to us, to make it intimate, to know it. In life and in the field of health, especially, the more and the better one knows a phenomenon, the more one learns to deal with it. Therefore, to better care for someone who is dying, we must talk about death: about his, about yours, about our death.

The phenomenon of death should be dealt in the same way as dealing with the phenomenon of birth. Caring for life means caring for death, because the professional responsibility is regarding the protection of life: of the one who is about to born, of the one who is about to die.

This reflection suggests that it is still fair and necessary to generate knowledge about death and the process of dying, about the care to those who are dying and to their families, about the care to those who are caring for people in these situations, since in practice, at the moment of death, the human desire is that we have friendly hands that will help us and comfort us in our death and, professionally, that we are the hands that others wish to have.

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